

School of Public Health

Cleft lip and palate – a comparative psychosocial study

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Thesis is presented for the Degree of
Doctor by Research Publication (D Public Health)
of
Curtin University

OCTOBER 2017

Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number # HR61/2015 and the Princess Margaret Hospital Human Research Ethics Committee (EC00268), Approval Number # 2014046EP.

Signature: *Wendy Nicholls*

Date: 15 October 2017

Acknowledgements

This work would not have been possible without the kind support of those people, both personal and professional, who have joined me throughout this journey.

I would like to thank my supervisors for their expert knowledge and input; Suzanne Robinson and Linda Selvey for their expertise in Public Health and Martin Persson for his expertise specifically in the area of Cleft Lip and Palate (and also for his humour and friendship – it is very much appreciated). I would also like to acknowledge the contribution of an Australian Government Research Training Program Scholarship in supporting this research.

My thanks also to the Dental Department and Craniofacial/Cleft Lip and Palate Team at Princess Margaret Hospital (soon to be re-located to the new children's hospital, which has been re-named Perth Children's Hospital). Your support and expert knowledge has been invaluable. I have worked with the people from these areas for fourteen years, and their expertise, dedication and kindness is commendable. I would also like to thank my national and international colleagues who have offered their friendship and support throughout my career in this area. Their perspective and advice has also been invaluable. I would also like to thank the healthcare professionals who contributed in the study to determine the perceptions and training needs of those working with patients with CL/P.

I wish to acknowledge and thank the people of Western Australia who were born with a cleft condition and who have so generously shared their experience and stories. Without your input this study could not have happened, and would be without meaning. Also to the parent support groups, CleftPALS and FaceUp, who have supported my studies and welcomed me into their meetings and into their lives, a very big thank you.

Finally I would like to thank my family and friends who have had to put up with my being less emotionally and physically available during this time, and have offered their support and kindness. I would like to thank them for their understanding and encouragement. However there has been one person who has offered me the greatest strength, encouragement, knowledge, support, and love, and that is my husband Craig. I could never repay your kindness but may make this my next big thing!

Wendy Nicholls

September 2017.

Abstract

Background

The treatment of individuals with a cleft lip and/or palate (CL/P) involves many years of appointments and surgical interventions involving a multi-disciplinary health care team. In addition to the physical aspects of this complex condition, consideration must also be given to the psychosocial implications that may arise from this long-term treatment commitment.

The aim of this thesis was to address current gaps in knowledge by investigating patient perceived impacts of CL/P on psychosocial adjustment and sociological life outcomes across three age-groups: children, adolescents and adults. It also explored the perceptions of healthcare professionals (HCPs) working in cleft units from Australia and Europe, regarding their confidence in treating patients with CL/P and associated psychosocial training requirements.

Methods

This thesis used a mixed methods approach and involved the following participants:

1. Patients with CL/P who were undergoing or had completed treatment at Princess Margaret Hospital for Children (PMH), Perth, Western Australia. The cohort comprised: 100 children aged 6-12; 101 adolescents aged 13-21; and 158 adults aged 22-42 years.
2. HCPs that treated patients with CL/P and other conditions resulting in a visible difference. The HCPs were aged 22-71 years with 50 from Australia, and 15 from each country of Bulgaria, Latvia, Serbia, and Turkey.

Data was collected from the children and adolescent age-groups as a convenience sample during PMH protocol clinic visits, and via a self-reporting postal survey for adults. Qualitative interviews were conducted with 15 self-selecting adults which were recorded, transcribed and results formulated using thematic analysis. The HCPs were self-selected from their respective cleft centres.

Four instruments were used:

1. Cleft Research Questionnaire (CRQ), collected data on: demographics, impacts of CL/P, importance and satisfaction with physical attributes and support received, teasing and bullying, relationships, and support resource information.
2. Body-esteem Scale (BES), collected data on body-esteem perceptions.
3. Qualitative interview schedule was used to obtain a deeper meaning of the impact of CL/P for adults.

4. Health Care Professionals Questionnaire (HCPQ), collected perceptions of HCPs regarding their confidence in providing psychosocial support and their training needs.

Results

The literature review indicated that individuals with CL/P do not appear to experience major psychological disorders, however, they are at a higher risk of developing specific psychosocial problems in four key domains: self-esteem and self-worth, social inhibition and isolation, depression and anxiety, and appearance dissatisfaction.

Key results from the thesis studies are:

1. In comparison to the Australian general population, the respondent adult study participants attained equivalent highest education levels, full-time annual income levels, occupational categories, employment rates, and home ownership levels. However, they were also more likely to be single and lived with their parents longer than the general population;
2. Seventy eight percent of adult study participants self-reported that they had experienced at least one psychosocial health issue, and experienced anxiety and depression at four and six times the rate of the Australian general population respectively;
3. The physical attributes of hearing and speech were reported to be of higher importance than facial and dental appearance across all three age-groups;
4. The support received from treatment providers was reported by study participants across all three age-groups to be nearly as important as the support they received from their parents;
5. Adult participants felt they would have benefitted from speaking to a psychologist or counsellor throughout their treatment time, and especially during their teenage years; and
6. Half of the Health Care Professionals surveyed did not feel confident in dealing with the psychosocial needs of people with a visible difference, and 87% indicated that they would like to receive formal training.

Conclusion

For many of the adult participants, having CL/P has been a lifelong challenge with the underlying recurring theme of wanting normality which influenced their self-perception, treatment compliance, life experiences and accompanying life satisfaction. The majority of participants reported social rejection which occurred mostly at school, but often did not last into adulthood. While study participants attained positive education, income, home-ownership and employment outcomes when compared to the Australian general population,

they did not report positive relationship and psychosocial outcomes. The reported rate of anxiety and depression requires urgent attention to determine potential causes and provide appropriate support and intervention.

Treatment providers hold a position of high influence and need to be aware of the importance of their support for patients. This has implications for clinical practice as frequent appointments over years of treatment offers the opportunity for clinicians to provide support and to instil confidence in patients. Post-treatment services and referrals should be made available to patients to address hearing and speech difficulties and psychological support.

List of publications included in the thesis

Four of the publications were accepted and published by the Cleft Palate Craniofacial Journal, which is the predominant journal for publications regarding cleft and craniofacial research. Publication status of each paper is indicated as at the time of thesis submission.

Paper 1. Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups.

Corresponding Author: Wendy Nicholls

Contributing Authors: Craig Harper, Linda Selvey, Suzanne Robinson, Gerald Hartig, Martin Persson.

Publication status: published online Cleft Palate Craniofacial Journal, 14 December 2017.

DOI: 10.1177/1055665617730362.

Paper 2. Adult specific life outcomes of cleft lip and palate in a Western Australian cohort.

Corresponding Author: Wendy Nicholls

Contributing Authors: Craig Harper, Suzanne Robinson, Martin Persson, Linda Selvey

Publication status: *in press*, accepted for publication June 2017 by the Cleft Palate Craniofacial Journal. Expected date of publication April 2018.

Paper 3. The psychosocial impact of cleft in a Western Australian cohort across three age-groups.

Corresponding Author: Wendy Nicholls

Contributing Authors: Linda Selvey, Craig Harper, Martin Persson, Suzanne Robinson.

Publication status: *in press*, accepted for publication June 2017 by the Cleft Palate Craniofacial Journal. Expected date of publication April 2018.

Paper 4. Adult narratives of the psychosocial impact of cleft in a Western Australian cohort.

Corresponding Author: Wendy Nicholls

Contributing Authors: Martin Persson, Suzanne Robinson, Linda Selvey.

Publication status: *in press*, accepted for publication May 2017 by the Cleft Palate Craniofacial Journal. Expected date of publication March 2018.

In addition to the four papers outlined above, chapter 8 includes results from a study that investigated Healthcare Providers' psychosocial support for patients with a cleft. This was undertaken in both Europe and Australia.

List of additional publications by the candidate

Please refer to Appendix 8 for a list of additional publications and conference presentations by the candidate.

Terminology

Please refer to Appendix 1 for a list of the most common Cleft Lip and Palate Terminology used in this thesis.

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Statement of Contribution of Others

The purpose of this statement is to summarise and clearly identify the nature and extent of the intellectual input by the candidate and any co-authors. The role of the co-author contributions per paper and statements from each author are included in Appendix 4.

I advise the contribution made by co-authors for all papers was for advice for data analysis, proof-reading and editing.

All other input was made by myself under supervision.

Signed: *Wendy Nicholls*

Wendy Nicholls (Student)

Dated: 15 October 2017

Signed: _____

Suzanne Robinson (Internal Supervisor)

Dated:

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Chapter 1 Introduction and Thesis Overview

1.1 Background

The long-term care of children with cleft lip and palate (CL/P) involves many years of appointments and surgical interventions with a multi-disciplinary team of health professionals. Treatment includes intervention for both function and aesthetics. Whilst the physical aspect of care is optimally addressed by the cleft care team, the psychological aspects of CL/P are not always readily identifiable or have been considered. The cleft condition and the associated years of treatment can have a considerable psychosocial impact on individuals throughout their lifetime and may also impact their families. There is evidence that this impact can be stressful and consequently put both the individual and their families at higher risk for psychosocial problems. These problems may include lower self-confidence and self-esteem, and increased anxiety and social inhibition which may directly affect their quality of life (Bilboul, Pope, & Snyder, 2006; Feragen, Kvalem, Rumsey, & Borge, 2010; Noor & Musa, 2007).

1.2 Aim and Objectives

The overall aim of this thesis was to contribute to the current gaps in knowledge by investigating and gaining an understanding of the patient perception of CL/P across three age-groups and by exploring the perceived impact of CL/P on sociological adjustment, functioning and life outcomes. The objectives of this thesis were as follows:

- Objective 1. Assess whether children, adolescents and adults with CL/P are at increased risk of developing psychosocial problems;
- Objective 2. Identify the types of psychosocial problems and the impacts of CL/P within each age-group;
- Objective 3. Investigate body-esteem within each age-group and compare with corresponding normative scores;
- Objective 4. Determine the importance and satisfaction ratings within each age-group for cleft-related physical attributes and for support given by others;
- Objective 5. Investigate adult-specific sociological outcomes and compare against the Australian general population;
- Objective 6. Explore the personal experience and deeper impact of CL/P amongst a subset of the adult age-group; and

Objective 7. Investigate the perceptions of healthcare professionals regarding their confidence in treating and supporting patients with CL/P or other visible difference, and their training requirements to better understand the psychosocial needs of such patients.

This research offers an understanding of the patient perspective of the impact of CL/P. The resulting recommendations for policy and practice will help improve the treatment experience for those individuals with CL/P, to improve the quality of current and future care, and help minimise adverse psychosocial impacts. Outcomes may also have implications for treatment providers; by identifying where improvement may be required for clinical practice and translate into health care recommendations to influence protocols to provide for ongoing and/or ad-hoc post-treatment assistance. Parents and patients may also feel reassured in knowing that individuals with a cleft have comparable life outcomes to the general population irrespective of cleft type or gender. Results will translate to comparable cleft units in Australasia and internationally.

1.3 Thesis Components

This thesis has the following components which address the indicated objectives:

- Literature review of the psychosocial impact of CL/P across three age-groups (objectives 1 and 2 described in Chapter 2).
- Body Esteem analysis across three age-groups (objective 3 described in Chapter 4 Paper 1).
- Psychosocial impact of CL/P across three age-groups (objectives 2 and 4 described in Chapter 5 Paper 2).
- Adult specific psychosocial impacts of CL/P (objectives 2 and 5 described in Chapter 6 Paper 3).
- Qualitative analysis of the psychosocial impact of CL/P for a subset of the adult age-group (objective 6 described in Chapter 7 Paper 4).
- Perceptions and training requirements of Health Care Professionals (HCPs) caring for patients who have CL/P or other visible difference (objective 7 described in Chapter 8).

The three age-groups comprised a cohort of current and former patients with CL/P from PMH. The health care professionals were comprised of participants from cleft units across four European countries, and Australia.

1.4 Overview of thesis chapters

Chapter one gives a background to the considerable physical and psychosocial issues of CL/P, and introduces the case study site, Princess Margaret Hospital (PMH), the single treatment unit in Western Australia.

Chapter two provides a literature review which investigated three main areas of interest; whether children, adolescents and adults with CL/P are at increased risk of developing psychosocial problems; the types of psychosocial problems developed within each age-group; and the recommendations (and particularly any trialled interventions) which addressed these problems.

Chapter three describes the thesis methodology and data analyses undertaken.

Chapters four to seven comprise the published papers, and chapter eight investigates the perceptions of Health Care Professionals (HCPs) who treat individuals with CL/P. Chapters nine to twelve comprise the results and discussion of this thesis including the contribution and recommendations.

1.4.1 Overview of the thesis papers

Chapter 4 includes the first of the published papers (paper 1). The focus of this paper was on the aspect of body-esteem by investigating the relationship between body-esteem and CL/P across three age groups in a Western Australian (WA) cohort to redress the paucity of research in this area. Objective 3 of this study was to investigate and compare study participant Body-esteem Scale (BES) factor scores with the corresponding non-cleft normative scores from the Mendelson BES studies (B. K. Mendelson, Mendelson, & White, 2001; B.K. Mendelson & White, 1993; B.K. Mendelson, White, & Mendelson, 1996, 1997), and to identify any significant associations between study BES factor scores and the Cleft Research Questionnaire (CRQ) variables of gender, self-reported body weight category, cleft type, and importance of facial appearance rating.

The BES is divided into 3 factors: BE-Appearance, BE-Weight, and BE-Attribution. BE-Appearance relates to how a person generally feels about their appearance; BE-Weight relates to a person's level of satisfaction with their weight; and the third factor, BE-Attribution, relates to how a person perceives that others evaluate their body and appearance.

It was anticipated that study participants would have significantly lower BES factor scores than the Mendelson studies in light of reported appearance dissatisfaction for individuals with CL/P (Endriga & Kapp-Simon, 1999; Feragen & Borge, 2010; Marcusson, Paulin, & Ostrup, 2002; Turner et al., 1998).

Two further issues for investigation were; a) that adults from this study would not have a significant effect for cleft type, as the majority had completed their definitive cleft treatment; and b) that across all CL/P age-groups, those participants who rated the importance of their facial appearance highly would have significantly lower BES scores, as higher importance of appearance may lead to higher self-criticism and lower self-esteem (Feragen & Borge, 2010; Rumsey, 2012; S. C. Thompson et al., 1998).

This is the first study for patients with CL/P from Australia and internationally that specifically addresses the impacts of CL/P on body-esteem across the life span using the BES scale, and builds on that of Crerand, Sarwer, Kazak, Clarke, and Rumsey (2017). At present, these impacts within this population are largely undetermined which may be resulting in unmet psychosocial needs. No studies from Australia and no studies specifically for CL/P were found to have used the BES. The BES instrument is a validated questionnaire, but has not been validated in individuals with CL/P.

Chapter 5 includes paper 2 which considered objective 1: to investigate and assess whether children, adolescents and adults with CL/P are at increased risk of developing psychosocial problems; objective 2: to determine the type of psychosocial problems and impacts developed within and across each age-group; and objective 4: to determine the importance and satisfaction with cleft-specific physical attributes and support given by others. It investigated the impact of CL/P including: attitude to life and academic achievement; importance and satisfaction with cleft-specific physical attributes and support provided by key groups; prevalence and effects of teasing and bullying; experiences and outcomes of treatment; and identifying the psychosocial support resources and information that may be helpful.

Chapter 6 includes paper 3 which focused on objective 5: to investigate the adult-specific sociological outcomes of adults with CL/P and compare against the general population. It investigated the type of psychosocial problems and impacts within the adult age-group, and assessed the social functioning of patients post-treatment in terms of their independence, education, occupation, income, relationships and health behaviours.

Chapter 7 includes paper 4 which focused on objective 6: to investigate the personal experience and deeper impact of CL/P amongst adults. The use of a qualitative approach achieved a deeper understanding of the psychosocial impacts for adults with CL/P and how their perceptions and experiences influenced their lives. An important area voiced by participants was advice offered to others based upon their personal experience.

In addition to the published papers, chapter 8 focused on objective 7: Investigate the perceptions of healthcare professionals regarding their confidence in treating and supporting

patients with CL/P or other visible difference, and their training requirements to better understand the psychosocial needs of such patients. This study surveyed HCPs to investigate their attitudes and requirements for feeling confident in providing care for those with visible difference including CL/P. The inclusion of participants from varying treatment roles as well as different locations and societies offered a diverse perspective.

The results from this research provide evidence concerning the patient perspectives of living with CL/P and the associated psychosocial and sociological outcomes. The evidence from this work is of importance to improving quality of care for patients with CL/P and has the potential to minimise adverse psychosocial impacts of the cleft condition.

1.5 Overview of cleft lip and palate

A cleft of the lip and/or palate is the most common congenital craniofacial anomaly and has been reported to have an average global incidence of 1 in 700 (500-750) livebirths which varies across racial groups (Mossey, Little, Munger, Dixon, & Shaw, 2009). Four thousand cleft-related deaths occurred globally in 2010 which is reduced from 8,400 in 1990 (Lozano, 2012). Watkins, Meyer, Strauss, and Aylsworth (2014) reported the highest prevalence rates for CL/P were for people of Native American and Asian origins, with people of African origins having the lowest prevalence rates. Prevalence rates per 1000 live births were reported as;

- Native Americans: 3.74;
- Japanese: 0.82 to 3.36;
- Chinese: 1.45 to 4.04;
- Caucasians: 1.43 to 1.86;
- Latin Americans: 1.04;
- Africans: 0.18 to 1.67.

However, the true prevalence rate of CL/P is subject to debate until there is consistency with genetic research differentiating between syndromic and non-syndromic cases (Nyberg, Sickler, Hegge, Kramer, & Kropp, 1995).

There are more than 300 associated syndromes which are present in 30% of patients with a CL/P. The most commonly occurring abnormalities occur in the facial region (21%), and then reduce in frequency in the ocular system, central nervous system, skeletal system, cardiovascular system, neck, auricular system, gastrointestinal system and urogenital system, with Trisomy 13 being the most commonly associated chromosomal abnormality (Nyberg et al., 1995).

The long-term care of patients with CL/P involves many years of multi-disciplinary therapy, treatment and surgical interventions at both fixed and varying time points through the lifespan. The range of treatment issues include:

- facial and palatal defects requiring reconstructive and revision plastic surgery;
- neonatal feeding problems requiring alternate practices of feeding, specialised equipment and pre-surgical appliances;
- speech and hearing abnormalities requiring ongoing therapy practices and surgery;
- dental and jaw abnormalities and subsequent malocclusion requiring dental, orthodontic and oral surgery treatment and surgical interventions.

People with CL/P may be different from their peers due to their facial appearance, potential hearing and speech difficulties, and the significant time spent attending appointments for multidisciplinary treatment and recovering from surgical interventions. These differences can lead to experiences of appearance-related concerns (Marcusson, Paulin, & Ostrup, 2002), teasing and bullying (Hunt, Burden, Hepper, Stevenson, & Johnston, 2006), social discrimination and stigma, and perceived or actual negative responses of other people (Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004). This may have a significant impact on the psychological foundation of the individual throughout their lifetime and put them at higher risk for psychosocial problems.

As well as the physical component of this complex condition, consideration must also be given to the emotional and psychosocial implications that may arise from this long-term treatment commitment (Cheung, Loh, & Ho, 2007). Whilst advances in surgical techniques have provided improved physical outcomes for the patient, there has also been an increased cognizance of the psychosocial impact of the cleft condition. This more holistic approach has increased the need for multi-disciplinary treatment providers including geneticists, paediatricians, liaison nurses and coordinators, psychologists and social workers that need to be both accessible and available across the lifespan (Gussy & Kilpatrick, 2006).

1.5.1 Types of clefts

Figure 1 illustrates the physical appearance of different types of CL/P.

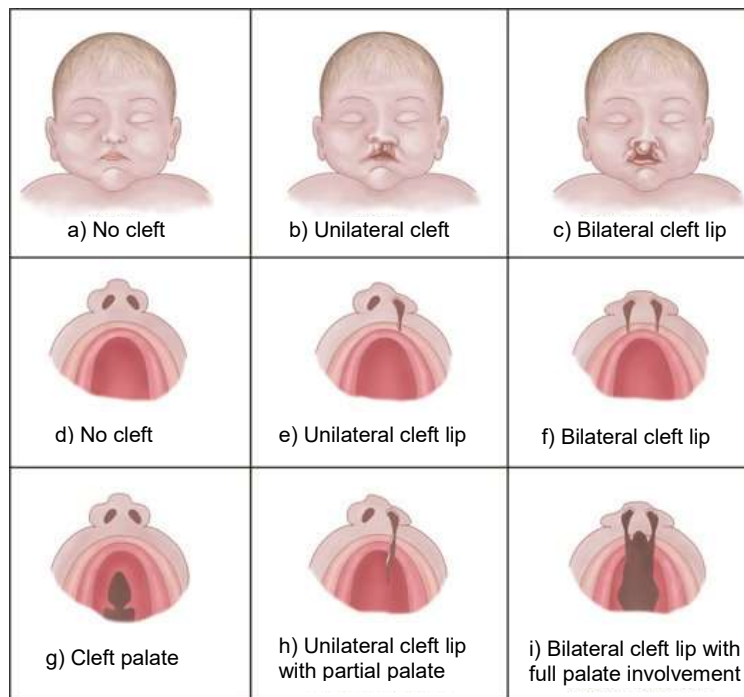


Figure 1. Physical appearance of different types of CL/P. (Parrotta & Corrias, 2010)

Cells b) and e) illustrate unilateral (i.e. one-sided) cleft lip with no palatal involvement which generally requires the least treatment intervention. Cells c) and f) illustrate bilateral cleft lip with no palatal involvement. In both cases, a cleft lip usually results in a visible facial appearance difference due to scarring from the lip repair.

Cell g) illustrates cleft palate-only which generally does not result in a visible facial difference but may be associated with dental anomalies, and speech and hearing difficulties;

Cells h) and i) illustrate cleft lip and palate which require the greatest treatment intervention and generally result in the greatest difficulties.

1.5.2 Aetiology

Although cleft lip and palate may occur together, they present as different aetiologies with their development being attributed to both genetic and environmental factors, or an interplay between the two (K. Moore & Persaud, 2008). Cleft lip and cleft palate have been identified to be caused by developmental problems which may occur during any stage of the developmental process. Cleft palate may result due to the following development issues;

- inadequate growth of the palatine shelves,
- the failure of the shelves to lift at the correct time or to fuse at the boundaries.

Cleft lip has been attributed to developmental issues which affect the maxillary prominence mesenchyme and the medial nasal process (Wong & Hagg, 2004).

In up to 10% of clefts affecting the lip and palate, 30% of clefts of the lip-only and 50% of all palate-only clefts, an association can be made with at least one of more than 500 chromosomal anomalies or syndromes, which suggests there is a genetic cause (Lidral & Murray, 2004; OMIM, 2009). However, the aetiology of clefts not associated with a syndrome (non-syndromic) remains largely unknown (Mangold et al., 2010) but may have unique genetic backgrounds which may become apparent by environmental factors.

Wong and Hagg (2004) identified specific environmental factors as potential causes of the cleft condition which include alcohol consumption, drugs that contain vitamin A, toxic substance exposure and nutritional deficiencies. They further highlight the process of fusion of the palatal shelves as being particularly vulnerable to the effects of toxic substances, environmental pollutants and nutritional imbalances. Several risk factors have been consistently identified in epidemiological studies such as maternal exposure to tobacco smoke, alcohol use, poor nutrition, viral infection, medicinal drugs, and teratogens (Carmichael et al., 2007; Chen, Wen, Fleming, Yang, & Walker, 2007; Jiang, Bush, & Lidral, 2006; Mossey, Davies, & Little, 2007).

Genetic counselling is recommended not only to allow the surgeon to identify and anticipate complications associated with various syndromes but also to indicate the likely recurrence, and to provide information for family planning (Sivertsen et al., 2008).

1.5.3 Antenatal detection and diagnosis

The antenatal diagnosis of a cleft involving the lip using transabdominal ultrasound may be made at approximately the 18th week of gestation with accuracy increasing as the foetus grows. The cleft type of palate-only is more difficult to detect antenatally using ultrasound, even with a view inside the mouth, and is rarely attempted at the anatomical scan (Nicholls, Jennings, Yeung, Walters, & Hewitt, 2017). Diagnosis of a palate-only cleft generally usually by physical examination after the baby has been born.

Antenatal anatomical screening including imaging of the face using transabdominal ultrasound is routinely conducted in Western Australia (and other states of Australia and New Zealand) between 18 and 20 weeks gestation (Royal Australian and New Zealand College of Obstetricians and Gynaecologists, 2016). Additional investigations at a range of gestational ages may be performed at the discretion of the treating clinician. If a cleft is detected, parents are referred to a Craniofacial / Cleft Lip and Palate Unit for antenatal counselling.

1.6 Timeline of physical issues related to the cleft condition

The following timeline highlights the scope and complexity of the physical issues and multidisciplinary nature of the cleft condition.

1.6.1 Feeding issues

Due to the altered anatomy of the mouth causing a lack of suction, an infant with a cleft palate or cleft lip and palate may have difficulty in feeding. Air may escape from the mouth through the cleft into the nose causing insufficient suction to draw milk easily (Masarei, Sell, & Wade, 2003; Mizuno, Ueda, Kani, & Kawamura, 2002; Reid, Reilly, & Kilpatrick, 2007). Babies with a cleft lip are not able to seal the oral cavity anteriorly due to lack of compression.

Feeding issues are managed with the use of specifically designed baby bottles and teats which keep fluids flowing downward and feeding the child in a more upright position to allow gravity to assist in preventing fluids from coming through the nose (Porterfield, 1988). Palatal obturators (plates) are made by Paediatric Dentists to form a barrier along the palate which assists in forming a seal during feeding (Schaaf, Casey, & McLean, 1995).

1.6.2 Presurgical orthopaedics

Presurgical orthopaedics (PSO) include a series of palatal obturators which may be used in conjunction with lip taping or strapping. This results in a gentle force being applied to the soft tissue structures to reduce the width of cleft (Berkowitz, Mejia, & Bystrick, 2004; Georgiade & Latham RA Maxillar, 1975; Ross & MacNamera, 1994).

1.6.3 Cleft lip repair

The timing of cleft lip repair is usually between 10-12 weeks of age McComb (1975, 1985). McComb and Coghlan (1996) describes the aims of cleft lip repair: to create an intact upper lip with sufficient vertical length and symmetry, to repair the underlying muscular structures for normal function; and primary treatment of the associated nasal deformity.

1.6.4 Cleft Palate repair

The timing of cleft palate repair is performed when the infant is approximately 7-12 months of age. Holdsworth (1954) and Kosowski, Weathers, Wolfswinkel, and Ridgway (2012) described the objective of cleft palate closure to be: separation of the nasal and oropharynx but still with the goals of normalized speech, hearing and maxillofacial growth.

1.6.5 Alveolar Bone-graft

The aim of alveolar bone-graft is to reconstruct the bony defect and replace the absent alveolar bone. The optimum time for an alveolar bone-graft is determined by the position of the crown, and when the root of the permanent canine is approximately half-formed (Abyholm, Bergland, & Semb, 1981; Ames, Ryan, & Maki, 1981; Bergland, Semb, & Abyholm, 1986; Boyne & Sands, 1972). This occurs at approximately 8 to 11 years for many patients with CL/P.

1.6.6 ENT Issues

Varying levels of hearing loss is a known complication of cleft palate but the extent of this problem is not generally appreciated. Children with a cleft palate may have many years of recurrent otitis media which affects hearing (Grant, Quiney, Mercer, & Lodge, 1988) and which may further delay speech and language development. Otitis Media is managed by the insertion of ventilation tubes (grommets) through the tympanic membrane under a general anaesthetic (I. J. Moore, Moore, & Yonkers, 1986; Robson et al., 1992; Weigel MT, Goldsmith, Postma, & Pilsbury, 1989). Follow-up review and investigation may be required into the adult years.

1.6.7 Speech

Children with a cleft palate are at a higher risk of developing abnormal speech patterns due to the oral anatomy being malformed. The aetiology of speech problems usually involves a number of factors and will generally require speech therapy and/or surgery for correction. (Grunwell, 2001; Wood & Jurkiewicz, 1999).

1.6.8 Dental aspects

Compared with the general population, patients with CL/P have been found to have a higher prevalence of dental anomalies, such as variations in tooth number and position, and reduced tooth size (most of which are found in the site of the cleft). There may be a variety of malformed, malpositioned, missing or duplication of teeth or defective enamel (Nicholls, 2016; Ribeiro, DasNeves, Costa, & Gomide, 2003).

1.6.9 Orthodontics

Orthodontic treatment requires a specific timed and sequenced regime to ensure the best functional and aesthetic result to correct both dental and skeletal discrepancies which add to dental malocclusion (Friede & Katsaros, 1998). The gold standard for measuring outcomes of dental and skeletal malocclusion is the Goslon yardstick (Nicholls, Singer, Southall, & Winters, 2014).

The focus of orthodontics during the mixed dentition stage is the preparation for alveolar bone-graft. The focus of orthodontics in the permanent dentition is to assess and plan the most effective outcome for both function and aesthetics for the patient, which may be undertaken by conventional orthodontic treatment techniques, or with the addition of surgery (Lilja et al., 2006). Prosthetics may also be required in terms of veneers, bridges, implants and crowns to offer the most aesthetic outcome (Bergland et al., 1986; Semb, 1991).

1.6.10 Orthognathic surgery

Surgery to correct the jaw relationship or orthognathic surgery is usually performed at growth completion, when the permanent dentition has fully erupted. Some patients will require surgical procedures on both the maxilla and mandible with or without rigid fixation utilising plates and screws (Phillips, Nish, & Daskalogiannakis, 2012).

1.6.11 Rhinoplasty

Nasal deformities associated with cleft may require secondary rhinoplasty which is performed at growth completion (Lo, 2006). The purpose of the primary repair is to reduce the abnormality during the years of growth and to provide a base for growth to have symmetry. The purpose of secondary rhinoplasty is to improve both function and appearance with attention to nasal breathing and facial appearance (Lo, 2006; Salyer, 1992).

1.6.12 End-stage

End-stage or definitive surgery can be complex, requiring precise surgical planning and techniques and may involve revision surgery of the lip and nose and is performed after all other skeletal and dental discrepancies have been corrected. Further speech therapy may be required once final surgeries are completed (Hester, Jurkiewicz, Meyer, Cunningham, & Eros, 1985).

1.7 Timeline of psychological issues related to the cleft condition

Just as the physical issues related to the cleft condition are complex, the psychological adjustment to the challenges of living with a cleft is also multifactorial, involving a combination of psychological and social factors. Patients with CL/P are considered to be at greater risk for psychosocial problems than those without the condition (Feragen & Borge, 2010; Murray, Arteché, Bingley, Hentges, & Bishop, 2010; Pinquart & Shen, 2010).

Accompanying the physical care component, psychological care and support is also required across the lifespan to meet the changing needs of patients and their families over time. To assist in exploring the perceived impact of CL/P on sociological adjustment, functioning and

life outcomes, the following timeline details the potential psychological issues within each age-group and across the lifespan.

1.7.1 Parenting and birth (0 to 5 years)

The birth of a child with CL/P is an emotionally demanding experience which may include a coincident combination of shock, guilt, despair, and grief (Vanz & Ribeiro, 2011). The quality and carriage of information the parents receive from health care professionals has a direct impact on the level of distress they experience and may influence their ability to cope (Chuacharoen, Ritthagol, Hunsrisakhun, & Nilmanat, 2009; Vanz & Ribeiro, 2011). Even though many clefts are only diagnosed after the baby is born, an antenatal diagnosis may offer parents more time to accept and prepare themselves emotionally and psychologically for the birth, or may add anxiety for which the birth brings emotional resolution (Davalbhakta & Hall, 2000). Parents experience varied emotions following the birth of the child including denial, anger, blame, distress and anxiety. As the one that carries and physically nurtures the unborn child, mothers often feel intense guilt and look to what they may have done or not done to be at least partly responsible for their child having CL/P (Chuacharoen et al., 2009; Martin, 1995). Stock and Rumsey (2015) report that following a diagnosis of cleft in their child, parents are likely to feel “shocked and daunted by the potential challenges that lie ahead (p.31).” Williams et al. (2012) identified the most common questions that parents have are:

- what caused the cleft to happen?
- why did this happen to us? and,
- will their child be ok?

Several factors which may affect the family adjustment and coping ability, including uncertainty regarding the child's immediate physical condition and long-term prognosis, severity of the condition, frequency of medical appointments, time needed for treatment therapies, lack of social and physical support and increased financial burden (Cohen, 1999; Macias, Saylor, Haire, & Bell, 2007; McKinney & Peterson, 1987). These factors may increase stress and disrupt the family balance and functioning (Folkman, 2008; Patterson, 2002).

Families may also need additional support for the following areas: dealing with the reactions for other people, adjusting to their child's change in appearance following surgery, being able to talk about CL/P with their child once their child has reached an appropriate age to understand, accessing genetic counselling and a comprehension of the environmental and genetic factors associated with CL/P (Stock & Rumsey, 2015).

The experiences of the first weeks after their child is born can affect parental adjustment and wellbeing. Negative reactions from friends, family members, healthcare professionals and members of the public can result in considerable distress and may lead parents to attempt to conceal the cleft, and has the potential to result in social withdrawal, at least until the initial surgery has been performed (Nelson, Kirk, Caress, & Glenny, 2012).

Parents may anticipate social difficulties for their child, in particular peer-integration, especially when starting at kindergarten or school. This may cause additional parental stress and concern (Nelson et al., 2012). During the years 0 to 5 parents will also experience the worry of their child undergoing surgical intervention for lip and palate repair, and possibly grommet insertion. There may also be the requirement for further plastic reconstructive revision of the lip or nose in readiness for the child to attend school and surgery for velopharyngeal insufficiency. There are also many follow-up outpatient visits which will be required for all the cleft specialties including dental, ENT and speech and extra corrective speech therapies at home. Parents may be ever observant for their child to successfully achieve the standard growth and developmental milestones. Parents have highlighted the physical and emotional demands, time and financial costs, and logistical travel and treatment complexities of having a child with a health condition such as CL/P as causing stress and anxiety (Kramer, Gruber, Fialka, Sinikovic, & Schliephake, 2008; Locker et al., 2005; Reichman, Corman, & Noonan, 2008).

1.7.2 Childhood (preschool and school-age, 6 – 12 years)

The age range of 6 to 12 years is a significant period in terms of social interaction and education. It is the most crucial period of lifespan development (WHO, 2007), when the foundations are placed for every individual's physical and mental capacities which influence their subsequent growth, health, and development. This is also the period of the life span which is the most highly sensitive to external influences and impacts that may affect the development of self-worth and personal interactions.

It is at this age that children make friendships, and experience changes to their social and community groups (i.e. schools, sporting clubs and extra-curricular groups). For a child with CL/P there are additional concerns with their appearance, both facial and dental, clarity of speech and level of hearing which may result in teasing and/or bullying. There is correspondingly a burden of care which directly relates to the time missed from school to attend appointments. This may include ENT and dental treatment, speech therapy, orthodontics and, potentially, to undergo an alveolar bone-graft. This treatment burden may strongly impact a child both socially and academically who may already have issues with friendship formation and social relationships (Damiano et al., 2006).

Previous research has identified children with CL/P to have increased social inhibition when compared to their peers without CL/P, (especially girls), to be less willing to jeopardise their established friendships, and have difficulty in instigating and maintaining friendships (Frederickson, Chapman, & Hardin-Jones, 2006; Murray et al., 2010; Pinquart & Shen, 2010; Pope, Tillman, & Snyder, 2005; Slifer et al., 2006). Feragen and Borge (2010) described children with CL/P as being less receptive and self-confident than their peers. They further found that children with CL/P may have greater degree of perceived peer persecution, appearance dissatisfaction and habits of learned helplessness (Hearst, Shearer, & Ranger, 2005).

Lower self-esteem and self-confidence, lower satisfaction with their physical appearance, and increased behavioural problems compared with their peers without the condition, has been reported by Pillemer and Cook (1989) and Hunt, Burden, Hepper, Stevenson, and Johnston (2007). Other studies (Broder & Strauss, 1989; Ramstad, Ottem, & Shaw, 1995) suggest that individuals with CL/P may be at risk of experiencing problems with adjustment, self-esteem, and social interactions. Pope and Ward (1997) found self-perceived facial appearance to be a central factor for adjustment because it is positively associated with overall self-esteem and self-viewed social approval, and negatively associated with social isolation.

Children with CL/P have been reported to have a lower self-concept when compared with their peers, with a self-view of social discomfort, more negative emotions, less likeable to their peers and report being less satisfied with their facial appearance (Broder & Strauss, 1989; De Sousa, Devare, & Ghanshani, 2009; Kapp-Simon, Simon, & Kristovich, 1992; Slifer et al., 2004). Pillemer and Cook (1989) found that greater facial and physical attractiveness was associated with increased overall adjustment, and that appearance satisfaction was an essential part of that adjustment. There are conflicting findings in the literature concerning adjustment in childhood. Social acceptance and satisfying relationships cannot be accurately predicted and in isolation to facial attractiveness, but included other elements relating to personality, social and family support and circumstances, personal life experiences and accompanying coping abilities and social confidence (Feragen et al., 2010).

Broder (2001) found that children with CL/P were teased more than their peers (without CL/P). Teasing was associated with speech and hearing difficulties and facial appearance. Participants reported frequent teasing about their facial appearance in childhood with 69% of 10-year-old children having experienced teasing and/or bullying on a regular basis (Noar, 1991; Turner, Thomas, Dowell, Rumsey, & Sandy, 1997). Sharif, Callery, and Tierney (2013) found in their systematic review of qualitative literature that most young people described having experienced bullying and negative reactions from others to their facial appearance.

They also found that teasing, bullying and negative reactions could be undermining to an individual's personal concept of not being different, and that talking about bullying with parents was reported as helpful, but was not readily or frequently engaged in.

1.7.3 Adolescence and early adulthood (13 - 21 years)

Lioffi (2003) describes adolescence as a chronologically difficult time, and for young people with CL/P this may be particularly difficult, as differences in appearance and/or speech and/or hearing may severely limit their ability to merge with their peers be perceived as 'typical', which is an integral aspect of adolescent wellbeing. There are many issues which affect psychosocial factors and outcomes such as speech and hearing difficulties, dissatisfaction with appearance (Berger & Dalton, 2011; Bilboul et al., 2006), perceived teasing and bullying which impacts self-confidence, overly critical subjective ratings of appearance and emotional distress (Feragen & Borge, 2010).

The inherent physical differences of the CL/P condition and the significant treatment burden further complicates a time where adolescents struggle with identity issues, puberty, peer recognition and acceptance, and conformity to peer norms. A cross-cultural meta-analysis has shown that regardless of culture, psychosocial functioning of individuals with CL/P is poorer than that of individuals without it (Hutchinson, Wellman, Noe, & Kahn, 2011).

The majority of problems reported by adolescents relate to difficulties with their peers, such as bullying, teasing, name calling, and being questioned about speech or scarring. It is therefore unsurprising that adolescents, who have concerns about their appearance or their speech, use avoidance strategies (e.g., social withdrawal) to cope with difficult situations (Endriga & Kapp-Simon, 1999; Kapp-Simon, 1995; Turner, Rumsey, & Sandy, 1998).

Adolescence is normally the first period of increased interest in significant other relations and intimate experiences which in general can be a time of heightened struggles with appearance-related concerns (O'Dea, 2006).

There may also be considerable anxiety for those patients who must cope with further reconstructive surgeries which will change their facial appearance (Hearst, 2007). Cleft-related orthognathic surgery is a procedure that does not occur until adolescents have reached skeletal maturity. Accordingly, there may be many years spent anticipating this surgery, constituting a significant burden of care for both the individual and the family. Adolescents may have unrealistic expectations of aesthetic change following surgery (Cadogan & Bennun, 2011) and may have difficulty in adjusting to their facial changes as a result of surgery.

1.7.4 Adults (22 - 40 years +)

The concept of attractiveness has an important effect on psychological development and social relationships. Anxiety and depression have been reported to be twice as prevalent among adults with CL/P compared with groups without CL/P. Ramstad et al. (1995) found that, compared to healthy controls, adults with CL/P reported anxiety and depression approximately twice as often, and these psychological problems were associated with concerns about appearance, dentition, speech, and desire for further treatment. Adults with a repaired cleft may report dissatisfaction with surgical outcomes and report express their interest for further corrective treatment and surgeries. Marcusson et al. (2002) reported in their study that 47% of the participants requested further surgeries to improve their facial appearance, particularly rhinoplasty. The transition into adulthood and the completion of definitive surgical treatment usually signifies the end of the care pathway, and the majority of patients lose touch with the services that have been a regular part of their lives until this point and the care responsibility is transferred to the individual. This may leave patients with uncertainty of how to access service providers and the burden of the care responsibility.

The general health of adults may also be influenced by having CL/P. Hunt, Burden, Hepper, and Johnston (2005) found evidence to support that those adults with repaired CL/P experience higher levels of psychosocial problems when compared to controls. Adults with CL/P were reported by Ramstad et al. (1995) to be twice as likely both to experience clinical levels of anxiety and depression and to take their lives in their later years, when compared to the population without CL/P. There was an increase in mortality rate of 55% for individuals with CL/P reported by Christensen, Juel, Herskind, and Murray (2004) which was constant over age intervals to 55 years.

Cheung et al. (2007) found that among adults with CL/P, compared to controls, social anxiety was increased, but self-esteem was lower. In the same vein, Berk, Cooper, Liu, and Marazita (2001) reported that, compared to siblings without CL/P, adults with CL/P had lower scores for self-esteem and social support, and higher scores for levels of social anxiety. They concluded that, compared to siblings without CL/P, adults with CL/P may be more disadvantaged with respect to competence and confidence with social interactions.

In contrast, Chetpakdeechit, Hallberg, Hagberg, and Mohlin (2009) found that young adults with CL/P who were receiving acknowledgement and appreciation from significant people in their lives reported higher self-esteem and greater ability to interact in their social lives. Eiserman (2001) also reported positive findings in that living with CL/P may provide the opportunity and experience to develop resilience, coping techniques and confidence to deal with life challenges.

This study also found that people who have CL/P may discover worthy friendships without regard to their appearance. A. Thompson and Broom (2009) found that people living with any kind of appearance difference may discover significance in other aspects of their lives other than appearance, such as family and their career, which may offer achievement and personal fulfilment.

1.8 Case Study Site

The majority of this research was conducted at one case site in Australia – the Child and Adolescent Health Service at Princess Margaret Hospital for Children (PMH). This is the oldest cleft unit in Australasia and is internationally recognised as a centre for excellence in cleft care. This site was chosen due to its reputation both for care and as a repository for record-keeping and audit. It is the workplace of the author of this thesis, and is the only cleft care centre in Western Australia.

The PMH CL/P Unit reviews and provides treatment to an average of 50 (range from 48 to 62) live born patients with cleft lip and palate each year. Patients with CL/P require treatment up to and beyond growth maturity which may extend to 28 years of age for particular patients. Treatment includes regular clinic follow-up, including individual specialty annual review and Cleft Clinic protocol reviews, specialist consultation and treatment, and review of ongoing surgical needs (see Table 1).

Over the treatment lifespan there is a potential requirement for access to psychological services of episodes of care, ranging from outpatient educational support, to therapy, assessment, outpatient and inpatient treatment and surgical intervention, particularly with appearance-altering surgery.

Although it is recognised as a centre for excellence in cleft care, the PMH CL/P Unit does not have dedicated psychosocial support as international best practice recommends (Shaw et al., 2005; Verhoeven, Kilpatrick, Heavey, & Reilly, 2013). Psychological services within the protocol, and prior to appearance-altering surgical intervention are undertaken by the following avenues;

- the Child and Adolescent Mental Health Services in community-based settings,
- privately funded Mental Health Practitioners, and
- General Practitioner referral programs funded under the Medicare Mental Health Scheme (CAHS, 2015).

The following table outlines the PMH Cleft Protocol Timeline of Patient Management.

Approximate Age of Patient	Surgical/Dental/ENT/Speech Pathology
Antenatal	Consult with plastic surgeon if diagnosed on ultrasound
Neonate	Neonatal Unit admission. Review by dental and plastic surgery. Photography. Newborn hearing screening
Neonate to 3 months age	Pre-surgical orthopaedics for all complete clefts
3 months	Lip and anterior palate repair
3 - 6 months	Parent counselling session with Speech Pathology
6 months	ENT review
9 months	Cleft palate repair +/- grommets
1, 2 ,3 years of age	Cleft lip and palate team review.
3 – 6 years	Close surveillance of dental development, hearing and speech (Pharyngoplasty if indicated)
7.5,9,12,15,18 years of age	Protocol records and cleft team reviews
8– 10 years	Mixed dentition orthodontics
9-12 years of age	Alveolar bone graft
12-15 years of age	Permanent dentition orthodontics
18 years of age onwards	Orthognathic surgery if indicated. Final rhinoplasty 3-6 month's post-orthognathic surgery.
Final Cleft lip and palate team review	12 months post-completion of all surgery and removal of all Orthodontic appliances.

Table 1. PMH Cleft lip and palate Timeline of Management

Chapter 2 Thesis Literature Review

2.1 Introduction

This chapter provides a summary of the literature published from January 1970 to June 2015 related to the psychosocial impacts of cleft across three significant developmental age cohorts:

- Childhood (preschool and school-age, 6 – 12 years);
- Adolescence and early adulthood (13 - 21 years); and
- Adulthood (22 - 40 years +) sequelae

The purpose of this review was to contribute to the current gaps in knowledge by investigating and gaining an understanding of the patient perception of CL/P across three age-groups. The review aimed to assess whether children, adolescents and adults with CL/P are at increased risk of developing psychosocial problems compared to the general population and to identify the types of psychosocial impacts and problems which may develop within each age-group. It explored the perceived impact of CL/P on sociological adjustment, functioning and life outcomes. This review also investigated any recommendations, including trialled interventions reported to address these problems and provided future research directions.

Individuals with CL/P may encounter many challenges and the ability to conceptualise these challenges requires a broad framework. The scope of the framework must have the ability to include and address the biopsychosocial factors involved including the wider social and cultural impacts, cleft-specific impacts, burden of care, appearance differences and potential psychological distress. It must also allow for the investigation of the deeper meaning for the individual. The literature lacks a consistent framework from which to both address and evaluate the challenges faced by individuals with CL/P and has many theories and models which have guided the studies and influenced practice, but have not offered comprehensive study tools which have been readily and widely adopted. There must also be not only recommendations for trialled interventions but also provide results from interventions undertaken.

This review of the current body of knowledge, in particular evaluating the similarities and inconsistencies in results reported in the literature and the differences in the methodologies used, highlighted gaps both in the literature and the methodologies used, and identified a need for mixed methods studies and studies which included evaluation across the age-span. It also highlighted the dearth of knowledge from an Australian perspective.

2.2 Research questions

The literature review utilised the identified gaps in knowledge in the current literature to guide the research undertaken in this thesis so to add to the current base of knowledge. The findings from the literature review were the key influences used to formulate the research questions and guide the methodological choices made in the thesis document. They offered a concise, focussed structure which was still broad enough to provide a platform from which to identify and evaluate the strengths and weaknesses of the literature and at the same time to answer the overarching premise of the thesis. The research questions and subsequent analysis were a platform from which to review the inconsistencies in results reported in the literature and the differences in methodologies used. Three research questions were formulated from the key influences of the literature review to structure and identify the gaps in knowledge.

- Are children, adolescents and adults with CL/P at increased risk of developing psychosocial problems?
- What types of psychosocial problems developed within each age-group?
- What are the recommendations and trialled interventions to address these problems?

2.3 Literature review methodology

2.3.1 Inclusion criteria

There was no restriction on study design or method of measurement of research papers. Randomized controlled trials, longitudinal studies, cross-sectional studies, and retrospective studies, all with and without controls, were considered for inclusion. Self-reports and the reports by others were considered suitable. Dissertations and papers from 1970 onward were included due to the paucity of data in certain areas of investigation including vocation and education. Literature reviews by other researchers were included to provide a background to previous research.

2.3.2 Exclusion criteria

Studies solely investigating parental or sibling perspective or solely investigating cognitive impacts were excluded as were studies involving syndromic CL/P. Searches were restricted to English language journals with one exception which was a translation from French to English (Danino et al., 2005). Studies with subjects outside of the age-groups were excluded.

2.3.3 Search strategy

The following sources were searched: PubMed (January 1970 to June 2015) and Medline (ovid) (January 1970 to June 2015). Many variations of the keyword of 'cleft' (including cleft lip, cleft palate and cleft lip and palate) with the "AND" operator with the keyword 'psychosocial' (including psychosocial problems and psychosocial impacts) were used to source the literature. The keywords and the terms psychosocial problems and impacts were searched and categorised into four key domains of adjustment for this review:

- self-esteem and self-worth;
- social inhibition and isolation;
- depression and anxiety; and
- appearance dissatisfaction.

The literature search was performed by the first author between October 2014 and December 2014, and was subsequently updated at the end of May 2015.

2.4 Results

2.4.1 Included articles

The initial search yielded 188 articles. The reference section of included articles was subsequently searched for relevant articles, and hand searching of two relevant journals of included articles; Cleft Palate-Craniofacial Journal and the European Journal of Orthodontics. This yielded a further 24 articles.

There were 212 abstracts initially identified as potentially meeting the inclusion criteria. Full examination of these abstracts against the inclusion criteria determined 136 were initially suitable. On examination of the full text articles only 83 were determined as meeting the inclusion criteria. These were comprised of 66 studies (10 mixed methods, 9 qualitative, 40 quantitative, 6 registry studies, 1 case study), and 17 review articles. The 66 studies came from 18 countries (the most represented being the USA (23), UK (11) and Canada (7)), 19 of which included a control group and 7 used normative values. Sample sizes varied with 27 studies having less than 50 subjects, 29 having less than 300, 6 having less than 700 and 4 with greater than 700 subjects.

The study focus, country, sample size, methods, major findings and recommendations for 66 papers are summarised and have been copied direct in the Supplemental Table (see Appendix 2). Review articles are not included in this table.

The findings pertaining to each domain are described in relation to their impact on individuals with CL/P across age-group, as well as the contributing factors of gender and type of cleft. Potential associations across the age-groups are also presented where appropriate. Findings were examined and presented to address the research questions.

2.4.2 Are children, adolescents and adults with CL/P at increased risk of developing psychosocial problems?

Overall, the literature reports that children, adolescents and adults with CL/P do not appear to experience major psychological disorders, however, they are at a higher risk of developing specific psychosocial problems in four key domains:

- self-esteem and self-worth (Endriga & Kapp-Simon, 1999; Pisula, Lukowska, & Fudalej, 2014; Turner, Rumsey, & Sandy, 1998),
- social inhibition and isolation (Kramer et al., 2009; Murray, Arteché, Bingley, Hentges, & Bishop, 2010; Peter & Chinsky, 1974; Snyder, Bilboul, & Pope, 2005),
- depression and anxiety (Foo, Sampson, Roberts, Jamieson, & David, 2012; Hunt, Burden, Hepper, Stevenson, & Johnston, 2006; Mani, Carlsson, & Marcusson, 2010; Pinquart & Shen, 2010; Ramstad, Ottem, & Shaw, 1995a),
- appearance dissatisfaction (Endriga & Kapp-Simon, 1999; Feragen & Borge, 2010; Marcusson, Paulin, & Ostrup, 2002; Turner et al., 1998).

The age range of 6 to 12 years is a key period in terms of a child's integrational abilities in educational and social contexts, which influences their development of self-worth and self-concept (Hearst, 2007). Of the 28 papers that included the children's age-group, 25 (89%) indicate that having a cleft condition leads to a heightened risk of developing psychosocial problems for children. Only 4 (14%) reported a low incidence of negative social experience (Feragen & Borge, 2010), a normative self-concept (Gussy & Kilpatrick, 2006), and to be functioning adequately within normal range on standardized psychometric measures (Pertschuk & Whitaker, 1982).

Adolescence has been described as a complicated time for young persons with a cleft condition (Lioffi, 2003) who must deal with a burden of cleft-related treatment commitments as well as differences in appearance, speech, hearing and cognition may restrict their capacity to merge with their peers which may in turn affect psychosocial adjustment (Berger & Dalton, 2011; Bilboul, Pope, & Snyder, 2006). Of the 38 papers that include the adolescent age-group, 34 (89%) reported a higher risk for developing significant psychosocial problems including: lower self-esteem and self-confidence; appearance and body-image dissatisfaction; social inhibition; and emotional anxiety (De Sousa, Devare, & Ghanshani,

2009; Feragen & Borge, 2010; Hunt, Burden, Hepper, & Johnston, 2005; Millard & Richman, 2001; Pisula et al., 2014). A cross-cultural meta-analysis by Hutchinson, Wellman, Noe, and Kahn (2011) has shown that, regardless of culture, psychosocial functioning of individuals with CL/P is affected negatively in comparison to those in their control group. Key psychosocial problems which present in childhood can become exacerbated in adolescence. In contrast, Berger and Dalton (2009) did not find increased psychosocial difficulties for the cleft group in their study. They propose reasons for these findings to be that the group with CL/P had the required social support, life experience of the condition, learnt coping skills or accessed support from their health care team. Another reason proposed was a sampling issue whereby those with psychosocial issues may not have contributed to their study.

For the majority of individuals in the adult age-group with CL/P, treatment for function and aesthetic improvement has been completed, however, the psychosocial impact of cleft may continue throughout the lifespan. Of the 30 papers that included the adult age-group, 25 (83%) reported negative psychosocial impacts of CL/P. The problems that emerged in childhood and were exacerbated in adolescence may become established in adulthood. Findings indicate there is a heightened risk for psychosocial problems in the four key areas (self-esteem/self-worth, social inhibition/isolation, depression/anxiety, and appearance dissatisfaction) in addition to insecure attachments, learning difficulties, and lower satisfaction with their relationships and family life (Broder, Smith, & Strauss, 1994; Hunt et al., 2005; Noar, 1991; Peter, Chinsky, & Fisher, 1975; Ramstad et al., 1995a; Turner et al., 1998).

There were 7 (23%) papers which reported positive outcomes from CL/P in adulthood. Chetpakdeechit, Hallberg, Hagberg, and Mohlin (2009) found that young adults (ages 24 to 33 years) with CL/P who were receiving recognition from significant others reported higher levels of self-esteem and increased ability to cope; Patel and Ross (2003) reported adults with CL/P felt that their cleft did not affect their family or marital life; and Eiserman (2001) reported the experience to develop coping techniques and confidence in dealing with life challenges.

Of the 66 studies reviewed, 12 (18%) presented some positive outcome for CL/P, while, 57 (86%) reported negative psychosocial problems across the age-groups. This may be due to a combination of factors including sampling and study focus. Eiserman (2001) proposed: a) that as a matter of course, researchers focus on results which show a negative effect and often do not consider what might be learnt from results which are positive in nature and b) that there would be great benefit in examining the outcomes of positive results to determine their ability to influence intervention programmes to focus on discovering and affirming personal strengths.

Two studies predominantly identified positive outcomes: Eiserman (2001) and Sinko et al. (2005), although the latter study did report that patients who desired further surgical treatment had significantly lower quality of life scores than patients who did not desire additional treatment.

2.4.3 What are the types of psychosocial problems developed within each age-group?

Psychosocial problems for children can manifest in behavioural and emotional issues such as: inappropriate and unwanted social behaviour (Richman & Eliason, 1982); experiences of stigma (Strauss & Fenson, 2005); withdrawal and internalisation of problems (Pope & Snyder, 2005); gaze avoidance (Slifer et al., 2006); and shyness (Boes et al., 2007). Children with CL/P have also been reported to see themselves as socially uncomfortable, more sad or angry, less appealing and less satisfied with their facial appearance (Broder & Strauss, 1989; De Sousa et al., 2009; Slifer et al., 2006).

Studies have shown an inter-relationship between appearance, social stereotyping and expectation (Clifford, Walster, & Pope, 1973; De Sousa et al., 2009; McComb, 1975). Differences in facial appearance are readily noticeable and are central to forming impressions and stereotypic assumptions (Berscheid & Gangestad, 1982; Clifford et al., 1973; Clifford, Walster, & Pope, 1978). Dion, Berscheid, and Walster (1972) describe findings indicating attractive children as being perceived as happier, and show more confident social behaviour than less attractive children. Pillemer and Cook (1989) found that greater facial and physical attractiveness correlated with better overall adjustment and that satisfaction with appearance was an essential part of that adjustment. Those children with a less attractive facial appearance have a less positive social behaviour and self-esteem, and a high incidence of teasing over their facial appearance (Bernstein & Kapp, 1981). The perceptions of children with a cleft by others have been found to be unfavourable, whereby teachers, peers and unfamiliar adults often rate them as less attractive, less intelligent and less popular (Broder & Strauss, 1989; De Sousa et al., 2009; Slifer et al., 2006).

Children with cleft are often reported to have social interaction difficulties. Murray et al. (2010) identify an increased risk for social inadequacy during this period especially in regard to developing friendships and participating in organisations and social groups. Turner et al. (1998) and Endriga and Kapp-Simon (1999) found that children with cleft condition may have difficulties with social interaction due to discomfort with their appearance. Brand et al. (2009) discuss the link between having a cleft condition and impaired psychosocial functioning, particularly a lower level of personality strengths and more difficulty with and reduced participation in daily life compared with a non-cleft group.

Results of their study indicated that children with a cleft were six times more likely than those without a cleft to have interactional difficulties and increased deficits in their general social behaviours. These difficulties were in situations outside of the family environment, predominantly in social situations with unknown people and/or with unknown expectations. Children with a cleft condition generally have a close bond with at least one of their parents, relying on them for social support in place of forming relationships with their age-appropriate peers. In some cases, this may be linked to parental over-protectiveness (Pope & Ward, 1997).

Children with CL/P, (especially girls), have been identified as more socially inhibited than their peers (Murray et al., 2010; Pope & Snyder, 2005). Difficulties with communication also can affect social interaction, relationships and psychological well-being. For a child with CL/P there are extra concerns with their appearance, clarity of speech and level of hearing. Feragen and Borge (2010) reported that most children with a cleft condition have satisfactory conversational skills, but are less responsive, assertive and confident than their peers. This may be a result of increased problems with speech and insecurity in regard to social relationships (Kramer et al., 2009).

The literature reports the incidence of teasing in children with CL/P is generally higher than in control groups which may directly influence the child's level of psychosocial wellbeing. Broder (2001) found that children with CL/P were teased more than their peers which was usually directed at issues of speech and hearing difficulties and facial appearance. Noar (1991) reported that 69% of 10-year-old children in their study who had a cleft experienced teasing and/or bullying on a regular basis. Hearst (2007) also found that children with a cleft condition, especially where there is a visible facial difference, had higher levels of perceived peer harassment, dissatisfaction with appearance and patterns of learned helplessness. Hunt et al. (2006) reported that being teased was a strong predictor of significantly lower psychological functioning and that children with CL/P were more likely to be teased in social settings, especially school, and reported more physical bullying, than those without.

A higher incidence of learning difficulties amongst children with CL/P and the added problem of time missed from school may strongly impact a child both socially and academically. Richman and Eliason (1982) found that a significant percentage of children with CL/P were academic underachievers, exacerbated by appearance-related behavioural inhibition, communication difficulties and the effect of decreased expectation by both teachers and parents. Knight, Cassell, Meyer, and Strauss (2015), Persson, Becker, and Svensson (2008) and Persson, Becker, and Svensson (2012) also found that children with CL/P had lower academic outcomes than peers without CL/P due to cognitive deficits and learning disabilities. Broder, Richman, and Matheson (1998) found the estimated rates of learning

disorders ranged from 30 to 40% (more common in boys) for children with CL/P compared to the general population range of 10 to 20%. Richman, McCoy, P, Conrad, and Nopoulos (2012) reported a 36% rate of reading difficulty, deficits in language expression, memory and processing speed in children with CL/P, and identified specific weaknesses with visual memory and reading ability. These weaknesses, coupled with the potential for many missed days from school to attend appointments, may make an overwhelming burden to attain and maintain an acceptable level of academic achievement.

Social interactional difficulties increase with the transition from childhood to adolescence. Brand et al. (2009) reported that the majority of problems for adolescents with CL/P relate to peer- difficulties, such as bullying, teasing, name calling, and being stared at or questioned about their speech or visible scarring. Adolescents with concerns about their appearance or their speech, may use behaviours of avoidance and social withdrawal as a way to cope with difficult situations (Endriga & Kapp-Simon, 1999; Kapp-Simon, Simon, & Kristovich, 1992; Turner et al., 1998). Slifer et al. (2004) found that teenagers with CL/P responded less often to questions from peers and made fewer choices during interactions in comparison with their peer-group. Brand et al. (2009) found adolescents with CL/P have social skills deficits in their overall social settings, reporting social difficulties six times more often than children and adolescents without CL/P.

During adolescence, facial appearance concerns and speech problems caused by CL/P are often major stress factors affecting social relationships (Kapp-Simon et al., 1992; Millard & Richman, 2001). There is also added stressors and potential social isolation due to further revision and reconstructive surgeries which both affect facial appearance and require significant recovery times (Hearst, Shearer, & Ranger, 2005). Teasing and bullying also affect social interaction (Rumsey & Harcourt, 2007), as well as experiences of stigma due to facial appearance differences (Beaune, Forrest, & Keith, 2004; Lowenstein et al., 2008; Strauss & Fenson, 2005). Noar (1991) reported that 58% of 15-year-old children with CL/P in their study were frequently teased about their facial appearance. Sharif, Callery, and Tierney (2013) found in their systematic review of qualitative literature that the majority of adolescents with CL/P described having experienced bullying and negative reactions of others to their facial appearance. They also found that this could undermine the sense of wanting to feel and be seen with a sense of normality.

Adolescence is also normally the first period of increased interest seeking intimate experiences. As a result of concerns with their appearance, the presence of CL/P becomes a matter of considerable concern for adolescents. Tiemens, Nicholas, P, and Forrest (2013) found that adolescent girls felt stress related to having a facial difference, but are able to develop strategies to assist in coping with the perceived difference.

This study further found that adolescent girls viewed plastic and reconstructive surgery as a valid strategy to improve their self-confidence by improving their perceived appearance.

Parent-child relationships have been reported to impact the psychosocial development of adolescents. Speltz, Greenberg, Endriga, and Galbreath (1994) describe that both overprotective and ambivalent family responses can impede emotional adjustment. Delays and struggles with independence from family and other significant adults may delay the adolescent's transition to adulthood. A factor which may also affect the adolescent's psychological adjustment is the degree to which they feel in control of their treatment or have had the opportunity to be part of the treatment decision making process. Adolescents may disagree with parents and/or health care professionals about treatment options and the point at which to end surgical or orthodontic treatment leading to conflict between the parties involved (Collett & Speltz, 2007). This may be linked to the difference in rating of appearance. Thomas, Turner, Rumsey, Dowell, and Sandy (1997) identified differences in ratings between parent and child at age 15 years suggesting that parents were more satisfied with the appearance than the adolescents themselves. Collett and Speltz (2007) describe an added complication of the requirement for further corrective or aesthetic surgery being suggested by the parent, who has the final outcome in mind, which may be misinterpreted by the adolescent as disapproval or harsh judgement of their appearance. Kapp-Simon (1995) discussed the situation of the adolescent stating their desire to cease further surgery, for reasons of self-acceptance or time away from treatment with the aim of gaining a time of normality in their life, and the parent being ever-vigilant to ensure their child has the opportunity to receive the best care at the best timing. The adolescent may also feel extra pressure to be instrumental in the decision-making aspects of their care and relate to health care professionals from a position which was previously solely the responsibility of their parents (Kapp-Simon et al., 1992).

A major treatment issue associated with CL/P is the difficulty in predicting the final outcome of treatment which may only be assessed once the patient has reached growth maturity. This may be when the patient has reached twenty years of age (Sinko et al., 2005) and may have been influenced by the patient's rate of growth, physical development, and inconsistent level of cooperation. Quality of life measures are often used to justify the need for further aesthetic or function-related surgery (Edwards et al., 2005), and also to gain an understanding of an adolescent's perspective. There has been an increase in research measuring quality of life for adolescents with a cleft condition (Edwards et al., 2005; Patrick et al., 2007), but this has been limited in understanding the experience of adolescents in anticipation of facial reconstructive surgeries. Patients may spend years anticipating this surgery and all it will entail, including dramatically changing their facial appearance.

Cadogan and Bennun (2011) reported that adolescents may have improbable or naïve expectations of the aesthetic change following surgery and may not anticipate the possible emotional impact. They found that patients experienced difficulty in adjusting to their facial changes as a result of surgery. Pertschuk and Whitaker (1982) found the timing of appearance-changing surgeries positively influenced self-esteem and lower social isolation if performed before the teenage years. However, this is not possible with cleft-related orthognathic surgery which is undertaken at skeletal maturity in late adolescence.

Studies have also found significantly lower general intellectual scores in adolescents with an isolated cleft palate (Persson et al., 2008) due to cognitive deficits and learning disabilities. This may subsequently affect educational achievement. Richman and Eliason (1982) and Persson et al. (2012) found that adolescents with a cleft condition underachieve in the classroom and experience significant deficiencies in their educational standards in compulsory school. Compared with the general population, the group with CL/P were less likely to achieve their school leaving certificates. Eide, Skjærven, Irgens, Bjerkedal, and Oyen (2006) also found intellectual functioning was adversely affected in the cleft palate only group in their study.

Amid the recognition of the many challenges and negative experiences of the cleft condition, there is a growing interest in recognising the positive potential that has been experienced including, sensitivity and understanding towards others; ability to help others, and resilience (Eiserman, 2001; Lowenstein et al., 2008; Strauss & Fenson, 2005). Locker et al. (2005) reported few differences when examining the quality of life between those in their group with CL/P and control group. The issues reported were problems with speech, missing school, being teased, and being questioned about their cleft but this study suggested the group with CL/P had the social skills to cope with these issues.

Adults with CL/P are reported to have much higher levels of social anxiety and lower levels of self-esteem. Berk, Cooper, Liu, and Marazita (2001) found that, compared to siblings without CL/P, adults with CL/P had poorer scores for self-esteem and social support, higher scores for social anxiety, and were disadvantaged with respect to social interaction and resilience/adaptation. Cheung, Loh, and Ho (2007) reported adults with a cleft had similar levels of social anxiety as the comparison group, but self-esteem was lower. Marcusson, Akerlind, and Paulin (2001) investigated adults with CL/P for life adjustment. Compared to the gender and age matched control group, adults with a cleft condition had significantly lower scores for quality of life, well-being, family life, social contacts, personal sense of worth, and participation in life outside of their personal sphere. However, there was no effect on the more practical activities of daily living. Heller, Tidmarsh, and Pless (1981) found that up to 33% of participants in their follow-up study reported psychosocial impacts including

appearance, hearing and speech dissatisfaction. There was also prolonged dependence on family and low levels of social integration with 50% having few leisure activities and 25% having few friends.

Personal satisfaction with facial appearance correlates positively with quality of life among adults with a repaired cleft condition (Oosterkamp et al., 2007; Sinko et al., 2005). Studies report that adults with CL/P report being dissatisfied with surgical outcomes and express a desire for further corrective treatment for their nose, lip and teeth. Marcusson et al. (2002) reported that 47% of study participants requested further surgeries to improve their facial appearance, particularly secondary rhinoplasty. The aesthetics of the surgery tends to hold more importance than the functional aspects for many adult patients. Even though satisfied with the original surgery, studies report that patients were not satisfied with the aesthetic result once they reached adulthood (Alansari, Bedos, & Allison, 2014). The Alansari et al. (2014) study also found that self-perception may improve at adulthood in part due to the physical improvement resulting from their completion or definitive surgery. However, even with an improved self-perception, there still were consequences for those with unresolved psychosocial issues who envisaged further surgery would offer even greater emotional reconciliation. Typically, this did not occur - further surgery invariably led to further dissatisfaction in these cases.

Sinko et al. (2005) found that 44.3% of all patients (62.5% of women and 43.8% of men) desired further treatment. Their study also found two further complex issues; some patients who were dissatisfied with their initial repair did not seek further treatment; and some patients who were very satisfied with their initial repair still desired further treatment. This personal dissatisfaction often resulted in poor long-term wellbeing and correlated with low health-related quality of life outcomes (Oosterkamp et al., 2007; Sinko et al., 2005). The Meyer-Marcotty, Gerdes, Reuther, Stellzig-Eisenhauer, and Alpers (2010) study found that adults with a residual cleft repair received more negative evaluation and longer attention drawn to the face, especially the lip and nose, than the control group. The authors concluded that this impacted the social competence of the group with CL/P and that patient request for further corrective surgery should have been given earnest consideration by clinicians.

Danino et al. (2005) found that a significantly lower proportion of adults with CL/P in the 20 to 23 years age range were married compared to the population norm, with less than 10% of the group with CL/P being married compared to 50% in the control group. They further found that the cleft group was significantly less likely to be living independently from their parents with 22% of the group with CL/P and 48% of the controls living independently. For both variables, the gap closed in the 24 to 27 years age range with 48% of the group with CL/P being married compared to 68% in the control group and 58% of the group with CL/P living

independently compared to 79% in the control group. Ramstad et al. (1995a) also reported that adults with a cleft were less likely to marry or be in a de-facto relationship than other people of the same age (56.1% in the group with CL/P, 72.1% in the control group). The type of cleft was an influence - those with a bilateral cleft lip and palate were twice as likely as the control group to be single (54.1% compared to 27.9%). Peter and Chinsky (1974) identified in their study the mean age for marriage for adults with CL/P was 24.2 years, 21.7 years for their unaffected siblings and 21.2 years for random controls. Females with CL/P married on average 4.0 years later than females in the control group ($p < 0.001$) whilst males with CL/P married on average 2.3 years later than males in the control group ($p < 0.05$). They further reported a significantly higher proportion of adults with CL/P had never married (26.5%) compared with their siblings (8.9% $p < 0.01$) and the control group (8.6% $p < 0.01$). With regard to divorce, this study reported a lower divorce rate in marriages of individual with CL/P (14.0%) than in the control group (18.0%) but not in the sibling group (12.0%). This result may in part be due to the group with CL/P marrying later in life. The group with CL/P were also significantly more likely to have childless marriages, or to have fewer children (mean number of children = 1.69) than their siblings (2.47 children, $p < 0.001$) or randomly chosen controls (2.62 children, $p < 0.001$).

There were both positive and negative associations reported between adults with CL/P and employment opportunity and educational attainment. Three reports indicated the educational achievements of people with CL/P are similar to those of people without CL/P (Bjornsson & Agustsdottir, 1987; McWilliams & Paradise, 1973; Peter et al., 1975). Ramstad et al. (1995a) found that the undertaking of further education was higher in the group with CL/P (76%) than in the control group (69%). However, Danino et al. (2005) reported that adults with CL/P had lower and delayed educational attainment and less consistent attendance at colleges and universities with nearly double the group with CL/P entering fulltime employment earlier than the control group in the 16 to 19 years age range.

Marcusson et al. (2001) reported the group with CL/P in their study had a significantly lower quality of life than the control group with lower educational levels and significantly higher levels of unemployment. In a study of employee bias associated with appearance, Scheuerle, Guilford, and Garcia (1982) found that the presence of CL/P unfavourably affected employers' decisions of whom to employ. Adults with CL/P were less likely to have positions which placed them in direct contact with the public. Ramstad, Ottem, and Shaw (1995b) found that adults with CL/P were generally well represented in various forms of employment with the exception of sales and clerical work. Danino et al. (2005) and Ramstad et al. (1995a) reported that average income was substantially lower in adults with CL/P in all groups (except married woman) compared to controls and that males with CL/P had a less

stable working history with a higher mean number of jobs (2.4) compared to the male control group (2.0, $p < 0.01$).

The negative impacts for children are concerned with behavioural issues and social integration. The impacts affecting adolescents and adults involve social integration and appearance dissatisfaction. The problems that may emerge in childhood, and exacerbate with adolescence, can become established in adulthood. It is important to determine whether problems experienced by children with CL/P continue into adulthood or only emerge in adulthood as this determines when interventions are most needed. None of the articles reviewed explore how the risk of psychosocial problems may be lessened by detecting and subsequently addressing the associated issues as early as possible in an individual's lifetime.

Positive outcomes were only found in papers that used only qualitative or quantitative methods. None of the mixed methods or registry studies described any positive effects from CL/P. This may be due to the study sampling but also indicates the importance of using a variety of methods to find meaning in the results. Oosterkamp et al. (2007) highlight the importance of qualitative methods to detect difficulties and concerns which are not readily detectable by quantitative methods alone.

The studies lack the uniformity to adequately summarize the psychosocial problems resulting from CL/P. There were no obvious comparable rates of occurrence and implied impacts (consequences) across the studies. This is a limitation of this reviewed research and may be in part due to the expansive date range in the inclusion criteria which included studies from 1970. Studies and methods that are over thirty years old may not have the same focus or relevance as those undertaken in the past ten years. The same applies for social data for relationship norms and standards of employment and education. Other methodological issues include: the lack of longitudinal studies, low number of control groups (although eight studies used normative values), the variability in measurement methods (interview versus self-report), and number of instruments used (over 50). The most times a single validated questionnaire was used between studies was five.

Alansari et al. (2014) highlighted that self-perception changes over time and this may be an important variable when planning future interventions. To confirm the timing of such findings, studies must have instruments and methods which may be used directly or amended appropriately to ensure understanding for different ages. Three studies appeared to compare aspects of CL/P across the timespan (Cheung et al., 2007; Hunt et al., 2006; Lowenstein et al., 2008) but due to differences in the definition of age ranges between this review and their study parameters, these articles compared aspects between two groups, namely child and

adolescents or adolescents and adults. Therefore, no study in this review compared aspects across the full timespan from childhood to adulthood.

2.4.4 What are the recommendations and trialled interventions to address these problems?

The majority of recommendations contained within the literature concerned the need for further and related studies for study validation and expansion. Five studies made the following recommendations for further study:

- Hearst (2007) identified the need to redefine outcomes away from a surgical quality focus and toward resilience and psychosocial well-being.
- Alansari et al. (2014) suggested that treatment should be guided by and tempered with the inclusion of self-perception measures;
- Berger and Dalton (2009) recommended further study of the factors which influence self-reporting measures.
- Berk et al. (2001) recommended cross-cultural comparisons to provide a more detailed understanding;
- Thomas et al. (1997) recommended pre-discharge assessment of patient appearance satisfaction to determine and counter social and adjustment issues.

Three studies proposed interventions. Eiserman (2001) proposed both further studies and intervention programmes to focus on discovering and affirming unique personal strengths and the benefits of positive outcomes. Interventions with a focus on improving confidence and competence in social situations were proposed by Feragen and Borge (2010) to assist in lessening the impact of appearance concerns. Kapp-Simon (1995) also suggested interventions should focus on teaching the skills with which to manage social situations. The review by Norman et al. (2015) could not find evidence of effective trialled interventions and recommended randomised controlled trials with rigour to correct the current shortage of studies.

The recommendations made in the studies and review articles are essentially those concerning further and related studies to validate and expand on the study focus, and the requirement for longitudinal studies. The greatest gap found in this review is for recommendations proposing intervention programmes to address identified problems. Only two studies (Eiserman (2001); Feragen and Borge (2010)) and one review (Kapp-Simon, 1995) made such recommendations. None of the reviewed studies published verified outcomes from developed and trialled intervention strategies. Ultimately, the literature indicates that there are negative issues and these have been identified to a degree.

Now there needs to be some implementation and follow-up of recommendations to either show improvement in negative circumstance or a sustained level of positive outcomes. Follow-up data is crucial to determine if change has been made, the timeframe for the change to be effective, if the change is sustainable and to validate outcomes. Without this follow-up of outcomes there can be no continuous improvement.

For research to provide a cross-cultural comparison and increased sample sizes, multi-centre and cross-centre studies are required. Three studies involved subjects across centres (Broder et al., 1998; Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004; Thomas et al., 1997) but none to date were multi-centre, although Berk et al. (2001) reported they were increasing their study to include a dataset from the USA.

There were only two longitudinal studies of interest of which only one was directly relevant in a clinical setting and had a control group (Murray et al., 2010). This study was based on teacher and maternal reports which indicated children with CL/P had difficulties with social integration but could not identify the duration of the negative impact given the children were assessed during infancy and then at 7 years of age. Further follow up research is required to ascertain the long-term impacts using suitably matched controls to identify the duration and whether significant developmental ages influence the impacts. Longitudinal studies could also be used to assess facial appearance as a result of outcome of facial growth, and the influence of surgical intervention prior to and including facial maturity.

There was also a lack of appropriate controls noted in this review. Less than half of the relevant studies (35% 19/54) used a control group. In seven of the studies, normative data or data from previously conducted national studies were employed (Berger & Dalton, 2009; Cheung et al., 2007; Foo et al., 2012; Gussy & Kilpatrick, 2006; Mani et al., 2010; Rumsey et al., 2004; Snyder et al., 2005). There were instances of inconsistent selection of comparative groups. Cheung et al. (2007) used normative data from a group of patients with functional gastrointestinal disorders and also from a study which had investigated the outcome of a counselling model on students. Well-matched control groups are essential for comparison to reflect appropriate community reactions and influences. In order to provide larger sample sizes and cross-cultural perspectives for both patients with CL/P and control group members, multicentre research using uniform and agreed methodology is a recommended option.

The use of condition-specific instruments to measure social determinants, life experiences, and specifically, patient experience is essential to be able to set reasonable norms and to validate outcomes in both research studies and intervention programmes.

These types of instruments and methods need to be sensitive to, and able to identify and encompass the issues relative to this complex area. For example, all of the six studies measuring health related quality of life used instruments which may have been deficient in measuring self-concept, a much-needed measure for CL/P as identified by Gussy and Kilpatrick (2006). Only four studies (Bilboul et al., 2006; Broder & Strauss, 1989; Gussy & Kilpatrick, 2006; Pertschuk & Whitaker, 1982) incorporated this variable into their studies. The review by Norman et al. (2015) summarised the required methodology for studies of psychosocial intervention to be effectively undertaken; appropriate, uniform methodology with reliable and effective study designs.

2.5 Further published literature of relevance.

A further search of the literature was undertaken in July 2017 to identify additional relevant papers published after May 2015 and not included in the initial literature review. Although the findings could not be included in the published papers, the inclusion of the eight following papers provided additional evidence to inform the discussion and conclusion chapters of this thesis.

The eight studies used a variety of study designs: mixed methods (1); qualitative (3); retrospective cohort (1); quantitative (2); and review article (1). The studies have been grouped under three headings: CL/P psychosocial impact and perspective; CL/P and body image; and CL/P and the impact of peer influence and teasing. Although the outcomes were supportive of those from this thesis, none addressed the research questions or used the same methodology. No study reported trialled interventions. The studies have been summarised under concept headings.

CL/P psychosocial impact and perspective:

In two studies (Stock, Feragen, & Rumsey, 2015, 2016) both used qualitative telephone interviews of 52 adults with CL/P and thematic response analysis. The findings of the first study suggest that there is an increased risk of individuals with CL/P developing psychosocial problems which is diminished by adulthood. One finding of interest was that adults who have been discharged from their child and adolescent treatment providers may feel reluctance or uncertainty of how to contact adult health services for additional treatment.

The findings from the second study provided a number of relevant factors and processes, associated with psychological adjustment for adults with CL/P many of which have not previously been studied in any depth including sexuality and adoption. The authors also provide discussion regarding measuring the identified factors and development of psychological interventions, both of which are missing in previous published work.

In a retrospective national cohort study, Berg, Sivertsen, Ariansen, Filip, Vindenes et al., (2016) found that adult outcomes for education, income and socio-economic status were similar to those of the general population of Norway. The authors also concluded that CL/P did not affect fertility rates.

CL/P and body image:

Like previous published work, Crerand, Sarwer, Kazak, Clarke, and Rumsey (2017) found that adolescent females reported greater body image dissatisfaction than males across both groups. Although the group with the craniofacial condition reported lower satisfaction with facial appearance (as may be anticipated) this group also reported lower investment in appearance (which was not anticipated). This study is one of few which takes into consideration the level of investment with facial appearance in relation to satisfaction with facial appearance. This is an essential element for obtaining a full understanding of the importance and satisfaction with appearance, and was also used in this thesis.

The findings of the Liddle, Baker, Smith, and Thompson (2015) review support the need for a mixed methods approach to ensure depth of knowledge, and also was used in this thesis. Furthermore, they noted the inconsistency in both timing and measurement / instrument choice, which influences the overall reliability of results. The authors provide argument for a little discussed factor of the potential need by the patient to validate their choice for having the surgery, which in turn, influences their reporting.

CL/P and the impact of peer influence and teasing:

Pope, Klein, and Bergman (2016) used a phenomenological qualitative approach and thematic response which contributes to a growing body of qualitative studies in the area of psychosocial research. They used study factors that focus on positive social experience and adjustment. Participants were self-selected and had membership to a support organisation which may be seen as adding bias. The results from this study are in contrast to those reported in this thesis literature review, where very few studies found positive outcomes of social experience in children with craniofacial anomalies. Although it included peer-related difficulties of negative attention from others and difficult social experiences, it also focused on the positive responses of participants.

Feragen and Stock (2016) used a retrospective longitudinal study approach which is both a valuable methodology and one which is missing in the current literature. The findings from this study support existing research that individuals with CL/P are at increased risk for psychosocial problems. However, in this study psychosocial problems were only measured in terms of a higher incidence of teasing leading to negative self-perceptions.

The findings from the Lee, Gibbon, and Spivey (2017) quantitative study are similar to existing studies and note an increased risk of individuals with CL/P developing psychosocial problems, in this case stigma and prejudgment. This study is one of very few which highlighted that the children without CL/P formed negative social and personal attribute judgments about children with cleft palate based solely on the intelligibility of their speech.

2.6 Summary

This review presented results of the psychosocial impacts of CL/P reported in the literature across three physical and psychologically significant developmental age cohorts: children, adolescents and adults. While some studies presented a positive outcome for CL/P, the majority reported negative psychosocial problems for all age-groups indicating there is an increased risk of developing psychosocial problems. The challenge is to deliver psychosocial intervention which meets developmental needs, is sensitive to social determinants and is effective in minimising the negative impacts on the lives of participants. Outcomes need to be further defined by psychosocial well-being, psychological strengths and resilience, and not just the technical quality of surgery. It is personal perception that needs to be within limits that can identify when further corrective surgery may be warranted without the risk of influences on myriad psychosocial factors.

The population with CL/P has an increased risk of negative psychological outcomes compared with their peers without CL/P. The challenges of living with CL/P are multifactorial, involving a complex combination of psychological and social factors. Patient centred and psychological care should be available across the lifespan to meet the changing needs of patients over time.

Overall, the literature reports the majority of children, adolescents and adults with CL/P do not appear to experience major psychological disorders. However, they are at a higher risk of developing specific psychosocial problems in four key areas: self-esteem and self-worth; social inhibition and isolation; depression and anxiety, and appearance dissatisfaction.

2.7 Recommendations (What is missing in the literature)

In order to minimise negative psychosocial impacts, study outcomes are required which may be translated into health care recommendations that will influence policy and protocols. The challenge is to use tools which will assess the need for psychosocial intervention which meets developmental needs, is sensitive to social determinants and is effective in minimising the negative impacts of CL/P.

The success of outcomes cannot just be judged by the technical quality of surgery, but also include measures of psychosocial well-being and strengths. This review found inconsistent reporting and limitations in methodology. There is an abundance of tools for attempting measurement of psychosocial problems with equally abundant recommendations for further verification and validation study but very few definitive recommendations for intervention strategies, and none with outcomes from trialled strategies. The lack of consistent tool sets and methods makes it difficult to draw definite conclusions across the research. Other instruments have lacked breadth to explore the patient perception of CL/P in both a comprehensive and meaningful way.

The Cleft Research Questionnaire (CRQ) was developed to fill that gap by providing a concise and comprehensive instrument which incorporated the many factors specific to the experience of having CL/P, including health, quality of life, psychological and sociological factors which may be used as a single instrument or to complement other instruments and measures at a variety of ages, to ensure a more complete picture of the patient treatment and life experience. The CRQ was validated as part of this research and was demonstrated to have the flexibility to complement both the BES questionnaire and the qualitative interview schedule. Appropriate methods and adequate sample sizes are required to provide confidence in the statistical analysis. Studies using a mixed methods approach offer the opportunity to capture both breadth and depth of knowledge.

Determining whether people with CL/P are at increased risk of developing psychosocial problems, and identifying the psychosocial impacts of CL/P, are central to discovering and recommending appropriate actions and interventions to address these effects. In particular, it is essential to determine the effects across the lifespan in order to offer targeted services which will support the individual at crucial times of their physical and emotional development and sequenced treatment interventions. The findings from this thesis are consistent with there being potential difficulties in psychosocial wellbeing within each age-group and across the lifespan for some individuals with CL/P. These difficulties are prevalent globally across age, gender and type of cleft. Just as the difficulties associated with CL/P are multi-faceted, the treatment and support provided must be multidisciplinary to ensure appropriate and satisfactory treatment and life outcomes.

A key goal of any psychosocial research is to identify areas of impact and recommend improvements which will assist in the individual achieving positive sociological life outcomes in their education, employment, relationships and mental health.

Psychosocial research involving CL/P needs to be compiled both in cross-sectional and longitudinal studies across the lifespan using a comprehensive range of study methods which may be used to compare psychosocial outcomes globally, irrespective of geographic area or socio-economic circumstance, as the impacts may transcend these factors.

2.7.1 Influence of literature review on methodological choices for this thesis

The purpose of the literature review was to identify gaps in knowledge in the literature and guide the research direction and methodology undertaken in this thesis so as to add to the current base of knowledge. The findings from the literature review indicated the requirement for more studies to incorporate a mixed methods approach. Liddle, Baker, Smith, and Thompson (2015) recommended the mixed methods approach as one which ensures greater depth of knowledge. This approach offered the opportunity to address the research questions more effectively and offer a more balanced analysis. The use of a mixed methods approach for this thesis enabled greater exploration and understanding of the impact of CL/P within this patient group. A clear gap identified from the literature review was the lack of contemporary research for psychosocial impacts of CL/P in an Australian cohort.

Chapter 3 Methodology

3.1 Introduction

This chapter describes the methodology used to collect patient-centred data to give insight into the perspectives of patients with CL/P and the health care professionals who treat them. This thesis used a mixed methods approach.

3.1.1 Participants

There were two categories of study participants involved:

1. Patients with CL/P who were undergoing or had completed treatment by the Cleft Team at the study site, Princess Margaret Hospital for Children (PMH), Perth, Western Australia, comprising three age cohorts:
 - The children age-group comprising 100 patients aged 6 to 12 years. This group was selected to demonstrate the impacts of CL/P and treatment experienced as appropriate for the age-related protocol.
 - The adolescent age-group comprising 101 patients aged 13 to 21 years. This group was also selected to demonstrate the impacts of CL/P and treatment experienced as appropriate for the age-related protocol.
 - The adult age-group comprising 158 former and current patients aged 22 to 42 years. This group was selected as they had received comparable care regarding technique and technology over many years with exposure across the full spectrum of treatment protocols. As the majority had reached their treatment milestones they also had time for reflection after completion of treatment.
2. Health Care Professionals (HCPs) including audiologists, dental clinicians, surgeons, nurses, speech and physical therapists, and support staff aged 22 to 71 with 50 HCPs from Australia, and 60 from Europe (15 each from Bulgaria, Latvia, Serbia, and Turkey) who treated patients with CL/P and other conditions resulting in a visible difference.

3.1.2 Instruments

There were four instruments used in this thesis;

1. The Cleft Research Questionnaire (CRQ),
2. The Body-esteem Scale (BES),
3. Qualitative interview schedule
4. Health Care Professionals Questionnaire (HCPQ).

The primary instrument, the CRQ, was specifically developed by the author to collect baseline data from current and former CL/P patients at PMH on the following topics:

- demographics,
- impacts of CL/P,
- importance and satisfaction with physical attributes and support received,
- teasing and bullying,
- relationships,
- support and resource information, and
- PMH service.

Three age-appropriate versions of the CRQ were developed, with the adult version having additional questions concerning psychosocial variables to enable investigation of adult-specific life outcomes. The majority of CRQ questions were closed-ended, however participants were invited to use the available free-form text fields to capture additional comments for specific questions.

Two secondary instruments were also used in this thesis. The first was the BES, a validated questionnaire developed to determine body esteem amongst the general population, with one version for children and another for adolescents and adults (Mendelson et al., 1993, 2001). The appropriate age-version of the BES was embedded in the respective CRQ.

The other secondary instrument was an internationally collaborative questionnaire designed by the author, in conjunction with HCPs to examine the perceptions of Australian and European HCPs regarding the following:

- The level of confidence in supporting patients with appearance-related concerns; and
- The training requirements of HCPs to be able to better understand the psychosocial needs of people with a visible difference.

For the qualitative component of this thesis a semi-structured individual interview schedule comprising open-ended questions was developed by the author for the adult patient age-group which covered the following themes identified from the literature and from discussion with expert clinicians involved in the treatment of patients with CL/P:

- The impact CL/P made on their lives.
- The people that made an impact on their lives.
- Things that could have been done differently.

- Advice to give to a teenager with CL/P.

See Appendix 3 for copies of the CRQ versions (with embedded BES), the qualitative interview schedule, and the HCPQ questions.

3.2 Mixed methods approach

A mixed methods approach was used for the thesis studies to optimise the strengths of each approach and maximise the study's potential. This provided a deeper and more complete understanding than would be possible just using one approach (Bingley et al., 2008). A further advantage is the ability to verify the results and enhance either methodological approach by providing the 'why' to the 'numeric' and the 'percentage' to the 'root cause'. By mixing both quantitative (breadth) and qualitative (depth) methods and data, there is the opportunity for greater understanding of the patient perspective. A mixed methods approach was recommended from the literature review as one which could effectively combine quantitative and qualitative methods to achieve study outcomes. This approach was used in this thesis to effectively address the research questions. The CRQ instrument was specifically designed to quantitatively identify and capture the types of psychosocial problems, sociological issues and the impacts of CL/P within each age-group. The qualitative interview schedule was designed to capture individual experiences, problems and impacts of having CL/P and provide the detail that cannot be collected with quantitative methodology. It gave a voice to the individual participants.

Patient-focused qualitative methodology provides insight and a deeper perspective than quantitative methods alone and may provide a clarity which quantitative methodology cannot. Nelson (2009) supports the appropriateness and validity of using qualitative methods for enquiry in healthcare. A qualitative approach may also allow for a greater appreciation of an individual's lived experience (Kayle, 1996), and can assist in the development of more appropriate ways to offer support to the individual (Bingley, Thomas, Brown, Reeve, & Payne, 2008). Each qualitative interview provided an individual and unique perspective of the person's life and the components and events which influenced their perspective.

The timing of the qualitative component in this study allowed for the data collection to complement and expand on that which was collected by the CRQ. By undertaking the qualitative component as a sequential collection, the first stage of the data collection (the CRQ- quantitative method) helped to inform and influence the second stage, by providing data which required further content or elaboration for a deeper understanding of the element being examined. Without the results of the quantitative data, opportunities for deeper enquiry and examination provided by the qualitative data may have been missed.

While the weight of the quantitative stage was more emphasised in the study design, both deductive and inductive logic were used to guide the study and make assumptions. The quantitative data influenced the qualitative schedule of questions which in turn, assisted in interpreting some of the data from the quantitative responses and strengthening the interpretation and analysis.

The following table summarises the mixed methods approaches used in this thesis:

Thesis Component	Instruments and Participants				Methods
	CRQ+	BES+	Interview Schedule+	HCPQ*	
Paper 1: Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups	Children Adolescent Adult	Children Adolescent Adult			Descriptive Stats Hypothesis Tests Linear Regression
Paper 2: The psychosocial impact of cleft in a Western Australian cohort across three age-groups	Children Adolescent Adult				Descriptive Stats Hypothesis Tests
Paper 3: Adult specific life outcomes of cleft lip and palate in a Western Australian cohort	Adult				Descriptive Stats Hypothesis Tests
Paper 4: Adult narratives of the psychosocial impact of cleft in a Western Australian cohort			Adult		Thematic analysis Word Clouds
Chapter 8: An international comparison of psychosocial support provision for patients with a cleft or other visible difference				Adult	Descriptive Stats Hypothesis Tests

Table 2. Summary of thesis component instruments and methods. Notes: + Participants were from the case-study site. * Participants were HCPs from the case-study site and national and international sites (Australia, Bulgaria, Latvia, Serbia, and Turkey).

3.3 Research Process

Figure 2 lists the stages of the research process (described in subsequent sections):

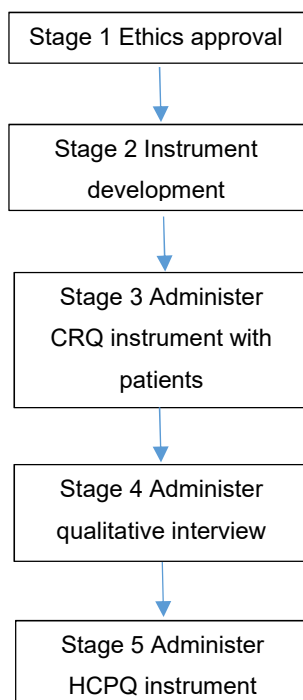


Figure 2. Flow diagram outlining the stages of the research process

3.4 Stage 1 Ethics approval

Ethics approval was received for this research study from the following committees: Curtin University Human Research Ethics Committee (EC00262), and the Princess Margaret Hospital Human Research Ethics Committee (EC00268).

3.5 Stage 2 Development of the Instruments

To address the objectives of this thesis, a series of investigations were undertaken using three quantitative instruments (two for use with patients and one for use with health care professionals), and one qualitative interview schedule developed for data collection.

3.6 Stage 3 Administer Cleft Research Questionnaire (CRQ)

The primary instrument employed was the Cleft Research Questionnaire (CRQ). This was designed and validated by the author in conjunction with experts from the PMH Cleft Team, and also incorporated feedback from patients and parents. Three age-appropriate versions of the CRQ were developed: children aged 6 to 12 years, adolescents aged 13 to 21 years, and adults aged 22+ years. Each CRQ included a copy of the questions from the relevant age-appropriate version of the Body Esteem Scale. (See Appendix 3 for copies of each CRQ including the embedded BES).

The CRQ (and BES) data addressed the following thesis objectives:

- Objective 2. Identified the types of psychosocial problems and the impacts of CL/P within each age-group;
- Objective 3. Investigated body-esteem within each age-group and compare with corresponding normative scores;
- Objective 4. Determined the importance and satisfaction ratings within each age-group for cleft-related physical attributes and for support given by others;
- Objective 5. Investigated adult-specific sociological outcomes and compare against the Australian general population.

3.6.1.1 Development and validation of the CRQ Instrument

Figure 3 illustrates the stages of development and validation of the CRQ instruments.

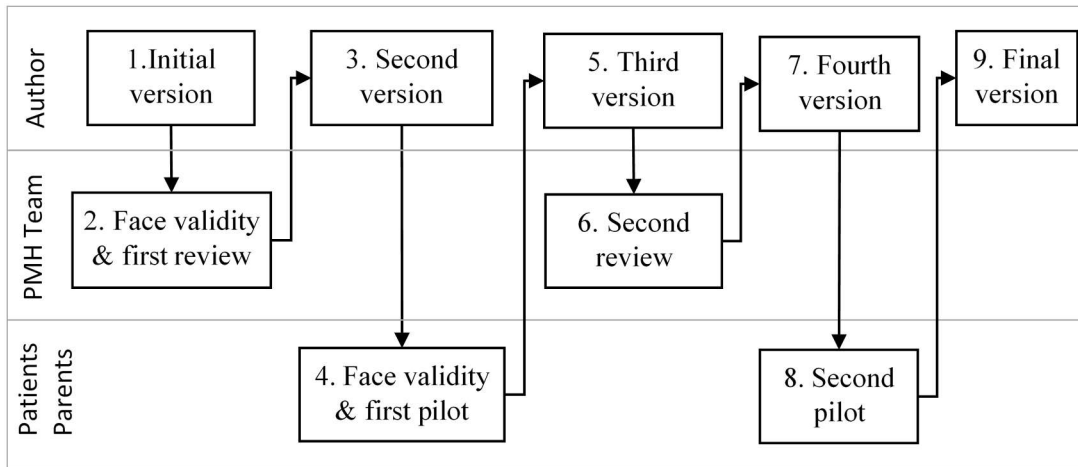


Figure 3. Process for developing CRQ instrument

Validation formed a part of the development of the CRQ instrument. There are various types of validity including: content, criterion, construct and internal validity. These are defined in the table below with relevant usage for the CRQ.

Type	Definition	Usage for CRQ
Content Validity - Subjective (Face Validity) - Objective	How well an instrument is able to capture and encompass all the conceptual aspects of each construct. The extent to which an instrument is subjectively viewed as covering the concept it was created to measure. Use of statistical methods such as factor analysis to verify the domains that the measure is tapping into.	Partially used. PMH patients (and parents), and PMH Cleft Team provided feedback as part of instrument development process. Principal Components Analysis was used to verify PMH patient results grouped as expected for a subset of the instrument items.
Criterion Validity - Retrospective (Postdictive) - Concurrent - Predictive	How well an instrument predicts or is associated with an observed indicator of a given concept or criterion. How well the instrument measures a construct in hindsight, i.e. after it has actually occurred. The extent to which the results of a particular measurement using two similar methodologies / tests correspond. How well a particular variable predicts a criterion (outcome) variable.	Partially used. Not used as historic records were not available to verify participant responses based on their memories of events. Not used as appropriate similar tests were not included for study measures. Multiple linear and logistic regression models were used to assess association between variables and BES scores.

Type	Definition	Usage for CRQ
Construct Validity	Whether the items in the instrument truly measure what they are supposed to be measuring.	Not used other than reuse of previously validated BES instrument.
- Convergent	The extent to which instruments assessing the same construct "converge," or are in agreement.	Not used as appropriate similar instruments were not included for study measures.
- Divergent	The extent to which measures of dissimilar constructs "diverge," in that they show no obvious relationship.	Not used as appropriate dissimilar instruments were not included in the study.
Internal Validity	Whether the effects observed in a study are due to the manipulation of the independent variable and not some other factor.	Not used as variables were not specifically manipulated to determine their effect.

Table 3. Instrument validity types and usage for CRQ

3.6.1.2 Pilot sample

The children version of the CRQ was piloted with 10 children with CL/P with assistance from one of their parents. The adolescent and adult versions were each piloted with 10 patients with CL/P from the respective age-groups. Children and adolescent age-group participants were selected from cleft clinic lists as convenience samples over three clinics with a mix of gender, cleft type, and area of residence. Adult pilot participants were selected from PMH database and sent a copy of the CRQ by post, with a similar demographic mix.

3.6.1.3 Testing CRQ validity

Subjective content validity (i.e. face validity) was undertaken as part of the initial pilot by test respondents who completed the accompanying checklist:

- Were the questions relevant to the aim of the study?
- Did the respondent understand what the question was asking?
- Did the question collect the information required?
- Were there further questions which could be added to collect information that would improve the study?
- Were there questions which were not relevant or appropriate to the study or the group being studied?
- Any further comments.

Face validity was also undertaken by four senior members of the PMH Cleft Team in the form of a focus group meeting, also using the above checklist, with an emphasis on whether the instrument covered the required areas to meet with the objectives of this study.

Two colleagues, independent of the PMH Cleft Team, were asked to complete the questionnaires to check the duration time for completion, and to comment on style and completeness of questions.

Post data collection, objective content validity was undertaken using Principal Components Analysis (PCA) to confirm that logically associated items did in fact load onto single principal components. Refer to Appendix 4 for details of this analysis.

There was limited criterion validity analysis undertaken as there were no historical records available to verify participant responses to past events (postdictive validity), nor were there similar tests included in the study to test for concurrent validity. Multiple linear and logistic regression was undertaken to identify the association of a small number of variables (gender, cleft type, importance of facial appearance, and body weight rating) and the BES factor scores. This gave a limited indication of predictive criterion validity; however, prediction was not an objective of this thesis.

Construct validity (convergent and divergent) for the CRQ instrument was not tested due to a lack of similar measures that could be used to compare against. Internal validity was also not tested as data was collected using a questionnaire - variables were not specifically manipulated to determine their effect.

3.6.1.4 Pilot findings

The PMH Cleft Team, and pilot respondents confirmed that the instrument covered all relevant items for effective content and measured the elements which made up the aims of this study. Minimal changes were requested and undertaken following the initial pilot tests and PMH Cleft Team review. The majority of changes were made to the Children version of the CRQ:

- Questions asking whether the respondent suffered from the following issues were asked to be removed: self-harm, low self-esteem, depression, and panic attacks.
- Questions asking whether the respondent would like to weigh less or more, or have more muscle were also asked to be removed.

Requesting patient height and weight measurements was explicitly rejected by participants in the pilot groups which made quantitative measurement to determine body weight category (e.g. using Body Mass Index) not possible. However, an approach was formulated which allowed for participants to self-report their body weight category as one of under, normal, little over or quite over weight. In the instructions accompanying the questionnaire, participants were asked to appraise their current body weight using the following self-reporting body weight categories with 5 kilogram (kg) increments as a guide:

- *under* equated to being 5kg under what they would consider their ideal or normal weight;
- *little over* equated to 5kg above their ideal/normal body weight;
- *normal* equated to their ideal/normal body weight; and
- *quite over* equated to being 10kg or more over their ideal/normal body weight.

Although not an exact measure, all age-groups were more comfortable in providing their weight with these ranges.

In addition to testing for face validity the questions in the instrument underwent review by clinical experts from PMH Cleft Team. They confirmed that the instrument covered all relevant items for effective content and addressed the elements which made up the objectives of this thesis.

A second pilot of the amended questionnaire by the test participants and a second peer review by the PMH Cleft Team resulted in no further changes recommended. The final instrument encompassed a range of quality of life and sociological outcome and treatment issues which were deemed appropriate (by the pilot sample and clinical experts) in language and understanding for the targeted respondents.

3.6.1.5 Final CRQ Questionnaire

The final questionnaire consisted of a majority of closed-ended quantitative style questions, and free text form fields that captured additional qualitative comments. The following table summarises the number of closed-ended questions in each of the CRQ instruments by variable category.

Item Category	Children	Adolescent	Adult
Demographics	4	5	11
Impacts of CL/P	10	12	17
Importance and satisfaction for physical attributes & support received	16	16	16
Personal health and cleft type	8	10	28
PMH service and treatment ratings	2	7	9
Relationships	2	2	12
Support and resource information	9	8	20
Teasing and bullying	2	2	3
Total	53	62	116

Table 4. CRQ Item Categories

The impact of CL/P on getting and doing work, and on special relationships (e.g. partner, boyfriend, girlfriend) were only included in the adolescent and adult versions of the CRQ. The adult version of the CRQ collected additional variables such as highest education level attained, annual income, age at first serious relationship, marital status, number of children,

suffer issues of anxiety, depression and self-esteem, and healthy life-style choices for drinking alcohol, smoking, using illicit drugs and exercise.

The CRQs used a range of response formats to collect variable data:

- Free form text fields for brief comments, and for more detailed suggestions (e.g. for PMH service improvements);
- Check boxes (e.g. for Yes/No answers). When selecting from a given list, a single selection was implied, however if multiple selections were appropriate, this was explicitly stated;
- Circle one of the indicated rating numbers.
 - Ratings for importance and satisfaction with physical attributes and the support received from others used a 5-point Likert scale (1=Extremely, 2=Very, 3=Somewhat, 4=Not Very, 5=Not at all).
 - The adolescent and adult BES scale used a 5-point Likert scale (0=Never, 1=Seldom, 2=Sometimes, 3=Often, 4=Always) as designed by Mendelson (1996, 2001).

3.6.1.6 CRQ Internal Reliability.

There are various types of reliability including: test/retest, and Cronbach's alpha reliability. These are defined in the table below with relevant usage for the CRQ instrument.

Type	Definition	Usage for CRQ
Test/Re-test reliability	A measure of reliability obtained by administering the same test twice over a period of time to the same group of individuals.	Not used. Although a pilot group of PMH patients completing the CRQ twice, the sample had insufficient power for analysis.
Cronbach's Alpha (CA) reliability	A measure of internal consistency, that is, how closely related a group of items are.	Principal Components Analysis was used to confirm variables were associated with a particular group, and CA calculated for those variables.

Table 5. Instrument reliability test types and usage for CRQ

Internal reliability was tested after the administration of the final questionnaire. This was due to the small sample size in the pilot group which would not provide the statistical rigour needed to test internal reliability, therefore CA calculations were conducted post-hoc on the full study sample datasets for each age-group.

Within each version of the CRQ instrument, a number of variables were logically associated with each other as the questions related to a common underlying concept. For example, the ratings given for importance of facial appearance, teeth appearance, hearing and speech were associated with physical attributes. In this case, responses by a participant would be

expected to be similar for these questions. Cronbach's Alpha (CA) was used as an internal reliability measure to determine how closely each participant answered logically grouped questions. The calculated CA values (which can range from 0 to 1) were rated using the commonly used scale from George and Mallery (2003) p. 231:

- Greater than 0.9 - Excellent
- Greater than 0.8 - Good
- Greater than 0.7 - Acceptable
- Greater than 0.6 - Questionable
- Greater than 0.5 - Poor
- Less than 0.5 - Unacceptable.

The approach used for conducting the internal reliability analysis of the CRQs was as follows:

1. Identify variables that were expected to group together that could also be numerically codified. This included variables for: Impact of cleft (e.g. on school, friends same age etc), Importance of physical attributes (speech, hearing, facial appearance and teeth appearance), Importance of support received (parents, treatment givers, siblings, teachers (employer for adults), Satisfaction with physical attributes, and Satisfaction with support received. Excluded were all free form text variables, demographic variables, PMH service ratings, questions on support resources, and all calculated variables. The BES questions were also excluded as these have previously been verified by Mendelson.
2. Conduct a Principal Components Analysis (PCA) to determine if the identified variable groupings loaded onto one principal component i.e. they could be reasonably be considered as one group. Each PCA was calculated using a polychoric correlation matrix for ordinal Likert scale responses, and a tetrachoric correlation matrix for binary responses. The number of principal components (PCs) selected for each PCA was determined using Kaiser's Rule (only PCs with an Eigenvalue > 1 were retained) and the Cumulative Variance Percentage Rule (count PCs up to the point where cumulative variance percentage was > 60%).
3. If the variables were part of a single principal component then their reliability was measured using Cronbach's Alpha and interpreted as per the rules described by George and Mallery, (2003).

Table 6 below shows the CA analysis results which indicated there was an acceptable degree of internal reliability for each of the variable groups in the instrument across the age-groups with an overall average CA score of 0.74. See Appendix 4 for the full details of the PCA and CA analysis.

> .9 Excellent, > .8 Good, > .7 Acceptable, > .6 Questionable, > .5 Poor, < .5 Unacceptable.

CRQ Variable Groups Tested	Cronbach's Alpha	95% Confidence Interval	Rating
Adults Impact Work Life: Doing Work, Getting Work, Independence, Job Interviews	0.77	(0.71,0.83)	Acceptable
Adults Impact Health: General Health, Physical Restriction, Sport	0.68	(0.59,0.77)	Questionable
Adults Impact School and Relationships: Academic, Friends Same Age, Friends Opposite Sex , Pubs & Clubs, School, Special Relationships	0.77	(0.71,0.82)	Acceptable
Adults Impact Self: Attitude to Life, Being Photographed, Public Speaking, Self Esteem	0.78	(0.72,0.84)	Acceptable
Teens Impact Health: General Health, Physical Restriction, Sport	0.52	(0.36,0.69)	Poor
Teens Impact School and Relationships: Academic, Friends Same Age, School, Special Relationships	0.70	(0.61,0.79)	Questionable
Teens Impact Self: Attitude to Life, Being Photographed, Public Speaking, Independence	0.65	(0.54,0.76)	Questionable
Children Impact Health: General Health, Physical Restriction, Sport	0.57	(0.43,0.71)	Poor
Children Impact School and Relationships: Academic, Friends Same Age, School	0.75	(0.67,0.83)	Acceptable
Children Impact Self: Attitude to Life, Being Photographed, Public Speaking, Independence	0.72	(0.64,0.81)	Acceptable
Adults Importance Physical: Facial Appearance, Teeth Appearance, Hearing, Speech	0.75	(0.68,0.81)	Acceptable
Adults Importance Support: Parent, Treatment Giver, Siblings, Employer	0.80	(0.75,0.85)	Acceptable
Teens Importance Physical: Facial Appearance, Teeth Appearance, Hearing, Speech	0.84	(0.79,0.90)	Good
Teens Importance Support: Parent, Treatment Giver, Siblings, Teachers	0.86	(0.82,0.91)	Good

CRQ Variable Groups Tested	Cronbach's Alpha	95% Confidence Interval	Rating
Children Importance Physical: Facial Appearance, Teeth Appearance, Hearing, Speech	0.78	(0.70,0.85)	Acceptable
Children Importance Support: Parent, Treatment Giver, Siblings, Teachers	0.73	(0.64,0.82)	Acceptable
Adults Satisfaction Physical: Facial Appearance, Teeth Appearance, Hearing, Speech	0.73	(0.66,0.80)	Acceptable
Adults Satisfaction Support: Parent, Treatment Giver, Siblings, Employer	0.79	(0.74,0.85)	Acceptable
Teens Satisfaction Physical: Facial Appearance, Teeth Appearance, Hearing, Speech	0.78	(0.71,0.85)	Acceptable
Teens Satisfaction Support: Parent, Treatment Giver, Siblings, Teachers	0.84	(0.78,0.89)	Good
Children Satisfaction Physical: Facial Appearance, Teeth Appearance, Hearing, Speech	0.73	(0.65,0.82)	Acceptable
Children Satisfaction Support: Parent, Treatment Giver, Siblings, Teachers	0.73	(0.64,0.82)	Acceptable

Table 6. Cronbach's Alpha calculation for CRQ variable groups.

Overall the reliability of the three CRQs as measured by Cronbach's Alpha was acceptable. However, the rating of poor was reported in two cases: Impact on Health for both Children and Adolescents, with Adults also being rated Questionable for the same variable group. This indicates the questions related to the Importance of Health may need to be revised. The impact of this result was minimal as these variables (General Health, Physical Restriction, and Participation in Sport) were not the main focus of the study.

3.7 Stage 4 Administer Qualitative component

3.7.1 Qualitative Interview schedule development

Qualitative methods of individual semi structured interviews with adult patients with CL/P were used to complement the quantitative component of the study (CRQ). This qualitative approach allows for a greater understanding of an individual's lived experience (Kayle, 1996), and can provide a greater understanding of an individual's needs including the development of more appropriate and successful ways to support the individual (Bingley et al., 2008).

The qualitative component investigated the following thesis objective:

Objective 6. Explore the personal experience and deeper impact of CL/P amongst a subset of the adult age-group;

The qualitative interview schedule was developed based on a number of relevant themes identified from the literature, from discussions with clinicians involved in treating CL/P, and from input by two co-authors who are experienced with qualitative methodology. The resulting questions were cross-referenced with the reported areas of psychosocial concern from the data collected from the CRQ. This interview schedule was developed around these themes:

1. The impact CL/P made on their lives.
2. The people that made an impact on their lives.
3. Things that could have been done differently.
4. Advice to give to a teenager with CL/P.

Each question had a specific aim and a probe to be used to encourage elaboration without influencing the participant's responses. See Appendix 3 for the complete schedule of questions.

Fifteen individuals agreed (by returning consent forms included with the CRQ) to be interviewed with ages ranging from 22 to 39 years. Interviews were conducted at PMH, audio recorded and responses transcribed by the author for subsequent thematic analysis. This technique identifies and organises patterns within a data set, and also interprets various aspects of the subject matter (Howitt & Cramer, 2011). Themes were identified in accordance with guidelines by Braun and Clarke (2006) and text mining and analysis was also undertaken using R statistical programming language version 3.3.0 (R Development Core Team, 2015). As a means to confirm accuracy of the thematic analysis and to address potential interviewer bias, the resultant themes were discussed in follow-up telephone calls with twelve of the participants (three could not be contacted) (Braun & Clarke, 2006; Yardley, 2000).

3.8 Stage 5 Administer Health Care Professionals Questionnaire (HCPQ)

The HCPQ was administered to HCPs from Australia and four European countries (Bulgaria, Serbia, Latvia and Turkey) who, at the time of the study, were working with individuals with a visible difference with the aim of addressing the following thesis objective:

Objective 7. Investigate the perceptions of healthcare professionals regarding their confidence in treating and supporting patients with CL/P or other visible difference, and their training requirements to better understand the psychosocial needs of such patients.

The HCPQ was developed by the author in collaboration with experts from across the countries involved in this aspect of the study. The questionnaire was piloted with members of the PMH Cleft Team who provided feedback on the following aspects; length appropriateness of the question format and applicability of the questions. Following review some minor changes were made regarding the format and order of the questions. The final version collected general demographic data of country, gender, age, years of service and current position, and comprised 14 closed-ended questions with space for free form text comments for each question. However, only the following three questions were related to the thesis objective and analysed as part of this study:

- To what extent do you feel confident in addressing the psychosocial needs of patients and their families?
- Have you received any training about the psychological impacts of disfigurement and how to meet the needs of patients?
- What would help you address the needs of patients and their families more effectively? (e.g. training – what sort; how should it be delivered; who needs it?)

Internal reliability (Cronbach's Alpha) for the HCPQ instrument was not calculated as the three questions analysed were independent of each other, i.e. they were not related to the same construct.

The questionnaire was translated from English to the native language of each European country, and responses then translated back to English for collation and analysis. The European respondents were interviewed in person by the respective clinic co-ordinator in each country, who was also responsible for all translations. The respondents from the Australian centres were interviewed by the author using various methods (telephone, face to face and by written responses). All responses were entered into Microsoft Excel 2016 which

was used to create summary tables. Hypothesis tests were conducted in the R statistical package.

3.9 Data Analysis

Refer to the Data Analysis section in each of the chapters 4 to 8 for descriptions of the respective analyses performed.

Having summarised the methods used in the study the following Chapters 4-7 will provide a commentary and copy of each of the published papers.

Chapter 4 Paper 1: Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups

4.1 Commentary for Paper 1

This paper addressed the third thesis objective which was to investigate body-esteem within each study age-group and to compare study results with normative scores from similar age-groups without CL/P.

With the strong and pervasive emphasis on appearance within contemporary society, attempting to understand the potential psychosocial effects of a visible difference may begin with determining a person's perception of their own appearance, and how they believe others perceive their appearance. The instrument used to make this assessment was the validated Body Esteem Scale (BES) questionnaire developed by Mendelson et al (1993, 1997) which differentiated a person's body esteem perception into three factors: BE-Appearance (an individual's satisfaction with their appearance), BE-Weight (an individual's satisfaction with their weight), and BE-Attribution (how an individual perceives that others evaluate their body and appearance). In all cases, higher BES factor scores indicate a more positive perception. The variable of body-esteem complemented the variables of study for the CRQ questionnaire with the intention to elicit a comprehensive understanding of the factors involved in the psychosocial health of the person with CL/P. Body-esteem is closely linked to self-esteem and influences other areas of interest including social functioning, life choices and behaviours, and long-term outcomes.

The results reported by Mendelson enabled quantitative comparison of BES factor scores from the Western Australian study participants with those from a large cohort without CL/P for the same age-groups from a similar culture (in this case Canada). This gave an indication of whether appearance concerns were of greater importance to individuals with CL/P than to comparable individuals without CL/P.

The BES factor scores within each study age-group were also analysed to determine if there were significant differences by gender, cleft type, self-reported weight category, and self-reported rating of how important facial appearance was to each person. This analysis offered insight into potential underlying factors associated with appearance perceptions, particularly whether those who held the importance of their facial appearance highly would have significantly lower BES scores. The concept of body-esteem may be of great interest and value for clinicians and others providing care for those with CL/P due to the variation in severity of effect to the facial appearance and the accompanying variation in response by the patient with regard to importance and satisfaction of the outcome.

4.2 Copy of Published Paper 1

Nicholls W, Harper C, Selvey L, Robinson S, Hartig G, Persson M. Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups. *The Cleft Palate Craniofacial Journal*, May 2017 (*in press*).

Abstract

Objectives: To determine if patients with cleft lip and/or palate (CL/P) from a Western Australian (WA) cohort were more dissatisfied with their body-esteem than a normative non-cleft cohort, and identify demographic variables that may have significant associations with body-esteem.

Design: Questionnaire study using the Body-Esteem Scale (BES) and Cleft Research Questionnaire (CRQ).

Participants: Self-selected participants from a Western Australian CL/P population across three age-groups (n=359).

Main outcome measures: The BES is comprised of three factors: BE-Appearance, BE-Weight and BE-Attribution. Study mean BES factor scores were compared to normative non-cleft scores. Regression analysis was used to determine significant associations within each age-group between BES factor scores and CRQ variables of: gender, self-reported body-weight category, cleft type and importance of facial appearance rating.

Results: Study mean BE-Attribution scores were significantly lower than the normative scores and significantly lower than the mean BE-Appearance and BE-Weight factor scores within the same age-groups of this study. Having a cleft type of lip and palate, being overweight and placing a high importance on facial appearance had significant negative associations with BES scores. Maintaining a normal body weight and placing a lower level of importance on facial appearance had significant positive associations. Gender had no significant associations.

Conclusion: In this study the attribution aspect of body-esteem had a greater negative impact on patients than their appearance and body weight. This has important implications for clinical treatment and support of patients.

Keywords: cleft lip and palate, appearance, body-esteem, body image.

Introduction

The care of patients with a facial appearance difference requires treatment and support for both the physical and emotional aspects resulting from the condition. For individuals with a cleft of the lip and/or palate (CL/P), facial difference can be noticeable and attract unwanted attention. Appearance dissatisfaction within this group has been well-reported regarding self-esteem (Kapp-Simon, Simon, & Kristovich, 1992; Richman, 1983; R. P. Strauss, Broder, & Helms, 1988; Thomas, Turner, Rumsey, Dowell, & Sandy, 1997) but not for body esteem.

Body-esteem refers to a person's self-evaluation, attitude and feelings about their body (Fisher & Cleveland, 1968). Husain and Aziz (2014) quote Schilder (1935) in describing body-esteem to be an image that a person develops about their body based upon the opinions of other people. Smolak and Levine (2001) describe body-esteem as one explicit domain of self-esteem. Mendelson, White, and Mendelson (1996) proposed that body-esteem is significantly interrelated with self-esteem and that a positive evaluation of a person's appearance and/or body contributes to positive self-esteem. Huang, Norman, Zabinski, Calfas, and Patrick (2007) report the inverse to also be true in that having a negative body-esteem predicts a negative self-view, appearance dissatisfaction, and a corresponding lower quality of life.

The social standards for appearance and body image, often portrayed in the media as a blemish-free, thin-ideal for women (Harrison, 2000), and a toned muscle ideal for men (Grieve & Helmick, 2008), are influential across all age-groups. Paxton, Neumark-Sztainer, Hannan, and Eisenberg (2006) suggested the inability to achieve the ideal body image may result in a lack of self-confidence, self-worth and overly critical self-perceptions. They further found that body image dissatisfaction was a risk factor for depression and negatively influenced self-esteem in teenagers of either gender. J. K. Thompson and Atabe (1991) found body dissatisfaction was particularly prevalent for adolescent females.

Given that the societal standards of appearance and body image are quite narrowly defined and a challenge to achieve, it may be seen as an even greater challenge for a person with a facial difference to meet these standards and therefore may be at greater risk for low body-esteem and self-esteem. Persson, Becker, and Svensson (2007) found that males with a cleft experienced an adverse impact on their physical development at approximately 19 years of age.

There are both intrinsic (self-judgements) and extrinsic influences (perceived as well as actual judgements by others) which may impact self-perception. Extrinsic influences may be from parents, family, peers, teachers, treatment givers, and others in social settings (Tripplett, 2007).

Mendelson and White (1993) hypothesized that an individual can differentiate their feelings about their intrinsic judgements of their own appearance and body weight, and the extrinsic judgements of others of their appearance. To determine the extent of these factors in a general population Mendelson et al., developed two Body-Esteem Scales (BES): one for children (BESC) (Mendelson & White, 1993) and the other for adults and adolescents (BESAA) (Mendelson, White, & Mendelson, 1997). These scales were incorporated into the Cleft Research Questionnaires (CRQ) administered to a cohort of patients with CL/P in Western Australia to provide a measure of how they view their own appearance (BE-Appearance) and body weight (BE-Weight), and how they believe others perceive their appearance (BE-Attribution).

Other studies that have used or validated the BES include Duncan, Al-Nakeeb, and Nevill (2004) negative ethnicity and obesity, Duncan, Al-Nakeeb, and Nevill (2013) inverse of obesity – the concept of leanness, Confalonieri, Gatti, Ionio, and Traficante (2008) validation and translation to an Italian sample, Frisen, Lunde, and Berg (2015) long-term study of body esteem in a Swedish cohort, and Burtaverde (2012) negative quality of life and obesity. No studies from Australia, and no studies specifically for CL/P were found to have used the BES.

This study explored the relationship between body-esteem and CL/P across three age groups in a Western Australian (WA) cohort to redress the paucity of research in this area. The aims of this study were to compare study participant BES factor scores with the corresponding non-cleft normative scores from the Mendelson studies, and to identify any significant associations between study BES factor scores and the CRQ variables of gender, self-reported body weight category, cleft type, and importance of facial appearance rating. It was expected that study participants would have significantly lower BES factor scores than the Mendelson studies given the reported appearance dissatisfaction for individuals with a cleft condition.

Two further expectations were; that adults from this study would not have a significant effect for cleft type, as the majority had completed their definitive cleft treatment; and across all CL/P age-groups, those participants who rated the importance of their facial appearance highly would have significantly lower BES scores, as higher importance of appearance may lead to higher self-criticism and lower self-esteem (Feragen & Borge, 2010; Rumsey, 2012; S. C. Thompson et al., 1998). This is the first study for CL/P patients from Australia that specifically addresses the impacts of CL/P on body-esteem across the life span using the BES scale. At present, these impacts within this population are largely undetermined which may be resulting in unmet psychosocial needs.

Hypothesis

The hypothesis of this study is that all study participants will have lower BES scores (higher dissatisfaction) than the corresponding (non-cleft) normative results from the Mendelson studies.

Methodology

Participants

Participants in this study comprised current and past patients of the Cleft Lip and Palate Unit at Princess Margaret Hospital (PMH) in Perth, Western Australia. This Unit has provided multi-disciplinary treatment for patients with CL/P for over 50 years including plastic and reconstructive surgery, orthodontics, speech therapy, and ear, nose and throat specialities. Participants were assigned to one of three age-groups (see Table 1). The first two age-groups (children 6-12 years and adolescent 13-21 years) attended age-related protocol clinics at PMH. These participants completed questionnaires at the clinics as a voluntary, anonymous convenience sample with the children age-group assisted by their parent or guardian, and the adolescent age-group were similarly assisted as required. The third age-group (adult 22-42 years) were originally identified from a Hospital database and sent a postal questionnaire which included a postage-paid return envelope to their last known address.

Institutional Ethics

The Princess Margaret Hospital for Children Ethics Review Committee approved this study (HREC: 2014046) and informed consent was obtained.

Instruments

Body-esteem scales

The Body-esteem Scale for Adults and Adolescents (BESAA) is a validated 23 item questionnaire which uses a 5-point Likert scale (0=Never to 4=Always) for each item. For approximately half of these items the responses of 'Often (3)' or 'Always (4)' indicate a favourable response, whereas for the remaining items the meaning is reversed: 'Often' or 'Always' become an unfavourable response. These latter items are represented in this paper by an asterisk (*). For analysis purposes these items had their numerical values reversed so that values 3 and 4 always indicated a favourable response, i.e. a higher score indicates a more favourable outcome. The BESAA is divided into 3 factors: BE-Appearance, BE-Weight, and BE-Attribution. BE-Appearance relates to how a person generally feels about their appearance and is calculated as the mean of 10 specific items in the questionnaire.

BE-Weight relates to a person's level of satisfaction with their weight and is the mean of 8 specific items. The third factor, BE-Attribution, relates to how a person perceives that others evaluate their body and appearance and is the mean of the 5 remaining items.

The Body-esteem Scale for Children (BESC) is a validated questionnaire consisting of 20 items with a Yes/No response, which were translated to 1 and 0 for analysis. As with the BESAA, for approximately half of these items 'Yes' indicates a favourable response with the remainder indicate an unfavourable response. These items are identified by an asterisk (*) and have had their numerical values reversed. The BESC is also divided into three factors: BE-Appearance, BE-Weight and BE-Attribution which have the same meaning as for the BESAA, however in this case, the score for each factor is calculated by summing the favourable item responses rather than calculating the mean. The BE-Appearance factor is calculated from 13 specific items and the BE-Weight factor is calculated from 3 specific items. Two items (4 and 19) were not associated with any factor and were excluded from further analysis, as per the Mendelson et al. (1996) study. Similarly, there were only 2 items (2 and 13) associated with the BE-Attribution factor which was not considered sufficient for analysis, as per the Mendelson et al. (1996) study. This study included these items for consistency with the original instrument. The children age-group results from the Mendelson et al. (1996) study and the adolescent and adult age-group results from the Mendelson, Mendelson, and White (2001) study were considered appropriate normative scores for comparison with this study as they were conducted in Canada, which has similar cultural and socio-economic conditions to Australia; and had large sample sizes taken from general populations of school and college-aged students.

Cleft Research Questionnaires

The Cleft Research Questionnaires (CRQ) was developed with three age-appropriate variations for the significant developmental age-groups; children (6 – 12 years), adolescent (13 - 21 years), and adult (22 - 42 years). Each questionnaire was comprised of three sections - patient demographics; cleft-specific variables; and patient satisfaction with PMH service.

In this study it was not possible to quantitatively determine body weight category (e.g. using Body Mass Index) as requesting patient height and weight measurements was explicitly rejected by test participants during the CRQ validation stage. The approach used was for participants to self-report their body weight category as one of *under*, *normal*, *little over* or *quite over* weight.

In the instructions accompanying the questionnaire, participants were asked to appraise their current body weight using the self-reporting body weight categories with 5 kilogram (kg) increments as a guide, for example, *under* would equate to being 5kg under what they would consider their ideal or *normal* weight. A body weight of *little over* would equate to 5kg above their ideal/*normal* body weight, with *quite over* being 10kg or more over their ideal/*normal* body weight. The variable of importance of facial appearance rating was divided into a five point Likert-scale of *extremely*, *very*, *somewhat*, *not very* and *not at all*.

Data Analysis

Due to self-selection by study participants, a check for study sampling bias was conducted for each age-group using z-score proportions tests. These tests compared the proportions of gender, area of residence and cleft types between study participants and corresponding PMH database records. Similarly, Wilcoxon signed rank tests were used to check for age bias within each age-group. Given the large number of tests performed ($m=18$), the Holm correction was applied to the initial p-values to produce adjusted p-values that were then compared to the alpha level of 0.05.

To determine the internal reliability of the BES scores from this study, Cronbach's alpha values were calculated for each BES factor within each age-group. These alpha values were evaluated using the recommendations of George and Mallery (2003, p. 231) who suggest the following rules of thumb, " $> .9$ – excellent, $> .8$ – good, $> .7$ – acceptable, $> .6$ – questionable, $> .5$ – poor, and $< .5$ – unacceptable. Values of .90 or greater suggests redundancies of items".

The BESC and BESAA scores for individuals were calculated differently - the former is the sum of relevant favorable item scores for each factor, whilst the latter is the mean of the relevant item scores. The possible scores for the children BE-Appearance factor were whole numbers from 0 to 13 and for BE-Weight, whole numbers from 0 to 3. The adult and adolescent age-group BES factor scores ranged continuously from 0 to 4. In order to enable comparison of specific item responses within and across the age-groups, the percentage of favorable responses and unfavorable responses were calculated for each item (taking into account the need to adjust items with a reverse meaning).

Within each age-group of this study the gender mean BES scores within each factor were compared to each other, and to the corresponding gender scores for the same factor and age-group from the Mendelson studies. The mean BES scores for all participants (i.e. genders combined) were also compared across the factors for the adolescent and adult age-groups within this study.

As this involved a large number of post-hoc two tailed t-tests to be performed, the Holm correction was applied to the p-values with the adjusted p-values then compared to the alpha level of 0.05 to determine significant differences.

The statistical modelling process outlined by Crawley (2014, pp. 388-448) was used to guide the regression analysis to determine significant associations between the study BES response variables and the CRQ explanatory variables. Each CRQ explanatory variable was converted to a factor as follows (reference levels are listed first and underlined): gender – female, male; self-reported body weight type – normal, little over, quite over, under, cleft type – palate-only, lip and palate, lip-only; importance of facial appearance – somewhat, extremely, very, not very, not at all. All coefficients within each regression model were reported as significant against their respective reference levels using the t-statistic at an alpha level of 0.05. Note that there was only one child in the *quite over* body weight category in the children age-group, hence the *little over* and *quite over* levels were combined into one level (*overweight*) for the analysis.

The children BE-Appearance response variable is ordinal, however, given it has a range of 14 possible values (0 to 13), it was treated as a continuous variable and analysed using Ordinary Least Squares Linear Regression (OLSLR) as were the continuous BES factors for the adolescent and adult age-groups. The children BE-Weight response variable is also ordinal, however, it has a range of only 4 possible values (0 to 3), hence was analysed using Proportional Ordinal Logistic Regression (POLR) using the process outlined in UCLA (2015).

Model simplification involved eliminating non-significant CRQ explanatory variables, and combining levels for remaining variables until a best minimal adequate model was reached where each remaining level was significantly different from the reference level. The level combinations were consistent for self-reported body weight category and cleft type, however were varied for importance of facial appearance. The final level combinations were as follows:

<u>Self-reported body weight</u> }	not overweight = under + normal overweight = little over + quite over
<u>Cleft type</u> }	not l&p = lip-only + palate-only
<u>Importance of facial appearance</u> }	important = very + extremely very-somewhat = very + somewhat some-not important = somewhat + not very + not at all some-important = somewhat + very + extremely not important = not very + not at all

Bootstrapping was used with 1,000 iterations to determine the 95% Confidence Interval for the remaining coefficients in the minimal adequate models to confirm significance.

OLSR interactions between each pair of explanatory factors were calculated for each BES response variable. These interactions were not included in the regression models due to the very small number of significant associations found and the complexity they add in the context of this study.

Data Analysis Software

Microsoft Excel 2016, (Microsoft Corporation Albuquerque, New Mexico, United States) was used for data storage, generating tables of descriptive statistics and creating charts.

Regression analysis, proportions tests and t-tests were conducted using the R statistical programming language 2015 (Version 3.2.3. R Foundation for Statistical Computing; Vienna, Austria) (R Development Core Team, 2015).

Results

Demographics and CRQ variables

The following table contains demographic details of the participants in this study including the CRQ variables used in the regression analysis.

	Children (6 to 12 years old)			Adolescent (13 to 21 years old)			Adult (22 to 42 years old)		
Variable	Male	Female	Total	Male	Female	Total	Male	Female	Total
Gender	48	52	100	63	38	101	71	87	158
Mean Age (SD)	9.7 (2.3)	9.6 (2.2)	9.6 (2.2)	16.9 (2.4)	17.1 (2.4)	17.0 (2.4)	31.2 (6.0)	30.3 (6.3)	30.7 (6.1)
Ethnicity (% Gender)									
Caucasian	40 (83%)	42 (81%)	82 (82%)	55 (87%)	34 (89%)	89 (88%)	62 (87%)	78 (90%)	140 (89%)
Asian	3 (6%)	2 (4%)	5 (5%)	3 (5%)	1 (3%)	4 (4%)	7 (10%)	7 (8%)	14 (9%)
Aboriginal/TSI	2 (4%)	5 (10%)	7 (7%)	4 (6%)	3 (8%)	7 (7%)	1 (1%)	1 (1%)	2 (1%)
Other	3 (6%)	3 (6%)	6 (6%)	1 (2%)	0 (0%)	1 (1%)	1 (1%)	1 (1%)	2 (1%)
Location (% Gender)									
Perth Metro	35 (73%)	33 (63%)	68 (68%)	44 (70%)	22 (58%)	66 (65%)	59 (83%)	66 (76%)	125 (79%)
WA Country	13 (27%)	19 (37%)	32 (32%)	19 (30%)	16 (42%)	35 (35%)	12 (17%)	21 (24%)	33 (21%)
Body Weight Type (% Gender)									
Under	6 (13%)	5 (10%)	11 (11%)	3 (5%)	1 (3%)	4 (4%)	4 (6%)	6 (7%)	10 (6%)
Normal	37 (77%)	33 (63%)	70 (70%)	36 (57%)	19 (50%)	55 (54%)	38 (54%)	39 (45%)	77 (49%)
Little Over	5 (10%)	13 (25%)	18 (18%)	17 (27%)	15 (39%)	32 (32%)	25 (35%)	31 (36%)	56 (35%)
Quite Over	0 (0%)	1 (2%)	1 (1%)	7 (11%)	3 (8%)	10 (10%)	4 (6%)	11 (13%)	15 (9%)
Cleft Type (% Gender)									
Lip	8 (17%)	5 (10%)	13 (13%)	9 (14%)	4 (11%)	13 (13%)	14 (20%)	11 (13%)	25 (16%)
Lip and Palate	14 (29%)	20 (38%)	34 (34%)	41 (65%)	14 (37%)	55 (54%)	44 (62%)	35 (40%)	79 (50%)
Palate	26 (54%)	27 (52%)	53 (53%)	13 (21%)	20 (53%)	33 (33%)	13 (18%)	41 (47%)	54 (34%)

Variable	Children (6 to 12 years old)			Adolescent (13 to 21 years old)			Adult (22 to 42 years old)		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
Importance of Facial Appearance (% Gender)									
Extremely	4 (8%)	10 (19%)	14 (14%)	7 (11%)	12 (32%)	19 (19%)	12 (17%)	27 (31%)	39 (25%)
Very	18 (38%)	19 (37%)	37 (37%)	22 (35%)	14 (37%)	36 (36%)	24 (34%)	32 (37%)	56 (35%)
Somewhat	16 (33%)	9 (17%)	25 (25%)	23 (37%)	10 (26%)	33 (33%)	23 (32%)	24 (28%)	47 (30%)
Not Very	8 (17%)	2 (4%)	10 (10%)	7 (11%)	1 (3%)	8 (8%)	7 (10%)	4 (5%)	11 (7%)
Not At All	2 (4%)	12 (23%)	14 (14%)	4 (6%)	1 (3%)	5 (5%)	5 (7%)	0 (0%)	5 (3%)

Table 1. Demographic details and CRQ variables used in regression analysis.

Caucasians made up the greatest proportion of participants across all three age-groups with the majority of participants living in the Perth metropolitan area. There was an even distribution between genders for all age-groups except for the adolescent group where females were under-represented.

The palate-only cleft type was the most represented in the children age-group and lip and palate in the adolescent and adult age-groups. In the children age-group 19% self-rated as being overweight (little over and quite over) compared to 42% in the adolescent age-group and 44% in the adult age-group. In the children age-group 24% indicated their facial appearance was not important (rated not very and not at all), compared to 13% in the adolescent age-group and 10% in the adult age-group.

The majority of adult age-group participants had completed their cleft treatment with the exception of 14 participants (8.8%) who required final treatment appropriate at skeletal maturity involving dental, oral and plastic surgery.

Response rate (adult age-group)

Using the Hospital database, 806 candidate study participants were identified in the age range 22 to 42 years. Excluding 468 patients with no known last address or an address that had not been updated within the last 10 years, the Adult CRQ and BESAA were posted to 338 former patients. A total of 112 questionnaires could not be delivered, leaving 226 potential respondents. Of those, 158 patients returned completed questionnaires giving a 20% of all 806 candidate participants (or 70% response rate for contacted participants).

Study Sampling Bias and BES Internal Reliability

Of the 15 z-score proportions tests and 3 Wilcoxon signed rank tests calculated to check for study sampling bias across gender, cleft type, residence area, and age, only one significant difference was found (cleft type of *lip and palate* for the adolescent age-group, holm adjusted $p < 0.001$). This suggests it was unlikely that there was sampling bias for this study.

The Cronbach's alpha values calculated for the children, adolescent and adult age-groups for the BE-Appearance factor ranged from 0.91 to 0.92 which corresponds to a rating of excellent. The alpha values for the BE-Weight and BE-Attribution factors for the adolescent and adult age groups ranged from 0.70 to 0.80 which corresponds to a rating of acceptable to good. An exception was the BE-Weight factor for the children age-group which had an alpha value of 0.64 which corresponds to a rating of questionable.

Favourable and unfavourable BES scores

Figure 1 shows the percentage of favourable scores (coloured) and unfavourable scores (clear) for:

- A) BESC item by factor for the children age-group.
- B) BESAA item by factor for the adolescent age-group
- C) BESAA item by factor for the adult age-group

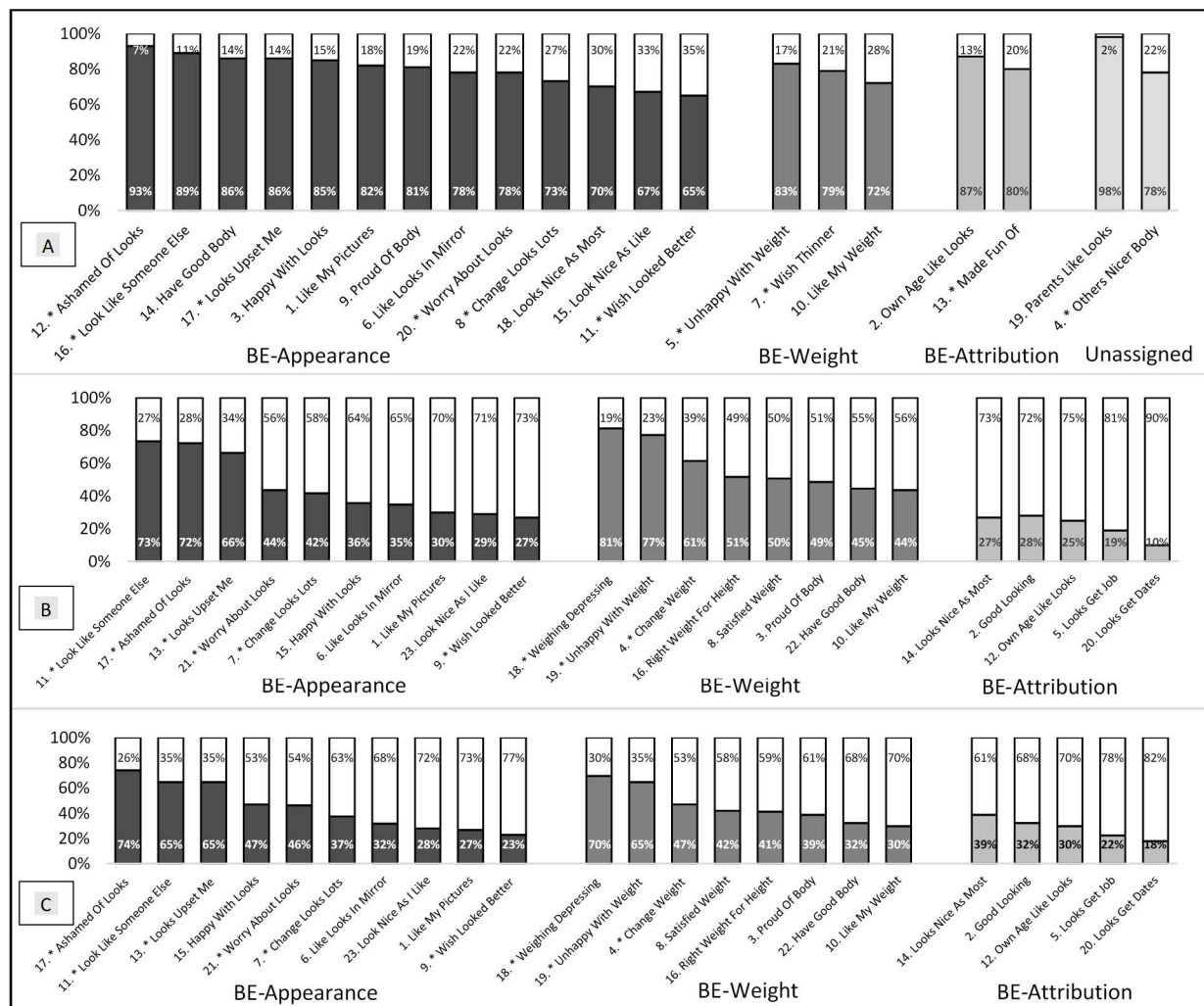


Figure 1. Percentage of favourable and unfavourable BES item scores for A: children, B: adolescent, C: adult age-groups.

The most favourable response for the children age-group was for item 12 “* I often feel ashamed of how I look” where 93% of participants indicated they were not ashamed of their looks. The least favourable response was for item 11 “* I wish I looked better” where 35% of participants wished they looked better.

The most favourable response for the adolescent age-group was for item 18 “* Weighing myself depresses me” where 81% indicated weighing themselves did not depress them. The least favourable response was for item 20 “My looks help me to get dates” where only 10% agreed with this statement.

The most favourable response for the adult age-group was for item 17 “* I feel ashamed of how I look” (the same most favourable item as for the children age-group) where 74% indicated they were not ashamed of their looks. The least favourable response was for item 20 “My looks help me to get dates” (the same least favourable item as for the adolescent age-group) where only 18% agreed.

Comparison of mean BES factor scores

Table 2 compares the mean BES factor scores by gender within each age-group from this study with the corresponding mean BES factor scores from the Mendelson studies. The highlighted values indicate the mean scores from this study that are significantly different to the Mendelson study scores (t statistic, Holm corrected p-values, m=16).

Study	No of Participants			BE-Appearance		BE-Weight		BE-Attribution	
	Male	Female	Total	Male	Female	Male	Female	Male	Female
Children									
This Study	48	52	100	11.2 (2.7)	9.5 (4.1)	2.5 (0.9)	2.2 (1.0)		
Mendelson 1996	159	220	379	11.2 (2.2)	9.7 (3.6)	2.4 (0.9)	1.9 (1.2)		
Adolescent									
This Study	63	38	101	2.5 (0.8) (p<.0001)	2.1 (0.8)	2.8 (0.9)	2.5 (0.9) (p=0.035)	1.6 (0.8) (p<.0001)	1.8 (0.8)
Mendelson 2001	488	630	1118	2.9 (0.7)	2.1 (0.9)	2.9 (0.9)	2.0 (1.1)	2.3 (0.8)	2.1 (0.8)
Adult									
This Study	71	87	158	2.4 (0.9)	2.3 (0.8)	2.5 (0.9)	2.2 (1.0)	1.8 (0.7) (p<.0001)	1.9 (0.7) (p<.0001)
Mendelson 2001	83	133	216	2.7 (0.7)	2.5 (0.7)	2.7 (0.8)	2.3 (1.0)	2.4 (0.8)	2.5 (0.7)

Table 2. Comparison of Mean (& Standard Deviation) of BES factor scores by gender from this study with Mendelson studies.

For all the participants (i.e. genders combined) in the adolescent age-group within this study, the mean BE-Attribution score (1.64) was significantly lower than the mean scores for BE-Appearance (2.34) (t statistic, p<.0001) and BE-Weight (2.68) (t statistic, p<.0001).

Similarly, for all of the adult age-group participants, the mean BE-Attribution score (1.84) was significantly lower than the mean scores for BE-Appearance (2.32) (t statistic, $p < .0001$) and BE-Weight (2.32) (t statistic, $p < .0001$). There were no significant differences between the mean BE-Weight factor scores and mean BE-Appearance scores for either the adolescent or adult age-groups in this study. These comparisons were possible due to the BESAA factors all sharing a common scale (minimum of 0 and maximum of 4). This cross factor comparison could not be conducted for the children age-group as the BESC factors do not share a common scale (BE-Appearance ranges from 0 to 13 and BE-Weight from 0 to 3).

Hypothesis

The hypothesis that all study participants will have significantly lower BES scores (higher dissatisfaction) than the corresponding (non-cleft) normative results from the Mendelson studies was not supported for the children age-group; was supported for the factors of BE-Appearance and BE-Attribution for males only in the adolescent age-group and was supported for the factor of BE-Attribution for both genders in the adult age-group.

Regression analysis of BES factors with CRQ variables

Table 3 shows the results of the OLSR analysis comparing BES factor response variables with CRQ explanatory variables for each age-group within this study. Each column represents an individual regression model for the indicated BES factor with the reference row at the top of the table representing the baseline score. The reference levels score is comprised of *female* gender, *normal* body weight, *palate-only* cleft type, and *somewhat* importance of facial appearance rating. The subsequent cells in the same column have coefficients that either add to (positive numbers) or subtract from (negative numbers) the reference score. Each cell has a t statistic p-value which indicates if the coefficient is significant at an alpha level of 0.05.

As an example of how the models work, in the BE-Appearance model for the adults age group, a male who was a little overweight, with a cleft type of *lip-only*, and rated his facial appearance as not important - the predicted BE-Appearance score would be 2.79 calculated as: 2.84 (reference) $- 0.07$ (male) $- 0.40$ (little over) $+ 0.01$ (lip-only) $+ 0.41$ (not important) = 2.79.

The Adjusted R-squared values indicate the strength of each regression model and range from weak (0.09) for BE-Attribution in the adult age-group to moderately strong (0.53) for BE-Weight in the adult age-group.

Variable	Children	Adolescents			Adults		
	BE-Appearance	BE-Appearance	BE-Weight	BE-Attribution	BE-Appearance	BE-Weight	BE-Attribution
Reference Levels (Intercept)	11.92 (p<.001)	2.83 (p<.001)	3.15 (p<.001)	1.85 (p<.001)	2.84 (p<.001)	3.09 (p<.001)	2.09 (p<.001)
Gender - male	0.96 (p=.145)	0.38 (p=.022)	0.17 (p=.317)	-0.02 (p=.897)	-0.07 (p=.574)	-0.05 (p=.665)	-0.16 (p=.213)
Body Weight - little over	-3.55 (p<.001)	-0.42 (p=.009)	-0.74 (p<.001)	-0.21 (p=.193)	-0.40 (p=.002)	-0.97 (p<.001)	-0.36 (p=.005)
Body Weight - quite over	*	-0.82 (p=.001)	-1.69 (p<.001)	-0.52 (p=.042)	-0.88 (p<.001)	-1.93 (p<.001)	-0.59 (p=.004)
Body Weight - under	-2.15 (p=.036)	-0.41 (p=.264)	-0.79 (p=.043)	0.08 (p=.823)	-0.26 (p=.283)	-0.33 (p=.152)	0.03 (p=.897)
Cleft Type - lip and palate	-2.04 (p=.004)	-0.54 (p=.002)	-0.07 (p=.719)	-0.53 (p=.003)	-0.17 (p=.202)	-0.03 (p=.805)	-0.20 (p=.141)
Cleft Type – lip-only	-1.44 (p=.149)	-0.24 (p=.329)	-0.06 (p=.808)	0.13 (p=.593)	0.01 (p=.940)	-0.06 (p=.745)	0.00 (p=.980)
Face Appearance - extremely	-0.89 (p=.401)	-0.30 (p=.171)	-0.03 (p=.891)	0.45 (p=.041)	-0.68 (p<.001)	-0.70 (p<.001)	0.08 (p=.599)
Face Appearance - very	-0.97 (p=.229)	-0.40 (p=.020)	-0.37 (p=.044)	0.10 (p=.546)	-0.12 (p=.401)	-0.12 (p=.351)	0.18 (p=.197)
Face Appearance – not very	1.10 (p=.342)	0.13 (p=.639)	0.05 (p=.871)	0.44 (p=.127)	0.41 (p=.092)	0.32 (p=.160)	0.10 (p=.663)
Face Appearance – not at all	0.80 (p=.441)	0.37 (p=.277)	0.67 (p=.062)	0.80 (p=.022)	0.71 (p=.041)	0.56 (p=.085)	0.53 (p=.118)
Adjusted R-squared	0.32 (p<.001)	0.28 (p<.001)	0.36 (p<.001)	0.20 (p<.001)	0.28 (p<.001)	0.53 (p<.001)	0.09 (p=.005)

Table 3. Ordinary least squares linear regression coefficients for BES factors and Cleft Research Questionnaire variables. * little over and quite over were combined into one level.¹

In six of the seven models there were no significant differences between males and females. The exception was for BE-Appearance in the adolescent age-group where the positive coefficient (0.38) indicated males had a significantly higher score (t statistic, p=0.022) than the reference level of females in this model.

The BE scores for respondents reporting their body weight types as *little over* and *quite over* were significantly lower (i.e. had negative coefficients with p values < 0.05) compared to the reference level of *normal* body weight in six of the seven models. The exception was BE-Attribution for adolescents where *little over* had a negative coefficient (-0.21) but was not significant (t statistic, p=0.193). The coefficients for the body weight type of *under* were negative or close to zero with two of the seven models being significant.

The BE scores for respondents with the cleft type of *lip and palate* was uniformly lower than the reference level of *palate-only*, with three of the seven models being significant (p values <0.05). There was no significant difference between *lip-only* and *palate-only* for any of the BES factors across the age-groups (p values >0.05).

¹ Body weight category was self-reported as either: under, normal, little over or quite over. Importance of facial appearance was self-reported as: extremely, very, somewhat, not very or not at all.

The BE-Appearance and BE-Weight scores were uniformly lower (had negative coefficients) for the facial appearance ratings of *extremely* and *very* compared to the reference level of *somewhat* with four of the ten coefficients being significant (p values < 0.05). In contrast, the BE-Attribution scores were all higher (positive coefficients) with the *extremely* rating for the adolescent age-group being significant (p=0.041). The BE scores across all age-groups were consistently higher (positive coefficients) for those who rated facial appearance as *not very* important or *not at all* important, with two being significant (p values < 0.05).

Table 4 shows the minimum adequate models for the BES factor response variables (all CRQ variable coefficients are significant with p values < 0.05). Gender was not included as this variable was not significant for any model.

Variable	Children	Adolescents			Adults		
	BE-Appearance	BE-Appearance	BE-Weight	BE-Attribution	BE-Appearance	BE-Weight	BE-Attribution
Reference Levels	not overweight not l&p	not overweight not l&p somewhat-not important	not overweight somewhat- important	not l&p somewhat- important	not overweight very- somewhat important	not overweight very- somewhat important	not overweight not l&p
Reference Levels (Intercept)	12.28 (p<.001)	3.05 (p<.001)	2.97 (p<.001)	1.89 (p<.001)	2.64 (p<.001)	2.94 (p<.001)	2.15 (p<.001)
Body Weight - little over	/	/	-0.64 (p<.001)	/	-0.40 (p=.001)	-0.93 (p<.001)	/
Body Weight - quite over	/	/	-1.51 (p<.001)	/	-0.87 (p<.001)	-1.87 (p<.001)	/
Body Weight – overweight	-3.60 (p<.001)	-0.50 (p<.001)	/	/	/	/	-0.40 (p<.001)
Cleft Type - lip and palate	-1.59 (p=.014)	-0.38 (p=.008)	/	-0.58 (p<.001)	/	/	-0.25 (p=.026)
Importance Face Appearance - extremely	/	/	/	/	-0.64 (p<.001)	-0.63 (p<.001)	/
Importance Face Appearance – important	-1.43 (p=.030)	-0.54 (p<.001)	/	/	/	/	/
Importance Face Appearance - not important	/	/	0.47 (p=.036)	0.51 (p=.016)	0.56 (p=.003)	0.48 (p=.007)	/
Adjusted R-squared	0.29 (p<.001)	0.26 (p<.001)	0.33 (p<.001)	0.18 (p<.001)	0.28 (p<.001)	0.53 (p<.001)	0.11 (p<.001)

Table 4. Minimal adequate models for BES factors and Cleft Research Questionnaire variables.

Across all of the minimum adequate models there was no significant difference between *under* and *normal* levels in the self-reported body weight category. These were combined to form a new reference level (*not overweight*), and in comparison, the overweight levels were uniformly lower (negative coefficients).

In three of the seven models, cleft type was not a significant variable and hence was excluded. In the remaining four models, there was no significant difference between *lip-only* and *palate-only*, hence they were combined into a new reference level of *not l&p* (*not lip and palate*). In comparison to this new reference level, the coefficients for *lip and palate* were uniformly lower.

In six of the seven models, importance of facial appearance rating was significant (the exception was BE-Attribution in the adult age-group). Model coefficients were consistently positive for those who considered facial appearance to be *not important*, and consistently negative for those who considered facial appearance to be *important* or *extremely important*.

The only significant variable for the POLR analysis of the BE-Weight factor in the children age-group was self-reported body weight category. Figure 2 shows the probability for *normal* weight children scoring a 3 (very high) was 0.77 (77%), whilst for an *overweight* child it was 0.06 (6%). Conversely *normal* weight children had less than 0.05 (5%) probability of having a 1 (low) or 0 (very low) score, whilst *overweight* children had a 0.72 (72%) probability of having either 1 (low) or 0 (very low) score.

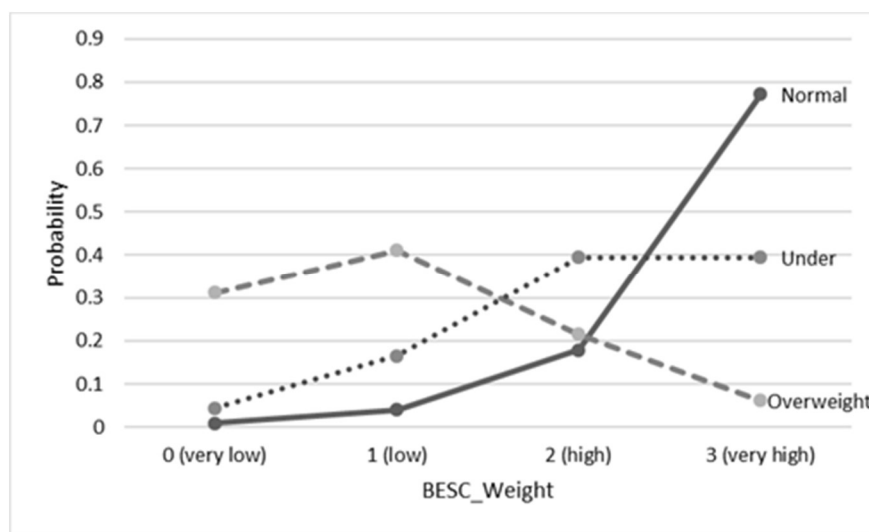


Figure 2. Children age-group POLR of BE-Weight by body weight.

Discussion

BES vs Mendelson

CL/P participants did not have lower BES scores for the BE-Appearance or BE-Weight factors (higher dissatisfaction) compared to the Mendelson normative scores, with the exception of BE-Appearance for the adolescent age-group where male study participants scored significantly lower than the males in the Mendelson study.

For the children age-group, possible explanations for this result are that participants may not yet have reached the time in their development in which relationship interests have raised the importance of personal appearance (Bull & Rumsey, 1988; Kapp-Simon et al., 1992; Turner, Thomas, Dowell, Rumsey, & Sandy, 1997) and they may have a more supportive environment due to their cleft condition from treatment givers and family members (Lansdown, Lloyd, & Hunter, 1991; Noar, 1991; Richman & Millard, 1997).

One further possibility is that some participants may not have experienced adverse levels of teasing due to concerted efforts within the education system to address the issue of teasing and bullying such as the Safe and Supportive School's Initiative (West Australian Department of Education and Training, 2015).

The unexpected lack of significant difference between the adolescent and adult age-groups with the normative BE-Appearance and BE-Weight scores does not discount these groups from having appearance and weight dissatisfaction, only that it is not greater than that of the normative groups. As the majority (91%) of adults had completed their definitive cleft treatment, it may appear that many were satisfied with their appearance outcomes. This is evidenced by the most favourable response from the BES for the adult age-group being for item 17 where participants indicated they were not ashamed of how they looked. For the adolescent age-group there was a mix of those whom had completed and were yet to complete their definitive cleft treatment which may have influenced this result and may require further investigation, however the significant lower result in BE-Appearance for adolescent males supports the expectation.

Weight

There were no significant differences between the mean BE-Weight and BE-Appearance scores for either the adolescent or adult age-groups within this study, however both scores were significantly higher than the study BE-Attribution scores. One possible explanation may be an emerging shift in global social attitudes regarding what constitutes being overweight. Ogden (2015) proposed that a normalisation of overweight status and obesity is occurring and cited recent research where 36% of UK adults perceived they were simply overweight when in fact they were clinically obese. This suggests that if an individual determines their weight status by comparing themselves to those around them, the majority of whom are overweight, then they will not see themselves as being overweight. The result is a reclassification of what is normal weight and a reduction or elimination of the negative perceptions associated with being overweight.

The same shift may be occurring in Australia where the Australian Institute of Health and Welfare (2015) estimated 63% of the population in 2011-12 were considered overweight or obese, including one in four children. This is evidenced by the most favourable response from the BES for the adolescent age-group being item 18 where participants indicated that weighing themselves was not depressing. In addition, the self-report approach used may have led to potential inaccuracies of body weight categorisation. This is supported in the Swedish study of the physical characteristics of young men with cleft (Persson et al., 2007) which found that self-reported weight category was contradictory to quantitative BMI measures.

BE-Attribution

The overall lower scores for BE-Attribution for the adolescent and adult age-groups compared to normative scores, and the other BES factors within the same age-groups may be explained by the study subjects having a higher focus of attention from others on their appearance over their lifespan due to their cleft. This is especially magnified in their treatment setting where most of the focus from the clinical team involves the correction of deficits in facial and dental appearance with frequent discussions on the aspects that need improvement. There may have been unwanted attention from both clinical and social settings which may have created a sensitivity to how they believe others perceive their appearance. In the literature this is described as; the fear of negative appearance evaluation by others, feelings of self-consciousness and anxiety especially in social circumstances, and avoidance of social situations (Berger & Dalton, 2009; Cheung, Loh, & Ho, 2007; Demir, Karacetin, Baghaki, & Aydin, 2011; Murray, Arteche, Bingley, Hentges, & Bishop, 2010; Stock, Feragen, & Rumsey, 2015). Alen (2015) found that negative peer associations and victimization adversely impacted body-esteem from childhood and into adulthood.

In addition, study participants from both the adolescent and adult age-groups indicated they did not believe they were attractive to potential partners as evidenced by the least favourable response from the BES questionnaire being item 20 "My looks help me to get dates".

Gender

There was no significant difference between genders within the study for the mean BES factor scores and regression analysis across all age-groups, with the exception of adolescent females who scored significantly lower than males. This is consistent with body dissatisfaction findings from the general population who did not have a cleft. J. K. Thompson and Atabe (1991) reported that body dissatisfaction was prevalent for adolescent females and Frisen et al. (2015) found in their BES study that there was a lower score for BE-Appearance for adolescent females.

Cleft type

There was no significant difference found between the cleft types of *lip-only* and *palate-only* in any of the regression models, however the children BE-Appearance, adolescent BE-Appearance and BE-Attribution, and adult BE-Attribution scores for respondents with cleft type of *lip and palate* was significantly lower than those with lip-only or palate-only cleft types. This may be due to this type of cleft being the most severe, with potential negative impact on facial appearance, speech and hearing. The expectation that adults from this study would not have a significant effect for cleft type was met for BE-Appearance and BE-Weight, but not for BE-Attribution.

This may have been influenced by the majority of participants in the adult age-group whom had completed their definitive treatment and surgical interventions which would mitigate the appearance impacts of their cleft, but not the life-long impact of the opinions of others.

Importance of facial appearance

The results from this study support other research findings that a higher level of importance attributed to appearance may lead to a higher level of self-criticism and a resulting lower level of appearance satisfaction. The less participants felt their facial appearance was important the more highly they scored (higher satisfaction) across all the BES factors, and conversely, the more important they felt it was, the lower they scored (lower satisfaction).

Hypothesis

The lack of significant differences between the children age-group from this study and the Mendelson study may indicate that children with CL/P had not yet reached an age where they have experienced problematic appearance and body esteem related issues. There were significant differences in the adolescent age-group that supported the hypothesis but only for males. This was unexpected as it is in direct contrast to the findings of Thompson and Atabe (1991) who reported a higher prevalence of body dissatisfaction amongst adolescent females. The overall lower scores for BE-Attribution for the adolescent and adult age-groups in this study supports the hypothesis, and may be explained by the study subjects having a high focus of attention on their appearance due to their cleft condition over many years by others, especially by health care professionals.

Limitations

A limitation of this study was that the normative BES scores used for comparison were from Canada, and were from 1996 for the children age-group and 2001 for the adolescent and adult age-groups (18 and 13 years prior to the data collection for this study respectively). A further limitation was that the age ranges from this study were not identical with those in the comparative studies: Mendelson et al. (1996) children: 8 to 13 years old compared to 6-12 in this study, Mendelson et al. (2001) 12 to 19 years old compared to 13 to 21 in this study. The subjects in the 20 to 25 years old sub group from the Mendelson et al. (2001) study were used as the comparative adult age-group in this study (21 to 42) in lieu of any other available data. The age-groups were not matched as the BES questionnaires in this study formed part of a broader research undertaking that required the study age-groups to be based on CL/P protocol treatment milestones.

Conclusion

The BE-Appearance and BE-Weight scores from this study were similar to those reported in the Mendelson studies, however, the BE-Attribution scores from this study were significantly lower than the corresponding Mendelson scores and also significantly lower than the other BES factor scores within this study.

Study participants with a cleft type of *lip and palate* were more likely to have appearance or attribution dissatisfaction than those with *lip-only* or *palate-only* clefts.

There were no significant differences between the genders within this study which indicates that *both* males and females with a cleft are susceptible to body-esteem dissatisfaction. The one exception was adolescent female study participants who scored significantly lower than adolescent male study participants in appearance.

Maintaining a normal body weight and placing a lower level of importance on personal appearance are important contributors to a positive self-image and body-esteem.

The overall lower scores (higher dissatisfaction) identified with the BE-Attribution results from this study highlights the importance of clinicians and support staff being aware that the attribution aspect of body-esteem has a greater negative impact on patients than their appearance and body weight. This has implications for clinical practice as clinicians hold a position of high influence and must ensure all interactions minimise the negative impact of attribution. Discussions concerning appearance require sensitive handling and may include recommending appropriate resources to support patients with this issue.

Although the BES is not a cleft-specific instrument, it has value in enabling comparisons between age-groups and between cohorts with and without a cleft condition.

Recommendations

There are implications for clinicians and support staff regarding the importance and impact of the attribution factor in patient's lives.

- Interactions with patients during treatment and treatment planning concerning their appearance should be appropriate and supportive, and training programs made accessible. Clinicians and staff should also have knowledge of how patients may access resources, both on-line and face to face, to assist with issues of teasing and appearance dissatisfaction.

- The Cleft Team are one of the groups that has an influence in their patients' lives - what is said and how it is said is important. Emphasis on being appearance-supportive instead of appearance-focussed is required to encourage patients to look to other areas of their lives apart from their appearance for confidence and interest. There needs to be the ability to recognise those with attribution issues and be able to offer appropriate resources whether they be on-line or a community program.
- Consideration needs to be given to adolescent males as well as females when considering body esteem issues.

Chapter 5 Paper 2: The psychosocial impact of cleft in a Western Australian cohort across three age-groups.

5.1 Commentary for Paper 2

This paper addressed the second and fourth thesis objectives which were: to identify the types of psychosocial problems and the impacts of CL/P within each age-group, and, to determine the importance and satisfaction ratings within each age-group for cleft-related physical attributes and for support given by others.

Due to the long-term commitment for CL/P treatment, the impacts of CL/P may be felt across a range of areas, and those impacts may vary at different periods in the life-span. Variables were measured across a range of psychosocial domains including social relationships and feelings of support, importance and satisfaction with physical attributes, issues of teasing and bullying, impacts across multiple settings and self-confidence. This paper used a cross-sectional approach to investigate the impacts of CL/P for three age-groups: children, adolescents and adults. The analysis was used to assess whether there were patterns to these impacts. For example; if the impact started in childhood, was exacerbated in adolescence and reduced in adulthood, or if they remained and still affected the person into adulthood.

The instrument used to quantify these impacts was three age-appropriate versions of the CRQ. Data analysis comprised quantitative methods of descriptive statistics, hypothesis tests and relative risk ratios which were used to compare results for common questions across the three age-groups by gender and cleft type. The analysis offered insight into potential underlying factors associated with the impacts of CL/P over time, which provide evidence for service provision and timing for structured support.

The components from this paper were the platform for providing data across the timespan, which emphasised the most highly influencing variables and which seamlessly blended with two further areas for examination. The first was the examination of outcomes in the adult age-group and the second was to find a deeper meaning of the data by using qualitative methods.

5.2 Copy of Published Paper 2

Nicholls W, Selvey L, Harper C, Persson M, Robinson S. The psychosocial impact of cleft in a Western Australian cohort across three age-groups. *The Cleft Palate Craniofacial Journal*, May 2017 (in press).

Abstract

Background: Management of a cleft of the lip and/or palate (CL/P) involves a multidisciplinary team approach lasting from birth to potentially post-skeletal maturity. This condition is complex, with both medical and psychosocial implications that may place individuals with a cleft at higher risk for developing psychosocial problems.

Methodology: A self-administered questionnaire was completed by a sample from the Western Australian cleft population comprising three age-groups: child (n=100), adolescent (n=101), and adult (n=158).

Results: Public speaking, being photographed, special relationships, and participation in school were identified as the areas most impacted by having a cleft. Hearing and speech were reported to have a higher importance than facial and dental appearance. Participants rated support given to them by their parents as the most important, with high ratings for treatment providers. For teasing, the impact of cleft was significantly higher among participants with cleft lip and palate for both the adolescent and adult age-groups. There was little significant difference by gender across the variables, which suggests that males are just as likely to require support as females.

Conclusion: The impact of a cleft across multiple psychosocial domains needs to be recognized and addressed as part of craniofacial team care across age-groups.

Keywords: psychosocial, cleft lip and palate, three age-groups.

Introduction

Management of a cleft of the lip and/or palate (CL/P) involves treatment and surgical intervention from birth to potentially post-skeletal maturity for facial, palatal and dental irregularities, and related speech and hearing difficulties (Kasten et al., 2008; Swan, Goodacre, Czernuszka, & Bucknall, 2008). Successful treatment of this complex condition must also include awareness and management of the psychosocial impact of CL/P with the objective of attaining a positive life adjustment (Cheung et al., 2007).

A person with a cleft may experience episodes of teasing and bullying (Hunt, Burden, Hepper, Stevenson, & Johnston, 2006), stigma and social exclusion, and perceived or actual negative responses of other people (Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004). This may influence their self-perception and how they believe others perceive them (Mendelson et al., 2001) and place them at higher risk for psychosocial problems in the following areas: low self-esteem and self-concept (Endriga & Kapp-Simon, 1999; Pisula, Lukowska, & Fudalej, 2014), appearance dissatisfaction (Feragen & Borge, 2010; Marcusson, Paulin, & Ostrup, 2002), shyness and social isolation (Bilboul, Pope, & Snyder, 2006; Kramer et al., 2009) and anxiety and depression (Pinquart & Shen, 2010; Ramstad, Ottem, & Shaw, 1995b; Roberts & Mathias, 2012).

While there have been a number of published studies investigating the psychosocial impact of CL/P, few have investigated this across the lifespan using a comparable instrument. We therefore aimed to gain an understanding of the patient perception of CL/P across three age groups by exploring the perceived impact of CL/P on attitude to life and academic achievement; the importance and satisfaction with physical attributes and social support provided by key groups; the prevalence and effects of teasing and bullying; the experiences and outcomes of treatment; and the psychosocial support resources and information that may be helpful.

Methodology

Participants

Participants were recruited from current and past patients of the Cleft Lip and Palate Unit at Princess Margaret Hospital (PMH) in Perth, Western Australia (WA) and were categorised into three age-groups (see Table 1). The first two age-groups (children 6-12 years, and adolescent 13-21 years) comprised 100 and 101 patients respectively who attended age-related protocol clinics at PMH. Patients completed questionnaires at the clinics as a voluntary, convenience sample, with the assistance of their parent or guardian as required. No identifying information was recorded. The third age-group (adult 22-42 years), comprised 158 former patients, the majority of whom had completed their definitive cleft treatment at PMH, and were sent a questionnaire by post to their last known address. Informed consent was obtained by requesting the parent/caregiver to sign a consent form for those under 16 years, the patient and parent to sign for those 16 years (assent and consent) but under 18 years and the patient to sign if over 18 years which was attached to the information booklet with the questionnaire. The consent form was removed and stored separately to the completed questionnaire to protect patient identity.

Response rate (adult age-group)

Using a PMH database, 806 candidate study participants were identified in the adult age range 22 to 42 years. Excluding 468 patients with no known or recently updated last address, the adult CRQ was posted to 338 former patients, of which 112 could not be delivered. Of the 226 potential participants, 158 patients returned completed questionnaires giving a response rate of 20% for all 806 candidate participants (or a 70% response rate for the 226 contacted participants).

Institutional Ethics

The Princess Margaret Hospital for Children and Curtin University Human Research Ethics Committees approved our study and informed consent was obtained.

Instrument

The Cleft Research Questionnaire (CRQ) is a cleft-specific questionnaire created and used by the first author at PMH. Three age-appropriate versions of the questionnaire (for children 53 questions, adolescents 62 questions and adults 116 questions) were used to assess the following categories of variables with a range of response formats: demographics (check boxes and free text), impact of cleft (yes/no and free text), importance and satisfaction with physical attributes and with support from others (5 point Likert scale), teasing or bullying (yes/no and free text), treatment satisfaction (4 point Likert scale and free text), and health impact (yes/no and free text). Questions were formulated by the first author from the literature and incorporated experience and knowledge from the PMH cleft team.

The impact of cleft on getting work, and on special relationships (e.g. partner, boyfriend, girlfriend) were only included in the adolescent and adult versions of the CRQ.

A Likert scale (extremely, very, somewhat, not very, not at all) was used for rating the importance of, and satisfaction with, four physical attributes (facial appearance, teeth appearance, speech and hearing), and also for the support they received from their parents, siblings, treatment providers, and teachers (substituted with employer for the adult age-group). These ratings were assigned numeric values (from 1=not at all, to 5=extremely). The adult version of the CRQ also collected responses for variables of anxiety, depression and self-esteem. Each version of the CRQ was piloted with 10 parents (for child version) and 10 patients with CL/P (for both the adolescent and adult versions) and face validation was undertaken in this process. Face validation was also undertaken by senior members of the PMH cleft team.

Data Analysis

Hypothesis tests for this cross-sectional study were undertaken using Chi-squared, Fisher's Exact, Wilcoxon-Mann-Whitney, and Kruskal-Wallis tests to compare proportions by gender, cleft type, and age. Study bias was calculated within each study age-group against the total proportions in the same age-groups extracted from a PMH database.

Microsoft Excel 2016, (Microsoft Corporation Albuquerque, New Mexico, United States) was used for data storage, calculating descriptive statistics, and generating tables and charts.

Hypothesis tests were conducted using the R statistical programming language version 3.3.1 (R Development Core Team, 2015) to identify significant differences by gender and by cleft type. The Holm correction was used to adjust p-values whenever the same variables were used repeatedly. All p-values (adjusted and unadjusted) were compared against the alpha level of 0.05. Adjusted p-values are identified in the text by an asterisk (e.g. $p^* < 0.001$).

Participant comments were analysed by thematic response.

Results

Demographics

Table 1 summarises the demographic details of the participants. There was a slightly higher ratio of females to males except for the adolescent age-group where females were under-represented. The majority of participants were Caucasian and lived in the Perth urban area.

Variable (% Study Total)	Children (6 to 12 years old)			Adolescent (13 to 21 years old)			Adult (22 to 42 years old)			Study Total
	Male	Female	Total	Male	Female	Total	Male	Female	Total	
Mean Age	9.7	9.6	9.6	16.9	17.1	17.0	31.2	30.3	30.7	21.0
standard deviation	2.3	2.2	2.2	2.4	2.4	2.4	6.0	6.3	6.1	6.9
Gender	48 13.4%	52 14.5%	100 27.9%	63 17.5%	38 10.6%	101 28.1%	71 19.8%	87 24.2%	158 44.0%	359 100.0%
Cleft Type										
Lip-only	8 2.2%	5 1.4%	13 3.6%	9 2.5%	4 1.1%	13 3.6%	14 3.9%	11 3.1%	25 7.0%	51 14.2%
Lip & Palate	14 3.9%	20 5.6%	34 9.5%	41 11.4%	14 3.9%	55 15.3%	44 12.3%	35 9.7%	79 22.0%	168 46.8%
Palate-only	26 7.2%	27 7.5%	53 14.8%	13 3.6%	20 5.6%	33 9.2%	13 3.6%	41 11.4%	54 15.0%	140 39.0%
Race										
Caucasian	40 11.1%	42 11.7%	82 22.8%	55 15.3%	34 9.5%	89 24.8%	62 17.3%	78 21.7%	140 39.0%	311 86.6%
Asian	3 0.8%	2 0.6%	5 1.4%	3 0.8%	1 0.3%	4 1.1%	7 1.9%	7 1.9%	14 3.9%	23 6.4%
Aboriginal/Torres Strait Islander	2 0.6%	5 1.4%	7 1.9%	4 1.1%	3 0.8%	7 1.9%	1 0.3%	1 0.3%	2 0.6%	16 4.5%
Other	3 0.8%	3 0.8%	6 1.7%	1 0.3%	0 0.0%	1 0.3%	1 0.3%	1 0.3%	2 0.6%	9 2.5%
Location										
Perth Urban Area	35 9.7%	33 9.2%	68 18.9%	44 12.3%	22 6.1%	66 18.4%	59 16.4%	66 18.4%	125 34.8%	259 72.1%
Western Australia Rural Area	13 3.6%	19 5.3%	32 8.9%	19 5.3%	16 4.5%	35 9.7%	12 3.3%	21 5.8%	33 9.2%	100 27.9%

Table 1. Demographics for all age-groups by gender.

Study sample bias

Table 2 shows the proportions for study variables, corresponding PMH database values, and the unadjusted p-values for the hypothesis tests conducted. The shaded cells indicate significant differences between these proportions.

Age-group	Gender		Cleft Type			Residence Area		Total
	Male	Female	Lip-only	Lip & Palate	Palate-only	Perth Metro	WA Country	
Children								
Study Participants	48 (48%)	52 (52%)	13 (13%)	34 (34%)	53 (53%)	68 (68%)	32 (32%)	100
PMH Database	242 (55%)	198 (45%)	101 (23%)	115 (26%)	224 (51%)	334 (76%)	106 (24%)	440
p-value	0.205		0.057			0.102		
Adolescent								
Study Participants	63 (62%)	38 (38%)	13 (13%)	55 (54%)	33 (33%)	66 (65%)	35 (35%)	101
PMH Database	266 (54%)	227 (46%)	111 (23%)	149 (30%)	233 (47%)	330 (67%)	163 (33%)	493
p-value	0.121		0.000			0.757		
Adult								
Study Participants	71 (45%)	87 (55%)	25 (16%)	79 (50%)	54 (34%)	125 (79%)	33 (21%)	158
PMH Database	443 (55%)	363 (45%)	162 (20%)	347 (43%)	297 (37%)	569 (71%)	237 (29%)	806
p-value	0.021		0.229			0.029		

Table 2. Proportions and P-values for comparisons of variables between study sample and PMH database.

Cleft type proportions in the adolescent age-group were significantly different with cleft lip and palate being over-represented in the study, and cleft palate only being under-represented. Similarly, gender and residence area were significantly different in the adult age-group with females being over-represented as were Perth urban residents. The proportions for each age in years within each age-group were also compared. The children age-group proportions were significantly different ($p < 0.001$) with 12 year-olds in the study being over represented (study 36.0%, PMH 14.8%), and 7 year-olds being under represented (study 1.0%, PMH 15.2%). The adolescent age-group proportions were significantly different ($p < 0.001$) with 15 and 18 year-olds being over represented (study 23.8%, PMH 11.8%), and 14 and 20 year-olds being under represented (study 4.0%, PMH 12.0%).

Impact of cleft

Figure 1 shows the percentage of participants who indicated there was an impact on specific areas of their lives within each age-group by gender and cleft type.

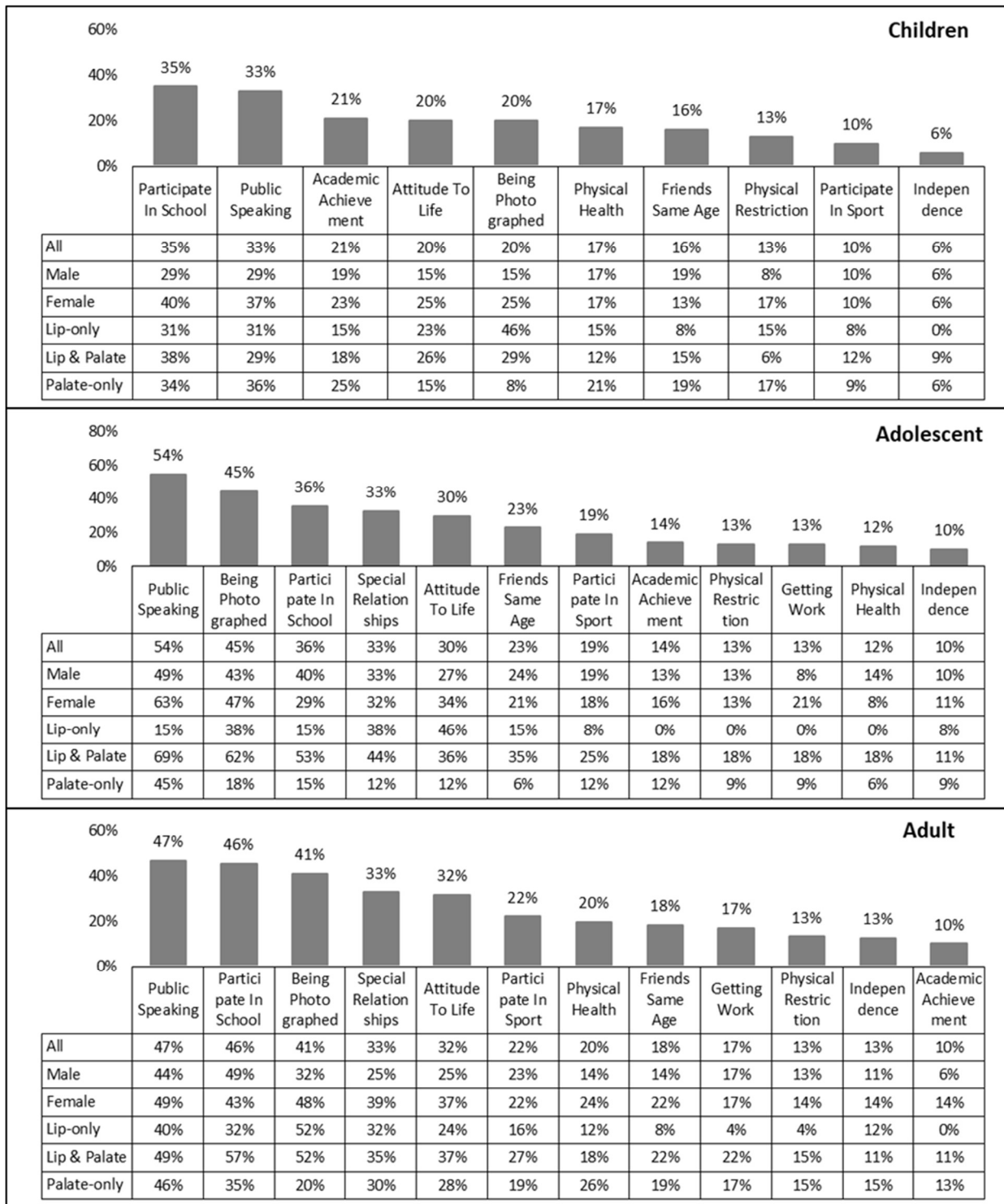


Figure 1. Impact of cleft for specific areas for each age-group by gender and cleft type.

The impact of cleft was consistently high within each age-group for the specific areas of participation in school (children 35%, adolescent 36%, adult 46%) and public speaking (children 33%, adolescent 54%, adult 47%), whilst the impact on independence was consistently low (children 6%, adolescent 10%, adult 10%).

Comments associated with participation in school included: 'lots of time off school', 'speech and learning difficulty', 'hearing problems', 'trouble with speech', 'teasing held me back', 'too shy to participate', 'people stare and ask what is wrong with my lip'. Comments associated with the impact on public speaking included: 'people struggle to understand me', 'too anxious', 'people stare at my scar', 'it terrifies me'. The impact on academic achievement was rated highly for the children age-group (21%), moderately for the adolescent age-group (14%) and was the lowest rated area for the adult age-group (10%).

Within each age-group there were no significant differences by gender for any of the specific areas ($p > 0.05$). A significant difference by cleft type across all age-groups was the impact on being photographed ($p \leq 0.001$) with cleft palate only reporting the least impact in each age-group. For the adolescent age-group there were significant differences by cleft type for the specific areas of: attitude to life ($p = 0.015$), friends same age ($p = 0.005$), public speaking ($p = 0.001$), participate in school ($p < 0.001$), and special relationships ($p = 0.006$). In each case, participants with cleft lip and palate reported the highest impact, and (with the exception of public speaking), cleft palate only had the lowest impact.

For the children age-group, 43% of participants reported no impacts for any of the specific areas, 14% reported one, and 43% reported two or more areas of impact. For the adolescent age-group, 27% reported no impact, 9% reported one, and 64% reported two or more areas of impact. For the adult age-group, 23% reported no impact, 17% reported one, and 60% reported two or more areas of impact.

The psychosocial issues of low self-esteem and self-worth were evidenced by comments such as: 'I lack confidence', 'too much teasing – no confidence', 'low self-esteem'. The psychosocial issue of appearance dissatisfaction negatively influenced participants being photographed with comments such as: 'not pretty enough', 'hate having my photo taken', 'I grew a beard to hide my lip scar', 'don't like my cleft side being photographed', 'lip-shape and messy teeth affect my smile', 'I still get embarrassed because my nose is very crooked and people still look at me and ask what happened?', 'my nose is still crooked after three

nose jobs and my lip scar is still prominent’, and ‘don’t like how I look in photos’. Similar comments for special relationships included: ‘I am not attractive and have low self-esteem’, ‘very conscious of my face’, ‘people don’t get me’, and ‘I felt no boy would ever like me’.

Results of treatment

Each age-group was asked if, as a result of their treatment, they feared going to the dentist or undergoing a general anaesthetic. Seventeen percent of the children age-group, 26% of adolescents and 28% of adults reported they feared going to the dentist, whilst 43% of children, 41% of adolescents and 20% of adults feared having a general anaesthetic. There were no significant differences by gender or cleft type.

When asked if they could chew properly, 13% of the children age-group, 16% of adolescents and 4% of adults reported that they could not. When asked if they were happy with their smile, 28% of the children age-group, 43% of adolescents and 32% of adults reported they were not. There were no significant differences by gender or cleft type.

Importance and satisfaction with physical attributes and support received

Figure 2 shows the mean importance and satisfaction ratings for the physical attributes and the support received from others for each age-group.

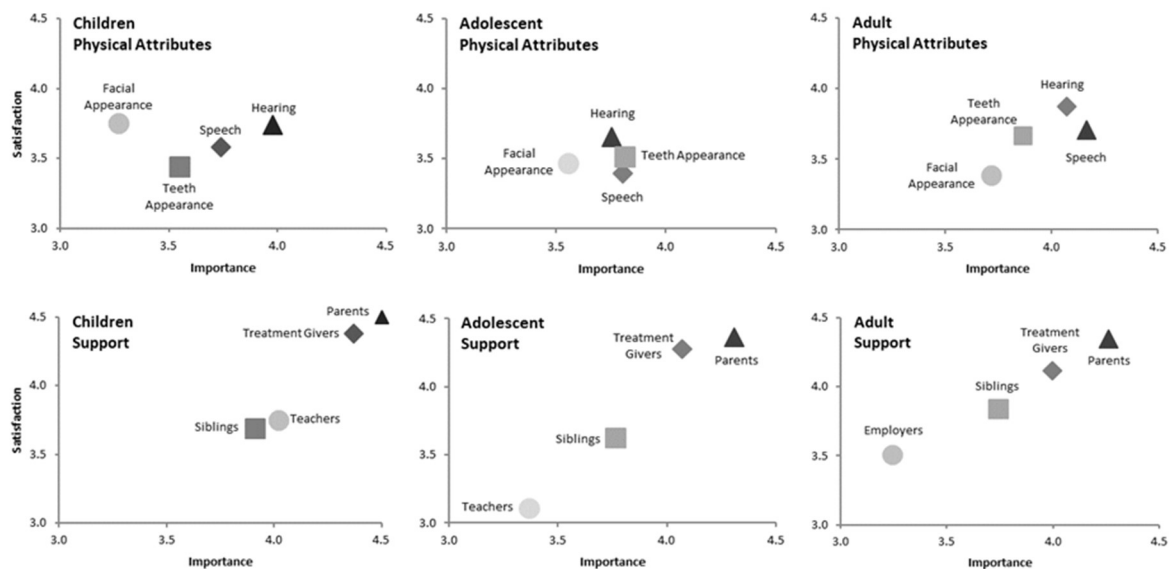


Figure 2. Mean importance and satisfaction ratings for physical attributes and support for each age-group.

For each age-group the importance ratings for the physical attribute of facial appearance were consistently lower than the other attributes with the differences in the children age-group being significant ($p^* < 0.03$). The importance of hearing and speech were rated consistently highly across the age-groups. For the adult age-group, satisfaction with facial appearance was significantly lower than the other attributes ($p^* < 0.008$).

The ratings for both importance and satisfaction with support from parents and treatment providers were significantly higher than from siblings or teachers/employers in each age-group ($p^* < 0.004$). Satisfaction with the support from teachers in the adolescent age-group and employers in the adults age-group were significantly lower than the other relationships ($p^* < 0.004$) although both were also the least important.

Teasing or bullying

Participants were asked whether they had ever experienced teasing or bullying because of their cleft condition, at what ages this occurred, and if they had stayed home to avoid this behaviour. For the children age-group, 30% reported that they had been teased or bullied due to their cleft condition. This increased to 60% for the adolescent age-group and 59% for the adult age-group. Approximately one third of the participants in each age-group who had been teased or bullied reported that they had stayed home at least once to avoid this behaviour.

Figure 3² shows the percentages by cleft type of all participants who reported being teased or bullied at each age in years³.

² The number for those who stayed home to avoid being teased or bullied are for those who had experienced teasing or bullying at any age.

³ The percentages for earlier years also included older participants. For example, an adult participant may have indicated they experienced teasing or bullying when they were 10 years old, which contributed to the percentage shown at age 10 for their cleft type.

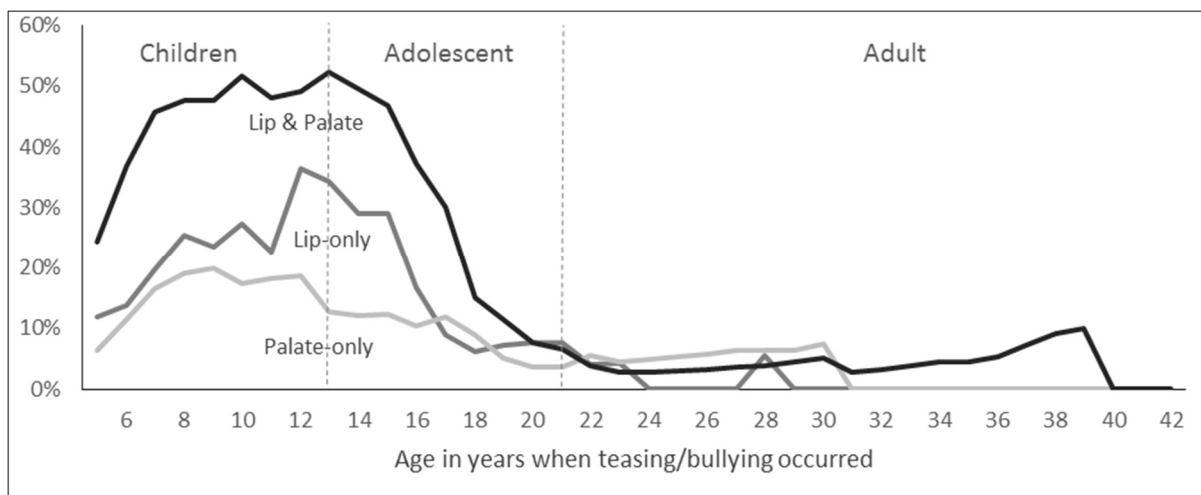


Figure 3. Percentage of study participants who reported teasing or bullying by age of occurrence and cleft type

Overall, teasing or bullying occurred most frequently from childhood through to late teenage years and then dropped away rapidly to less than 10% in adulthood. Participants with cleft lip and palate were significantly more likely to have experienced teasing or bullying than cleft lip only ($p=0.005$), or cleft palate only ($p=0.023$). There were no significant differences by gender ($p=0.24$). There was a significant association between reports from participants in the children age-group for teasing and bullying if they were not satisfied with their facial appearance ($p=0.003$), dental appearance ($p=0.001$), or speech ($p=0.037$). This association was also evidenced in the adolescent age-group for speech ($p=0.002$) and hearing ($p=0.005$).

The relative risk for participants in the children age-group was at least 26% higher risk for being teased or bullied if they were not satisfied with their speech ($RR= 2.89$, $95\%CI=(1.26,6.64)$) and at least 71% higher ($RR=6.86$, $95\%CI=(1.71,27.44)$) for the adolescent age-group. The result for the adult age-group was not significant.

Study participants in the adult age-group were asked if they had both been bullied, and had bullied others, to indicate whether they were potential bully-victims⁴.

⁴ Bully-victims are described as those persons who have been bullied themselves and who have also bullied others. In the general population it has been indicated that this group have the greatest challenges in their social relationships and affects in later life (Cook et al., 2010).

Overall, 24 reported that they had bullied others, and of these, 5 had not been teased or bullied themselves whilst a significantly larger proportion of 19 ($p=0.041$) had experienced teasing or bullying. There were no significant differences by gender or cleft type. For those 19 participants who were identified as potential bully-victims, there was an increase in the rates of depression (58% vs 41%), anxiety (53% vs 47%) and difficulties with social relationships for same-age friendships (26% vs 17%) when compared to the 139 remaining participants. However, none of these differences were statistically significant ($p>0.2$).

Experience of treatment

The adolescent and adult age-groups were asked to select the most important positive experience of their cleft-related treatment from four choices: overall outcome, knowing there were treatment options, interactions with staff, and that treatment had finished. In the adolescent age-group 73% indicated overall outcome, and 15% selected treatment options. In the adult age-group 56% indicated overall outcome, 18% selected interactions with staff, and 17% selected that treatment had finished. There were no significant differences by gender or cleft type in either age-group. Comments included 'staff were amazing', and 'very grateful'.

The same age-groups were also asked to select the most important negative experience of their cleft-related treatment from four choices: pain and recovery, number of appointments, interactions with staff, and treatment is a reminder of having a cleft condition. In the adolescent age-group 59% selected pain and recovery, and 35% the number of appointments. In the adult age-group the order was reversed: 45% selected the number of appointments and 40% selected pain and recovery. There were no significant differences by gender or cleft type in either age-group. Comments included "the biggest thing I hated was the multidisciplinary meetings where everyone would stare, poke and prod me, and then make comments like "her nose is flat" and " her teeth need to come along way".

No-one would actually talk to me. I was shy and found it to be overwhelming, like I was a freak of nature being analysed', and 'Ensure doctors are trained in treating scared kids to reduce fear', and 'Staff need to learn to talk to patients in a kind manner'.

Both age-groups were asked if they felt that they were adequately prepared for their treatment and if they had the opportunity to make decisions concerning their own treatment. Significantly higher proportions of the adolescent age-group felt they were adequately prepared compared to the adults (97% vs 88%, $p=0.011$) and were involved in their treatment decision making compared to the adults (84% vs 53%, $p<0.001$).

Expressed interest in pamphlets and talking to someone as a supportive resource

Participants were asked if they thought it would be beneficial to have information pamphlets and/or to talk to someone (professional counsellor, clinic coordinator, peer with CL/P, support group, nurse/support staff, friend) as a supportive resource for the following issues: appearance, self-esteem, social skills, and teasing (see Table 3). The percentages of those who would have found this beneficial increased with the age of the participant. The adult age-group were also asked if pamphlets on depression, overview of cleft, or cleft treatment would be helpful, with 59% indicating that at least one of these would have been. There were no significant differences by gender or cleft type.

Psychosocial Issue	Children		Adolescent		Adult	
	Pamphlet	Talk	Pamphlet	Talk	Pamphlet	Talk
Appearance	11 (11%)	6 (6%)	16 (16%)	12 (12%)	67 (42%)	60 (38%)
Self Esteem	16 (16%)	8 (8%)	18 (18%)	15 (15%)	67 (42%)	60 (38%)
Social Skills	10 (10%)	7 (7%)	15 (15%)	14 (14%)	65 (41%)	57 (36%)
Teasing	18 (18%)	8 (8%)	31 (31%)	22 (22%)	53 (34%)	47 (30%)
At least one	27 (27%)	13 (13%)	37 (37%)	24 (24%)	88 (56%)	80 (51%)

Table 3. Expressed interest in pamphlets and talking to someone for psychosocial issues.

There were significant differences by gender for the adolescent age-group, with females indicating they would have found it more helpful to talk to someone for each of the psychosocial issues than males ($p<0.012$). The adult age-group were also asked if talking to someone who also had a cleft would be helpful, with 59% indicating that it would be.

Discussion

Impact of cleft

We found that 43% of children, and around one quarter of adolescents and adults with CL/P did not report any specific impact of CL/P on their lives. Across all age-groups, public speaking and participation in school were consistently the highest impact areas and independence was the least. Those who described impact of CL/P on public speaking expressed concerns about speech as well as anxiety and shyness. Those who described an impact of CL/P on school participation commented on the high number of days missed from school due to attending appointments, communication problems (particularly due to speech and hearing issues), learning difficulties, teasing and bullying, and appearance concerns.

There have been mixed reports in the literature regarding educational achievement being negatively influenced by having a cleft. Rumsey and Harcourt (2005), Lorot-Marchand et al. (2015) and Bruce et al. (2015) all reported that the significant treatment burden of cleft impacted school attendance. Snyder and Pope (2010), Wehby et al. (2014) and Knight, Cassell, Meyer, and Strauss (2015) used direct academic measures to report lower academic achievement for those with a cleft compared to those without. In contrast, Collett et al. (2014) did not find any difference in academic achievement based on having a cleft.

Our study found one fifth of the children age-group self-reported a perceived impact on academic achievement, mostly attributed to speech and hearing difficulties, and time missed from school due to appointments. This impact reduced in the adolescent age-group, and was reported as the lowest impact area for the adult age-group. This suggests that the patient-perceived impact of cleft on academic achievement may diminish over time, however additional educational assistance and support may be required for the children age-group.

Visible facial differences resulted in many study participants indicating they did not like to be photographed, with specific reference to scarring and the shape of their nose or lip.

Participants commented on feeling self-conscious and unattractive, with one participant describing growing a beard to camouflage his scar and others describing only being photographed on the non-cleft side of their face. The implications are that any setting which involves those with CL/P being photographed needs to be handled with sensitivity and it may be useful to teach adaptive coping strategies for these situations. At the very least, practitioners need to ask permission from patients in a way which allows for their input and decision-making.

For the adolescent age-group there were significant differences between cleft types for the categories influencing social functioning and integration (friends same age, public speaking, participate in school, and special relationships). In each case participants with cleft lip and palate reported the highest impact, which may reflect the greater effect socially of having a visible difference combined with possible speech and hearing concerns. Others have also found that cleft-related differences may have restricted the capacity for the individual to fit in with their peers (Berger & Dalton, 2011; Bilboul et al., 2006; Lioffi, 2003).

Results of treatment

In the Australian general population Armfield, Spencer, and Stewart (2006) found a high prevalence of fear of going to the dentist (up to 43%), with a higher prevalence for females. In contrast we found that approximately 25% of the adult and adolescent age-groups and 17% of children age-group reported a fear of going to the dentist. This may be explained by the high frequency of appointments involved in treatment of patients with a cleft making these visits more routine than the general population.

A high proportion of participants in our study reported they could chew properly, increasing with age (96% in the adult age-group), which reflected the success and satisfaction with this functionality from treatment. This is consistent with reports by Sharp et al. (2008) and Hens et al. (2011) of improved function resulting from treatment.

However there was also a high proportion of participants in our study who reported dissatisfaction with their smile, which was highest in the adolescent age-group with comments concerning the appearance of their teeth and shape of their lip.

This is in contrast to Noor and Musa (2007) and Byrne, Chan, and O'Broin (2014) who reported only a minority of patients that believed their appearance had not improved from treatment. This has implications in the clinical setting for practitioners to ensure adolescents are given the opportunity to provide feedback, particularly regarding any concerns about their treatment, with the assurance that it will be actioned. Avenues for this opportunity may occur at protocol meetings (where a pre-meeting survey can be completed), before/during scheduled appointments with clinicians, or at any time through the clinic coordinator who may organise appointments with the relevant clinicians.

Importance and satisfaction with physical attributes and support

The importance of physical attributes (as opposed to satisfaction), has not been well-investigated in the literature. Importance ratings offer context to the reported levels of satisfaction. Given the prominence of appearance-related issues in the media and literature, our unexpected findings suggest that the physical attributes of speech and hearing were *more* important to participants than their facial and teeth appearance. This was primarily due to the impact of speech and hearing on participants' ability to communicate effectively.

For adults, the significantly low satisfaction with facial appearance may be related to appearance dissatisfaction following completion of their treatment, which may not have resulted in the desired outcome, or not achieved social appearance norms. Hunt et al. (2006) and Gkantidis, Papamanou, Karamolegkou, and Dorotheou (2015) also found that appearance satisfaction declined with age, especially individuals with a cleft in adulthood, and Hamlet and Harcourt (2015), and Stock et al. (2015) found evidence in their qualitative studies of appearance dissatisfaction being a significant issue for respondents in older age-groups. It is acknowledged that the older treatment protocols of adults might have had greater variability or less favourable outcomes compared to more recent treatment standards in place with the younger participants.

We found that parents were considered by respondents in all age groups to be the most important source of support. Others have found that support given by parents has been a significant protective factor for psychological adjustment (Baker, Owens, Stern, & Willmot, 2009; Broder, 2001), shielding in social circumstances (Hall, Gibson, James, & Rodd, 2013; Tiemens, Nicholas, P, & Forrest, 2013)) and a great guidance concerning the outlook of the individual to their cleft (De Sousa, Devare, & Ghanshani, 2009). Treatment providers were also important sources of support for respondents in all age groups.

We found that adolescents had relatively low levels of satisfaction with support from teachers and adults had relatively low levels of satisfaction with support from their employers compared to other relationships. Broder and Strauss (1989), Slifer et al. (2006), and De Sousa et al. (2009) found teachers and other adults had unfavourable perceptions of children with a cleft, including labelling them as less attractive and less popular. Changing Faces (2008) found discrimination, low awareness and poor understanding of cleft in the general population. There is potential for raising awareness amongst educators and employers of cleft-related differences and complex treatment issues associated with CL/P, especially in childhood and prior to completion of definitive treatment. Peer friendships may also be an important source of support; however, this was not examined in the current study.

Teasing or bullying

Teasing and bullying was reported to be most prevalent during late childhood and early adolescent years in our study. Lovegrove and Rumsey (2005), Berger and Dalton (2009) and Lorot-Marchand et al. (2015) reported the highest prevalence to occur in adolescence. The majority of teasing for participants in our study occurred at school which is consistent with reports by Van Lierde et al. (2012) and Lorot-Marchand et al. (2015) with some stigma reported at participants' place of employment (Stock, Feragen, & Rumsey, 2016).

Participants with cleft lip and palate reported significantly higher rates of teasing or bullying than both cleft lip only and cleft palate only participants.

This may suggest that cleft visibility or type was an influencing factor. The literature reports that appearance is an influencing factor for teasing or bullying (Berger & Dalton, 2009; Hunt et al., 2006; Lorot-Marchand et al., 2015; Noor & Musa, 2007), which was supported by the results in our study for the children and adult age-groups. This was not the case for the adolescent age-group, who reported speech and hearing as greater influencing factors. Watterson, Mancini, Brancamp, and Lewis (2013) reported that problems with speech may result in social isolation and bullying. This was evidenced in our study with those participants in the children and adolescent age-groups who were not satisfied with their speech being significantly more likely to have been bullied. This highlights the essential role that speech therapy has in assisting with positive social interaction. In addition, team members should screen for and provide resources for teasing and work closely with psychology practitioners to address these issues.

A higher proportion of adult participants in our study (59%) reported having being teased or bullied at some time, compared with the general Australian population proportion of 20% (Rigby, 2016). One fifth of those also reported having also bullied others. Of those participants who were identified as bully-victims (Cook et al., 2010), there were higher percentages reported for depression, anxiety and difficulty with same-age relationships, however with the small sample size, the results should be treated with caution.

Experiences of treatment

Overall outcome, including function and appearance, was identified by the adolescent and adult age-groups as the most important positive experience of treatment, which is supported by the literature (Hens et al., 2011; Munz, Edwards, & Inglehart, 2011; Noor & Musa, 2007; Stock et al., 2015). Pain and the volume of appointments were identified as the most important negative experiences, as supported by Munz et al. (2011) and Alansari, Bedos, and Allison (2014), who found that the extent of pain directly influenced the treatment experience. There were participants in our study who found the multidisciplinary meetings to be overwhelming and a negative experience. The implication for treatment providers is that

there must be an awareness of the potentially intimidating nature of these meetings for some patients and steps should be introduced to limit or alleviate this from occurring.

The majority of the adolescent and adult age-groups in our study reported that they felt they were adequately prepared for treatment and had been involved in their treatment decision-making process. The higher proportion of adolescents, compared to adults, who reported their involvement may be indicative of an improvement in treatment service protocol and clinician attitude. Increased patient autonomy and inclusiveness has been encouraged and supported by recommendations from the Clinical Standards Advisory Group (Williams et al., 2001) and more recently the Face Value training program for health professionals (Face-Value, 2017). This is in contrast to concerns reported by some individuals in other studies including difficulty expressing their worries with clinicians (Hall et al., 2013; Noor & Musa, 2007), finding the information difficult to comprehend, (Noor & Musa, 2007) and feeling pushed to accept the treatment recommended (Havstam, Laakso, Lohmander, & Ringsberg, 2011; Noor & Musa, 2007; Norman et al., 2015).

Pamphlets & talking to others as a supportive resource

Teasing and bullying, cleft treatment, self-esteem, social skills, and appearance issues (and depression for the adult age-group only) were identified as the most important subjects for pamphlets and other resources. Interest in supportive resources of pamphlets and talking to others increased with age with twice as many in the adult age-group indicating this would be helpful than the other age-groups. Stock et al. (2016) reported the value of meeting others with a cleft for mutual peer support, which was also supported by the adults from our study. The overall low request for pamphlets as an information resource by younger participants may not be a true representation of a lack of interest, but indicative of this being an out-dated mode of information delivery. With access through social media to support groups and information websites, including Facebook© closed member pages and forums, patients and parents have the opportunity for fast and convenient information, advocacy and support resources (CLAPA, 2017; Cleft Palate Foundation, 2014; CleftPALS WA, 2016).

Study Limitations

Study sampling bias was found for age (children and adolescent age-groups), gender (adult age-group), cleft type (adolescent age-group) and area of residence (adult age-group).

Using postal self-administered questionnaires for the adult age-group, and convenience sampling for the other age-groups, enhanced the risk of selection bias. The majority of respondents were Caucasian which limits the study of ethnic influences. The study sample was drawn from a Western Australian cohort which may limit generalisation to other populations. Our study was cross sectional, which means that we cannot draw any conclusions about cause and effect. Non-participation bias has limited the response from rural areas and may not have offered a true indication of the inconvenience for service provision in these areas. A control group without cleft from the same catchment areas in Western Australia would have provided more context for findings, but was not possible due to resource constraints. The sample size was relatively small once broken down into subgroups. Using a multi-site methodology would have offered greater weight and improved the external validity.

Conclusion

The higher importance study participants awarded to the physical attributes of hearing and speech over their facial and dental appearance was an unexpected key finding and indicates any barriers to effective communication are significant issues. Whilst hearing and speech therapies are a part of cleft treatment protocols, post-treatment services and referrals should be made available to adult patients to address residual hearing and speech difficulties in order to attain satisfactory adult life outcomes.

The importance of support offered by treatment providers has implications for clinical practice as frequent appointments over the years of treatment gives the unique opportunity for clinicians to influence and instil confidence in patients.

Participants with cleft lip and palate reported the highest impact and rates of teasing, which may reflect the influence of cleft type or visibility. Teasing and bullying was highly reported overall, with a pattern of peaking in adolescence and receding in adulthood. The importance and need for psychological support was highlighted as a required but inaccessible service by the adult age-group which may have provided additional coping strategies for teasing during their earlier years of treatment.

The basic treatment-related factors of fear of the dentist, fear of having an anaesthetic, happiness and satisfaction with smile and ability to chew properly are benchmarks for functional and aesthetic outcome measures and inclusion in further studies will determine their value.

Recommendations

- Treatment providers need to be aware of the importance of their support for patients, and the potentially intimidating nature of multidisciplinary meetings. Future studies should consider if current protocols may be improved by focusing on post-surgical pain relief and reducing the number of appointments.
- In addition to pamphlets, on-line information and support group contact details should be available to patients and parents for reference.
- Craniofacial teams should raise awareness of parents, educators and employers of the impact of CL/P across the lifespan and promote programs to improve self-esteem, social skills, confidence in public speaking and appearance dissatisfaction.
- Psychological support should be provided both during and following treatment across age-groups.

Chapter 6 Paper 3: Adult specific life outcomes of cleft lip and palate in a Western Australian cohort.

6.1 Commentary for Paper 3

This paper addressed the fifth thesis objective which was to investigate adult-specific sociological outcomes of CL/P and compare against the Australian general population.

For many parents of a child with CL/P a common concern is knowing whether their child will be ok as they grow and mature into adults. Whilst the criteria for 'being ok' changes over time, it is still the ongoing focus for parents and includes life areas such as; occupation, annual income, highest education level, living arrangements, relationship status, physical health, and psychosocial health. The reviewed literature generally did not have a positive outlook for people with CL/P, indicating that this group remained living with their parents longer, formed relationships later, were less likely to be married or have children, did not access higher education nor have as high an income as those without CL/P. However, many of the papers were outdated, with none reporting from an Australian perspective. This study provided an opportunity to address these gaps by surveying a cohort of West Australian adults with CL/P to collect information across a variety of life areas, and to compare their outcomes with the Australian general population using data from a variety of sources including the Australian Bureau of Statistics (ABS) and the Australian Institute for Family Studies (AIFS).

The instrument used to quantify these adult-specific outcomes was the adult version of the CRQ which included additional questions compiled for this purpose. Quantitative analysis methods of descriptive statistics, hypothesis tests and odds ratios were used to compare results within the study cohort by gender, cleft type and age-group. This analysis offered insight into potential underlying factors that may impact life outcomes for people with CL/P in adulthood.

Where possible, questions in the CRQ were framed in the same way as the data sources which allowed comparability for the outcomes of occupation, annual income, highest education level, living arrangements and relationship status. This gave an indication of how well this cohort of people with CL/P were doing compared to others of the same age. Another variable for study was the self-reporting of lifestyle habits which offered insight into the use of social substances (illicit drugs) and exercise habits, both areas of contemporary importance. This paper provided evidence of the impacts of CL/P in the adult age-group from a quantitative data perspective and is complemented by qualitative methods which provide further insight and unique meaning from an individual perspective.

6.2 Copy of Published Paper 3

Nicholls W, Harper C, Robinson S, Persson M, Selvey L. Adult specific life outcomes of cleft lip and palate in a Western Australian cohort. *The Cleft Palate Craniofacial Journal*, June 2017 (in press).

Abstract

Background: People with a cleft of the lip and/or palate (CL/P) differ from their peers due to their facial appearance, hearing and speech difficulties, and the significant time spent attending appointments and recovering from surgical interventions. These differences may impact life outcomes including occupation, income, education, relationships, psychosocial health issues and lifestyle choices.

Methodology: A self-administered questionnaire was posted to 338 former and current patients of the Cleft Lip and Palate Unit of Princess Margaret Hospital (PMH), Perth, Western Australia.

Results: Completed questionnaires were returned by 158 former and current patients. In comparison to the Australian Bureau of Statistics (ABS), study participants attained equivalent highest education levels, full-time annual income levels, occupational categories, employment rates, and home ownership levels. They did not marry later and demonstrated positive health-related lifestyle behaviours. Independent living was significantly delayed and the number of romantic relationships, marriages, and children were lower, with separation/divorce rates also being lower. A key finding was that 78% of participants self-reported that they experienced at least one psychosocial health issue and more than half experienced anxiety and/or depression.

Conclusion: When comparing the sociological outcomes for the study participants, the psychosocial outcomes were the areas of most concern. Further investigation is required to determine causes for the high self-reported rates of anxiety and/or depression found in this study.

Keywords: psychosocial, cleft lip and palate, self-esteem, adult outcomes.

Introduction

People with a cleft of the lip and/or palate (CL/P) are different from their peers due to their facial appearance, hearing and speech difficulties, and the significant time spent attending appointments and recovering from surgical interventions. The burden of treatment and unwelcome attention of others may present substantial psychosocial challenges (Rumsey & Harcourt, 2005). Although the majority of adults with a cleft will have completed treatment for both function and aesthetics, the impacts of these psychosocial challenges may remain. The literature reports that having a cleft may lead to psychosocial difficulties in adulthood including depression and anxiety (Foo, Sampson, Roberts, Jamieson, & David, 2012; Hunt et al., 2006; Mani, Carlsson, & Marcusson, 2010; Pinguart & Shen, 2010; Ramstad, Ottem, & Shaw, 1995a), delayed independence and reduced significant relationships (Danino et al., 2005; Marcusson, 2001; Ramstad et al., 1995a), and may also negatively influence life outcomes including occupation and income (Ramstad et al., 1995a).

Examining adult-specific life outcomes offers the opportunity to assess the social functioning of patients with a cleft of how they perform independently after treatment has completed in terms of their education, occupation, income, relationships and health behaviours. Outcomes may have implications for treatment providers; by identifying where improvement may be required for clinical practice and translate into health care recommendations to influence protocols to provide for ongoing and/or ad-hoc post-treatment assistance. Parents and patients may also be offered reassurance in knowing that individuals with a cleft have comparable life outcomes to the general population irrespective of cleft type or gender.

This study examined adult specific life outcomes of occupation, income, education, living arrangements, relationships and psychosocial and lifestyle health issues for a sample of adults with a cleft in Australia, and provides a much-needed contemporary addition to international literature. The published studies for sociological outcomes in the cleft population including marriage, education and income (McWilliams & Paradise, 1973; Peter &

Chinsky, 1974; Peter, Chinsky, & Fisher, 1975; Van Demark & Van Demark, 1970) are dated which limits the comparability of their findings for some contemporary societal issues.

Methodology

Participants

Potential study participants were identified using a hospital database of all patients who have attended the Cleft Lip and Palate Unit at Princess Margaret Hospital for Children (PMH), Perth, Western Australia from 1973 to 2012. The PMH Cleft Lip and Palate Unit is the longest serving cleft unit in Australasia and provides treatment to a median of 50 CL/P births each year. PMH is the only paediatric tertiary hospital which services the whole of WA. It is government-funded and the only referral centre for cleft. Treatment access for cleft is granted through eligibility under the Medicare Cleft Lip and Palate Scheme and did not change over the course of the study.

The main inclusion criteria were for patients in the age range 22 to 42 years at the time of the study who underwent their definitive treatment at PMH. This age range balanced patients having sufficient life experience against the reduced likelihood of contacting older patients, and also covered a time period where they received comparable care regarding technology and technique. The average age of the study participants at the time cleft related surgery was performed was: lip repair (3 months); palate repair (9 months); alveolar bone-graft (8.3 years); pre-discharge lip revision (17.3 years); secondary rhinoplasty (17.9 years) and orthognathic surgery (19.9 years). Of the 806 former patients identified, 468 were excluded due to an unknown address, or an address that had not been updated within the last 10 years. Questionnaires were posted to 338 former patients and included a pre-paid return envelope. To maintain privacy, there was no follow up contact or reminders sent.

Institutional Ethics

The Princess Margaret Hospital and Curtin University Health Ethics Review Committees approved this study. Informed consent was obtained from participants.

Instrument

The Cleft Research Questionnaire (CRQ) was designed by the author to collect demographic, cleft-specific impacts, and treatment satisfaction for current and former CL/P patients at PMH. Three age-appropriate versions of the questionnaire were developed. The adult CRQ included additional questions concerning relationships, psychosocial health issues, highest education level, vocational occupation and annual income, to enable investigation of specific adult life outcomes. Questions in the CRQ were framed in the same way as the data sources (Australian Bureau of Statistics (ABS), Australian Institute for Family Studies (AIFS), Australian and New Zealand Standard Classification of Occupations (ANZSCO), and Household, Income and Labour Dynamics (HILDA)) which allowed comparability for the outcomes of occupation, annual income, highest education level, living arrangements and relationship status. The questions for the outcomes of psychosocial health issues and health-related behaviours were similar however statistical comparisons could not be made⁵.

The CRQ was piloted by a group of 10 patients with CL/P who provided face validation and feedback on relevance of questions resulting in minimal modifications over two iterations. Face validation was also undertaken by senior members of the PMH cleft team, also resulting in minimal modifications to the CRQ.

Data Analysis

Microsoft Excel 2016, (Microsoft Corporation Albuquerque, New Mexico, United States) was used for data storage and creating tables. Data were reported by three categories: gender (male, female); cleft type (lip-only, lip and palate, palate-only) and the Australian Bureau of Statistics (ABS) defined age-groups of 20-24, 25-34 and 35-44 years.

⁵ ABS National Health Survey and the National Drug Strategy Household Survey 2013 questions included amount, frequency and duration of physical activity and substance use and could not be compared to study results.

Hypothesis tests to identify significant differences within these categories and between study results and external data sources were conducted using Fisher's Exact Test for Count Data in the R statistical programming language 2015 (Version 3.2.3. R Foundation for Statistical Computing; Vienna, Austria) (R Development Core Team, 2015). When more than three tests were carried out for the same variable comparison, p-values were adjusted using the Holm method (denoted as p*). All p-values (adjusted and unadjusted) were compared against the alpha level of 0.05. Where significant differences were identified, unadjusted Odds Ratio (OR) with 95% Confidence Interval (CI) were calculated to give an indication of the scale of the differences.

Results from this study were compared to those reported by the ABS for adults in the age range 25-44 years from the general population of Western Australia (approximately 780,000 people) and Australia (approximately 6.7 million people). The ABS 20-24 year age-group was not included in comparisons due to the relatively small number of study participants in this age-group (18%), with the youngest being 22 years old. Data sources included the following surveys: Employee Earnings, Benefits and Trade Union Membership Australia, August 2013 (ABS, 2013) ; Marriage in Australia (AIFS, 2013), National Health Survey 2014-15 (ABS, 2015c), and 2015 Labour Force by Sex Report (ABS, 2015b). No significant differences were found between the study participant age and gender distributions compared to the ABS Western Australian population (2014), therefore age and gender standardisation was not required.

Other data sources included the 2006 Australian and New Zealand Standard Classification of Occupations (ABS, 2016) and the Household, Income and Labour Dynamics in Australia Survey Wave 11 and Wave 14⁶ (AIFS, 2016).

⁶ The HILDA Project was initiated and is funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and is managed by the Melbourne Institute of Applied Economic and Social Research (Melbourne Institute). The findings and views reported in this paper, however, are those of the author and should not be attributed to either FaHCSIA or the Melbourne Institute.

The percentages for each occupation category for study participants was compared to the ABS Western Australia Employed Persons by Occupation data for the May quarter of 2014 (ABS, 2014b).

The ABS reported income by age-group for full-time employed persons only using weekly income categories (ABS, 2013). These weekly categories were annualised and then combined into the same categories used in this study to enable comparison with annual incomes reported by full-time employed study participants.

For the highest education level achieved by participants, the category TAFE Cert/Diploma refers to certificates and diplomas attained via Technical and Further Education training and is typically undertaken by vocational and trade apprentices. The University Post Graduate category included Masters and Doctorate degrees.

The living arrangement category of Own Home included both those who had a mortgage and those who owned their home outright. The category of Parents/Family refers to those participants who still lived with their parents or other parental caregivers. The Government/Work category identifies participants whose housing is provided by a government agency or by their workplace.

To identify health related lifestyle choices study participants were asked to rate how often they drank alcohol, smoked cigarettes (tobacco), used illicit drugs and exercised. Frequency of use was the key information requested, hence details regarding the volume or type of substance consumed was not captured. Exercise was defined as physical activity for fitness and/or transport. A five-point scale was provided to rate frequency of use: never, seldom, monthly, weekly or daily. For presentation, the seldom and monthly levels were combined into one level - infrequently.

Results

Response rate

Of the 806 candidate participants identified from the PMH database, 468 were excluded due to missing or out-of-date last known address details. The CRQ was posted to the remaining 338 former patients, with a total of 112 questionnaires not being delivered, leaving 226 potential participants. Of those, 158 patients returned completed questionnaires giving a 20% response rate of the initial 806 candidate participants (or 70% response rate for the 226 contacted former patients).

Study Sampling Bias

Hypothesis tests were used to compare study sample proportions against PMH database records for gender, cleft type, age-group and area of residence. There were two significant differences found between the two groups, gender: the study sample had a higher proportion of females (study=55%, PMH=45%, OR=1.50, CI=(1.05, 2.14), p=0.023) and area of residence: the study sample had a higher proportion of participants residing in the Perth metropolitan area (study=79%, PMH=71%, OR=1.58, CI=(1.03, 2.46), p=0.033).

Demographics

Of the 158 study participants, the majority were Caucasian (89%), followed by Asian (9%), Aboriginal and/or Torres Strait Islander (1%), and other (1%), with a mean age of 30.7 years and standard deviation of 6.1 years. There were more participants having the cleft type of lip and palate (50%) than palate-only (34%) or lip-only (16%).

Occupation

Table 1 shows the frequencies and percentages of the 125 study participants (79%) who were allocated to an ANZSCO major occupation category by gender, cleft type and age-group. Excluded from the table were 33 participants (21%) who could not be allocated to an ANZSCO category⁷.

⁷ Those excluded included 13 students, 8 performing home duties, 6 unemployed, 5 with a disability pension, and 1 prisoner (these categories were also excluded from the ABS data).

The table also compares the percentages for participants aged 25-44 in each occupation category with the general Western Australian population (ABS, 2014b).

ANZSCO Major Occupation Category (n=125)	Gender		Cleft Type			Age-group			Study vs ABS Age 25-44 (n=104)
	Male (n=60)	Female (n=65)	Lip-only (n=25)	Lip & Palate (n=61)	Palate-only (n=39)	20-24 (n=21)	25-34 (n=67)	35-44 (n=37)	
Professionals (n=33)	11 (15%)	22 (25%)	8 (32%)	15 (19%)	10 (19%)	1 (3%)	23 (28%)	9 (19%)	31% vs 25% p=0.213
Technicians & Trades (n=28)	20 (28%)	8 (9%)	8 (32%)	13 (16%)	7 (13%)	6 (21%)	13 (16%)	9 (19%)	21% vs 19% p=0.528
Clerical & Admin (n=18)	7 (10%)	11 (13%)	4 (16%)	8 (10%)	6 (11%)	4 (14%)	8 (10%)	6 (13%)	13% vs 13% p=0.768
Community & Personal (n=18)	4 (6%)	14 (16%)	3 (12%)	7 (9%)	8 (15%)	7 (24%)	8 (10%)	3 (6%)	11% vs 9% p=0.606
Managers (n=9)	4 (6%)	5 (6%)	1 (4%)	6 (8%)	2 (4%)	0 (0%)	4 (5%)	5 (10%)	9% vs 11% p=0.534
Labourers (n=9)	8 (11%)	1 (1%)	0 (0%)	5 (6%)	4 (7%)	2 (7%)	5 (6%)	2 (4%)	7% vs 9% p=0.602
Machine Op & Drivers (n=6)	5 (7%)	1 (1%)	0 (0%)	5 (6%)	1 (2%)	0 (0%)	4 (5%)	2 (4%)	6% vs 8% p=0.585
Sales (n=4)	1 (1%)	3 (3%)	1 (4%)	2 (3%)	1 (2%)	1 (3%)	2 (2%)	1 (2%)	3% vs 7% p=0.165

Table 1. Frequencies and percentages for ANZSCO major occupation categories (excluding 33 unallocated participants) by gender, cleft type, and age-group, and with comparison to the Western Australian population aged 25-44 (ABS 2014b).

The ANZSCO major occupation category of Professionals was the highest represented category for female study participants. It was also the highest category for each of the cleft types, and for the 25-34 and 35-44 age-groups. The highest represented category for male study participants was Technicians and Trades which was significantly higher than females (males=33.3%, females=12.3%, OR=3.53, CI=(1.33, 10.23), p=0.006). There were no significant differences in occupation category for study participants by cleft type (p=0.819) or age-group (p=0.138), nor between study participants and the West Australian general population (ABS, 2014b) for the 25-44 age-group (see Table 1).

Eighty percent of study participants allocated to an ANZSCO major occupation category indicated they worked full-time hours and 20% worked part-time with no significant difference by gender (p=0.26), cleft type (p=0.80) or age-group (p=0.12). In comparison to the general Western Australian population of working adults aged 25 to 44 years (ABS, 2014b), a significantly higher proportion of female study participants worked full-time (study=79%, ABS=60%, OR=2.47, CI=(1.25, 5.34), p=0.01) with no significant differences identified in

work hours for males ($p=0.33$). The unemployment rate for Western Australia in March 2014 was 5.9% with a participation rate⁸ of 68.8% (ABC, 2014) whereas for study participants, the unemployment rate was 4.6% with a participation rate of 82.9%.

When asked whether having a cleft had an impact on getting work, 27 (17%) of all 158 study participants agreed. There were no significant differences by gender ($p=1.0$), cleft type ($p=0.12$) or age-group ($p=0.13$). Similarly, when asked whether having a cleft had an impact on performing their work, 22 (14%) of all study participants agreed. Again, there were no significant differences by gender ($p=0.5$), cleft type ($p=0.13$) or age-group ($p=0.14$). For those who were impacted, the most common reason given was speech and hearing limitations which made verbal communications difficult.

Annual Income

Table 2 shows the frequencies and percentages for annual income (in Australian dollars) for the 100 full-time employed study participants by gender, cleft type and age-group (with the same exclusions as for occupation³). The table also compares the percentages for each annual income category for full-time⁹ employed study participants aged 25-44 against the general Australian population (ABS, 2013).

Full-time employed annual income (\$AUS) (n=100)	Gender		Cleft Type			Age-group			Study vs ABS Age 25-44 (n=86)
	Male (n=51)	Female (n=49)	Lip-only (n=21)	Lip & Palate (n=49)	Palate-only (n=30)	20-24 (n=14)	25-34 (n=53)	35-44 (n=33)	
< \$30,000 (n=6)	4 (8%)	2 (4%)	0 (0%)	4 (8%)	2 (7%)	1 (7%)	4 (8%)	1 (3%)	6% vs 3% $p^*=0.414$
\$30,000 - \$60,000 (n=42)	21 (41%)	21 (43%)	10 (48%)	16 (33%)	16 (53%)	12 (86%)	17 (32%)	13 (39%)	35% vs 45% $p^*=0.329$
\$60,000 - \$100,000 (n=35)	11 (22%)	24 (49%)	7 (33%)	19 (39%)	9 (30%)	1 (7%)	24 (45%)	10 (30%)	40% vs 31% $p^*=0.329$
> \$100,000 (n=17)	15 (29%)	2 (4%)	4 (19%)	10 (20%)	3 (10%)	0 (0%)	8 (15%)	9 (27%)	20% vs 21% $p^*=0.793$

Table 2. Frequencies and percentages for annual income category for full-time employed participants by gender, cleft type and age-group, and with comparison to full-time employed Australian population aged 25-44 (ABS, 2013)¹⁰.

⁸ The labour force (employed + unemployed) as a percentage of the resident population aged 15 and over.

⁹ Data for part-time employed persons was not available from the ABS.

¹⁰ For those who were employed on a part-time basis, $n=25$, and those who were not in the workforce, $n=33$.

Amongst study participants, there was no significant difference in annual income category by cleft type ($p=0.46$), however, there was a significant difference by gender with more males than females in the top \$100,000+ category (males=29%, females=4%, $OR=9.59$, $CI=(2.03, 91.85)$, $p<0.001$), whilst the reverse applied for the \$60,000-\$100,000 category (females=49%, males=22%, $OR=3.44$, $CI=(1.35, 9.26)$, $p=0.006$).

In comparison with the Australian general population, there were no significant differences in annual income category percentages for full-time employed study participants in the age range 25-44 (see Table 2).

Highest education level

Table 3 shows the frequencies and percentages for the highest education level attained by study participants by gender, cleft type and age-group. The table also compares the percentages of study participants aged 25-44 who attained each highest education level against the Australian general population (ABS, 2014a).

Highest education level attained (n=158)	Gender		Cleft Type			Age-group			Study vs ABS Age 25-44 (n=129)
	Male (n=71)	Female (n=87)	Lip-only (n=25)	Lip & Palate (n=79)	Palate-only (n=54)	20-24 (n=29)	25-34 (n=81)	35-44 (n=48)	
University Post Grad (n=18)	5 (7%)	13 (15%)	7 (28%)	5 (6%)	6 (11%)	1 (3%)	9 (11%)	8 (17%)	13% vs 8% $p^*=0.156$
University Degree (n=43)	14 (20%)	29 (33%)	3 (12%)	22 (28%)	18 (33%)	11 (38%)	26 (32%)	6 (13%)	25% vs 27% $p^*=1.000$
TAFE Cert/Diploma (n=50)	23 (32%)	27 (31%)	11 (44%)	23 (29%)	16 (30%)	7 (24%)	26 (32%)	17 (35%)	33% vs 33% $p^*=1.000$
High School (n=47)	29 (41%)	18 (21%)	4 (16%)	29 (37%)	14 (26%)	10 (34%)	20 (25%)	17 (35%)	29% vs 30% $p^*=1.000$

Table 3. Frequencies and percentages for highest education level attained by gender, cleft type and age-group, and with comparison to the Australian population aged 25-44 (ABS 2014a).

Amongst study participants, there was no significant difference in highest education level by age-group ($p=0.078$). There was however a significant difference by gender with more males than females having high school as their highest education level (males=41%, females=21%, $OR=2.63$, $CI=(1.24, 5.70)$, $p=0.008$). The percentage of females who had either a university degree or a post-graduate degree was significantly higher than for males (females=48%, males=27%, $OR=2.54$, $CI=(1.24, 5.33)$, $p=0.008$).

In comparison with the Australian general population, there were no significant differences in highest education level achieved by study participants in the age range 25-44 (see Table 3).

Living Arrangements

Amongst study participants there was no significant difference in living arrangements by gender ($p=0.69$) or by cleft type ($p=0.71$), however there was a significant difference by age-group ($p<0.001$) with home ownership increasing with age, and living with parents or parental care-givers decreasing with age. There was no significant difference ($p>0.05$) in renting and government or work provided housing across the age-groups.

In comparison to the home ownership rates for the Australian general population reported in the ABS Housing Occupancy and Costs 2013-14 survey (ABS, 2015a) there was no significant difference in home ownership for the 25-34 age-group (study=36%, ABS=39%, $p=0.650$) nor for the 35-44 age-group (study=58%, ABS=63%, $p=0.553$).

In comparison to the ABS Australian Social Trends June 2009 survey (ABS, 2009), study participants reported a significantly higher proportion who lived with their parents or parental care-givers in the age range 25-29 years (study=35%, ABS=17%, OR=2.72, CI=(1.41, 5.06), $p=0.002$), and for the age range 30-34 years (study=24%, ABS=8%, OR=3.58, CI=(1.40, 8.19), $p=0.004$). Of the 53 study participants who lived with their parents or parental care-givers, 46 (87%) were single.

Relationship Status

There was no significant difference in the number of relationships by gender ($p=0.98$) or cleft type ($p=0.08$). Of the 110 (70%) study participants who had experienced at least one serious romantic relationship, the age at which their first relationship occurred ranged from 15 to 33 years with the median age being 19 years for both males and females. This was significantly later ($p<0.0001$) than the Australian general population median age of 15 years for both males and females (Price, Hides, Cockshaw, Staneva, & Stoyanov, 2016). Low self-confidence and self-esteem, and shyness were reported as contributors for the significant delay (4 years) in meeting a potential partner, and for those who had never experienced a romantic relationship in the 35-44 years age-group.

Table 4 shows the frequencies and percentages of the registered marital status for study participants by gender, cleft type and age-group. The table also compares the registered marital status of study participants aged 25-44 against the Western Australian general population (ABS, 2011).

Registered Marital Status (n=158)	Gender		Cleft Type			Age-group			Study vs ABS Age 25-44 (n=129)
	Male (n=71)	Female (n=87)	Lip-only (n=25)	Lip & Palate (n=79)	Palate-only (n=54)	20-24 (n=29)	25-34 (n=81)	35-44 (n=48)	
Married (n=42)	12 (17%)	30 (34%)	7 (28%)	18 (23%)	17 (31%)	0 (0%)	16 (20%)	26 (54%)	33% vs 51% p<0.001
Never Married (n=112)	56 (79%)	56 (64%)	16 (64%)	60 (76%)	36 (67%)	29 (100%)	64 (79%)	19 (40%)	64% vs 41% p<0.001
Separated / Divorced (n=4)	3 (4%)	1 (1%)	2 (8%)	1 (1%)	1 (2%)	0 (0%)	1 (1%)	3 (6%)	3% vs 8% p=0.035

Table 4. Frequencies and percentages of registered marital status by gender, cleft type and age-group, and with comparison to the Western Australian population aged 25-44 (ABS 2011).

Within the study there were no significant differences in registered marital status by gender (p=0.07) or by cleft type (p=0.28), however, there was a significant difference by age-group (p<0.001) with younger study participants more likely to be single than older participants, as would be expected.

In comparison to the general Western Australian population, study participants aged 25-44 married significantly less often (study=33%, ABS=51%, OR=2.13, CI=(1.45, 3.15), p<0.001), however, once married, they separated or divorced significantly less often (study=3%, ABS=8%, OR=2.76, CI=(1.05, 10.28), p=0.035).

In comparison to the Australian Institute of Family Studies Marriage in Australia (AIFS, 2013), the median age of female study participants at first marriage was significantly lower (study=26.0, AIFS=28.3, CI=(24.5, 27.0), p=0.002), however there was no significant difference for males (study=28.0, AIFS=29.9, CI=(26.0, 31.0), p=0.36).

Of the 158 study participants, 117 (74%) did not have children. Of the 41 (26%) who did have children, 10 (24%) had a child who also had a cleft (with no significant differences by gender or cleft type of the parent). Comments from those whose child also had a cleft included that there was a benefit to having been through the experience themselves so they may understand and protect their child.

When participants were asked if they believed that people who have a cleft should seek genetic counselling prior to pregnancy, overall 49% responded 'yes'. Of the 10 participants who had a child with a cleft, 4 responded 'yes'. There was a significant difference identified for all participants by cleft type ($p=0.027$) who responded 'yes' (lip and palate=60%; lip-only=30%, palate-only=39%).

Psychosocial health issues

Table 5 shows the frequencies and percentages of study participants for the indicated psychosocial health issues by gender, cleft type and age-group, and in total.

Psychosocial health issue	Gender		Cleft Type			Age-group			Study Total (n=158)
	Male (n=71)	Female (n=87)	Lip-only (n=25)	Lip & Palate (n=79)	Palate-only (n=54)	20–24 (n=29)	25–34 (n=81)	35–44 (n=48)	
Anxiety	25 (35%)	50 (57%)	11 (44%)	35 (44%)	29 (54%)	12 (41%)	42 (52%)	21 (44%)	75 (47%)
Depression	26 (37%)	42 (48%)	10 (40%)	34 (43%)	24 (44%)	11 (38%)	35 (43%)	22 (46%)	68 (43%)
Lack Motivation	36 (51%)	44 (51%)	14 (56%)	41 (52%)	25 (46%)	15 (52%)	42 (52%)	23 (48%)	80 (51%)
Panic Attacks	8 (11%)	26 (30%)	3 (12%)	15 (19%)	16 (30%)	6 (21%)	23 (28%)	5 (10%)	34 (22%)
Self-esteem	42 (59%)	58 (67%)	17 (68%)	58 (73%)	25 (46%)	16 (55%)	54 (67%)	30 (63%)	100 (63%)
Self-harm	9 (13%)	19 (22%)	1 (4%)	14 (18%)	13 (24%)	4 (14%)	15 (19%)	9 (19%)	28 (18%)
Suicidal Thoughts	18 (25%)	20 (23%)	4 (16%)	20 (25%)	14 (26%)	5 (17%)	22 (27%)	11 (23%)	38 (24%)
Unworthy	31 (44%)	40 (46%)	11 (44%)	40 (51%)	20 (37%)	11 (38%)	41 (51%)	19 (40%)	71 (45%)
At least one psychosocial health issue	51 (72%)	72 (83%)	20 (80%)	67 (85%)	36 (67%)	21 (72%)	67 (83%)	35 (73%)	123 (78%)

Table 5. Frequencies and percentage for psychosocial health issues by gender, cleft type and age-group, and in total.

Females reported significantly higher rates for anxiety (females=57%, males=35%, $OR=2.47$, $CI=(1.24, 5.00)$, $p=0.007$) and also higher rates for panic attacks (females=30%, males=11%, $OR=3.33$, $CI=(1.34, 9.20)$, $p=0.006$). Study participants with a cleft type of lip & palate reported a significantly higher impact of cleft on their self-esteem (lip & palate=73%, other cleft types=53%, $OR=2.42$, $CI=(1.19, 5.02)$, $p=0.013$). There were no significant differences by age-group. Overall, 123 (78%) of study participants reported they were impacted by at least one of the listed psychosocial health issues with no significant differences by gender ($p=0.12$), cleft type ($p=0.05$) or age-group ($p=0.31$).

Health-related behaviours

Table 6 shows the frequencies and percentages of study participants for health-related behaviours by gender, cleft type and age-group, and in total.

Health-related behaviours	Gender		Cleft Type			Age-group			Study Total (n=158)
	Male (n=71)	Female (n=87)	Lip-only (n=25)	Lip & Palate (n=79)	Palate-only (n=54)	20–24 (n=29)	25–34 (n=81)	35–44 (n=48)	
Drink Alcohol									
Never	7 (10%)	18 (21%)	3 (12%)	13 (16%)	9 (17%)	3 (10%)	15 (19%)	7 (15%)	25 (16%)
Infrequently	23 (32%)	33 (38%)	4 (16%)	33 (42%)	19 (35%)	13 (45%)	26 (32%)	17 (35%)	56 (35%)
Weekly	31 (44%)	33 (38%)	14 (56%)	28 (35%)	22 (41%)	10 (34%)	36 (44%)	18 (38%)	64 (41%)
Daily	10 (14%)	3 (3%)	4 (16%)	5 (6%)	4 (7%)	3 (10%)	4 (5%)	6 (13%)	13 (8%)
Smoke Tobacco									
Never	53 (75%)	73 (84%)	16 (64%)	65 (82%)	45 (83%)	24 (83%)	63 (78%)	39 (81%)	126 (80%)
Infrequently	9 (13%)	5 (6%)	6 (24%)	6 (8%)	2 (4%)	3 (10%)	7 (9%)	4 (8%)	14 (9%)
Weekly	1 (1%)	1 (1%)	1 (4%)	1 (1%)	0 (0%)	0 (0%)	1 (1%)	1 (2%)	2 (1%)
Daily	8 (11%)	8 (9%)	2 (8%)	7 (9%)	7 (13%)	2 (7%)	10 (12%)	4 (8%)	16 (10%)
Use Illicit Drugs									
Never	48 (68%)	73 (84%)	13 (52%)	62 (78%)	46 (85%)	21 (72%)	62 (77%)	38 (79%)	121 (77%)
Infrequently	18 (25%)	13 (15%)	12 (48%)	13 (16%)	6 (11%)	7 (24%)	15 (19%)	9 (19%)	31 (20%)
Weekly	4 (6%)	1 (1%)	0 (0%)	3 (4%)	2 (4%)	1 (3%)	3 (4%)	1 (2%)	5 (3%)
Daily	1 (1%)	0 (0%)	0 (0%)	1 (1%)	0 (0%)	0 (0%)	1 (1%)	0 (0%)	1 (1%)
Physical activity									
Never	1 (1%)	7 (8%)	0 (0%)	2 (3%)	6 (11%)	1 (3%)	3 (4%)	4 (8%)	8 (5%)
Infrequently	21 (30%)	24 (28%)	9 (36%)	23 (29%)	13 (24%)	7 (24%)	24 (30%)	14 (29%)	45 (28%)
Weekly	26 (37%)	37 (43%)	6 (24%)	36 (46%)	21 (39%)	10 (34%)	33 (41%)	20 (42%)	63 (40%)
Daily	23 (32%)	19 (22%)	10 (40%)	18 (23%)	14 (26%)	11 (38%)	21 (26%)	10 (21%)	42 (27%)

Table 6. Frequencies and percentages for health-related lifestyle choices by gender, cleft type, and age-group, and in total.

Amongst study participants there were no significant differences in alcohol consumption by cleft type ($p=0.22$) or by age-group ($p=0.55$), however there was a significant difference by gender ($p=0.03$) with a higher proportion of males drinking alcohol daily (males=14%, females=3%, $OR=4.55$, $CI=(1.11, 26.79)$, $p=0.02$).

For study participants there were no significant differences in tobacco smoking by gender ($p=0.40$), cleft type ($p=0.06$) or age-group ($p=0.98$), but there were significant differences in using illicit drugs by gender ($p=0.04$), and cleft type ($p=0.007$), but not by age-group ($p=0.97$). A higher proportion of females abstained from using illicit drugs (females=84%, males=68%, $OR=2.48$, $CI=(1.10, 5.78)$, $p=0.023$). A higher proportion of study participants with a cleft type of lip-only used illicit drugs infrequently (lip-only=48%, other cleft types=14%, $OR=5.46$, $CI=(1.96, 15.29)$, $p<0.001$) and a lower proportion never used illicit

drugs (other cleft types=81%, lip-only=52%, OR=3.94, CI=(1.46, 10.7), p=0.004). There were no significant differences for physical activity by gender (p=0.25), cleft type (p=0.22) or age-group (p=0.68).

Discussion

When compared to the Australian general population, participants in this study attained equivalent highest education levels. Study participants also had equivalent income, occupational category, and home ownership levels. They did not marry later, nor have a higher rate of unemployment, and reported positive health-related behaviours.

There are mixed results reported in the literature regarding the impact of cleft on the highest level of educational attainment. Collett et al. (2014), van der Plas et al. (2012) and Cheung et al. (2007) did not find any significant differences between the group with a cleft and controls, however Knight et al. (2015) and Wehby et al. (2014) reported that groups with a cleft have significantly lower educational attainment than controls. In contrast, Ramstad et al. (1995a) reported the undertaking of higher education was greater in the group with a cleft compared with the control group.

The results from this study support those of Ramstad et al. (1995a) but with a key finding that participants with a cleft type of *palate-only* had the highest percentage for the education level of University and Post Graduate Degrees. A possible reason for this result is that participants may have felt the need to work harder than their peers and achieve more – a trend also demonstrated by a recent qualitative study (Stock et al., 2015) where participants indicated that they had to work considerably more than their school mates to ensure equitable achievements.

The result of no significant difference for the annual income category percentages between the full-time employed study participants and the Australian general population (ABS, 2013) is in contrast to Ramstad et al. (1995a) who reported that average income was substantially lower in adults with a cleft in all groups compared to controls.

There is a paucity of research for this area and the previous studies may be seen as outdated and lacking relevancy to contemporary Australian populations.

Although not statistically significant, this study found the Sales category to be the lowest of all occupation categories (3%), and less than half of the 7% reported in the WA population (ABS, 2014b). Ramstad et al. (1995b) also found that adults with a cleft were not well-represented in employment positions with direct public interaction. This may be due to potential prejudicial attitudes in the workplace (Chan, McPherson, Whitehill, & L., 2006; Lorot-Marchand et al., 2015) (Stock et al., 2015) including communication problems inherent with a history of speech and hearing disorders resulting from their cleft (Stock et al., 2015) or differences with their facial appearance (Scheuerle, Guilford, and Garcia (1982).

Oosterkamp et al. (2007) reported that having a cleft had very little influence when seeking work, and both (Oosterkamp et al., 2007) and (Stock et al., 2015, 2016) reported that having a cleft had not influenced work performance or achievements and may even be beneficial in bringing attention to the person. The present study is in agreement with those results, the majority of study participants indicated that having a cleft did not impact their ability to get work (83%) nor to do the work they chose (86%). However for those study participants who did report difficulties with their work related to their cleft, speech and hearing limitations were identified as having the greatest impact.

This study also found that independent living was delayed and the number of romantic relationships, marriages, and children were lower than the general population. A key finding was that 78% of participants self-reported that they experienced at least one psychosocial health issue and more than half experienced anxiety and/or depression. The literature suggests that those with a cleft live with their parents longer and are delayed in their progression to independent living (Danino et al., 2005). Even though it has been reported that young adults globally are living with their parents longer (CGK, 2015), the percentage of study participants who lived with their parents was significantly higher than the Australian general population, with the proportion in the 30-34 years age group being triple that of the

general population. The majority of those who lived with their parents were single which may have offered a valuable social support network,

For individuals with a cleft, self-confidence may be negatively affected during adulthood (Havstam et al., 2011; Hamlet & Harcourt, 2015; Stock et al., 2015), which may have a marked impact on social life (Berk, Cooper, Liu, & Marazita, 2001; Danino et al., 2005; McWilliams & Paradise, 1973; Noar, 1991; Peter & Chinsky, 1974; Ramstad et al., 1995b; Turner, Rumsey, & Sandy, 1998) including difficulty in forming romantic relationships. Havstam et al. (2011) found in their study that respondents with a cleft had their first romantic relationship later than their friends, and had concerns that to have a relationship would be a validation of physical attractiveness. This was also observed in the current study both with the one third of participants reporting they had never experienced a romantic relationship and the remainder who had their first relationship 4 years later than the Australian general population. Contributing factors reported by study participants were low self-esteem, shyness, lack of confidence and feeling unattractive. This also provides a rationale for why study participants married less often than the Australian general population.

While the majority of study participants did not have children, a situation which has been reported for adults with a cleft when compared to the general population (Yttri, 2011), this would be influenced by the lack of, and delay in forming, romantic relationships. Study participants also reported positive aspects of having a child with a cleft, which were similar to those found by (Stock et al., 2015; Stock et al., 2016; Stock & Rumsey, 2015b) including the opportunity to draw on their own experiences to assist and protect their child and those of other families.

Nearly half of the study participants responded that they thought that people who have a cleft should seek genetic counselling prior to pregnancy to determine the likelihood of their child having a cleft. Of those, the majority were of the cleft type of *lip and palate*. This is not unexpected due to the level of severity of this cleft type.

It is likely that an individual's appraisal of their own experiences affects how they perceive the idea of becoming a parent and the possibility of their child being affected by cleft (O'Hanlon, Camic, & Shearer, 2012; Stock & Rumsey, 2015a).

While the survey questions were phrased differently¹¹ and therefore must be interpreted with caution, this study found the overall self-reported rates for anxiety were five times higher, and depression nearly six times higher than the general Australian population. In the ABS National Health Survey 2014-2015 (ABS, 2015c) anxiety related conditions were reported by 9.2% of the general adult Western Australian population aged 25-44 years, which is considerably lower than the 48.8% of study participants in the same age range who indicated they had suffered from anxiety, but were not necessarily being treated at the time of the questionnaire. The same survey (ABS, 2015c) also reported 7.8% of the adult Western Australian general population aged 25-44 years suffered from depression, which is also considerably lower than the 44.2% of study participants in the same age range who indicated they had suffered depression.

The Mental Health Council of Australia (MHC, 2007) states that most prevalent mental health disorders in Australia are anxiety and depression. Emotional instability and a poorer level of functioning, including a higher level of depressive symptoms, have been reported in individuals with cleft compared to population norms (Hunt et al., 2006; Hunt, Burden, Hepper, Stevenson, & Johnston, 2007; Mani et al., 2010; Sinko et al., 2005), and increased levels of anxiety (Hunt et al., 2007). Ramstad et al. (1995a) found that adults with a cleft were twice as likely as the general population to experience clinical levels of anxiety and depression and Nilsson, Merlo, Lyberg-Ahlander, and Psouni (2015) and Pedersen, Wehby, Murray, and Christensen (2016) found that individuals with cleft had increased rates of psychiatric illness and higher rates of use of psychotropic drug use.

¹¹ The ABS required participants to be receiving medication or treatment for mental health conditions.

In contrast, there have been many other studies which found individuals with a cleft that reported emotional problems at levels which were similar or at lower levels than control groups (Brand et al., 2009; Cheung et al., 2007; Feragen & Stock, 2014; Feragen, Stock, & Kvalem, 2015; Gussy & Kilpatrick, 2006; Hunt et al., 2006; Millar et al., 2013; Munz et al., 2011; Oosterkamp et al., 2007; Wehby et al., 2012). Stock et al. (2015) reported from their study that only a minority of respondents attributed both their chronic and current emotional difficulties to be the result of their cleft.

The highest reported psychosocial issue overall was self-esteem, which was also identified as one of the contributing factors for delayed formation of relationships and was most observed in the *lip and palate* cleft type, which is consistent with the effects of this being the most severe form of cleft. Although females reported higher rates than males for all of the psychosocial health issues, except suicidal thoughts, significantly higher differences were only observed for anxiety and panic attacks. It therefore must be noted that males are just as likely as females to experience the majority of psychosocial issues.

The many years of treatment, preparation for surgical intervention, and being monitored for aesthetic outcomes, particularly dental appearance, may have positively influenced study participants' health-related behaviours. This may be observed with the higher numbers of study participants who abstained from cigarette smoking for both genders, compared to the general population. Studies of health-related behaviours in individuals with cleft have not been reported in the literature and further studies are required to determine if results are typical.

Limitations

Significant study sampling bias was found for gender and area of residence compared to the PMH population. The study sample had a higher proportion of females, and a higher proportion of participants resided in the Perth metropolitan area. The use of a postal self-administered questionnaire inherently enhances the risk of selection bias.

The majority of respondents were Caucasian which limits the study of ethnic influences. Certain questions in the CRQ were not standardised to official surveys of the Australian population which may enhance the risk of misclassification bias.

The study sample was drawn from a Western Australian cohort which may limit generalisation to other populations. A non-cleft control group from the same catchment areas in WA may have provided a better comparison than using population data. Using a multi-site methodology may have increased the number of participants and improved generalisation of results.

Conclusion

This study offers a contemporary observation of adult-specific life outcomes and societal influences for adults with a cleft, and presents a snapshot of a Western Australian cohort. When comparing the sociological outcomes for the study participants, the psychosocial outcomes were the areas of most concern, particularly significant levels of anxiety and/or depression. Assisting and providing services to improve social support both for family and work-related situations may positively influence outcomes for education, employment opportunities and mental health.

Implications for treatment providers from this study are to provide on-going and ad-hoc post-treatment services for:

- speech therapy and ENT services to improve communication difficulties which may hamper work-place effectiveness;
- psychological support services to address issues of anxiety and depression and to assist with self-esteem and self-confidence; and
- social interaction skills training to assist in social functioning.

There were no previous published outcomes for health-related behaviours identified for adults with cleft. Further studies are required to supplement these outcomes.

A key finding of this study is that 78% of participants self-reported that they experienced at least one psychosocial health issue. Participants experienced anxiety and depression at four and six times the rate of the Australian general population. Further quantitative and qualitative investigation is required to determine causes for this marked difference and also to provide greater understanding of participant choices that underpin sociological outcomes.

Chapter 7 Paper 4: Adult narratives of the psychosocial impact of cleft in a Western Australian cohort.

7.1 Commentary for Paper 4

This paper addressed the sixth thesis objective which was to investigate the personal experience and deeper impact of CL/P amongst adults.

Whilst quantitative measures may indicate whether there was an impact, a qualitative approach provides an opportunity to more fully explore those impacts from the patient's perspective, and why they were significant for them. This approach also allows for information to be collected for questions that may not have been considered at the time of question formulation, and an opportunity to share and appreciate the life experience of another. It was an emotional and insightful experience to share the stories of the participant's lives. It was also an opportunity for validation for some and for examining the experiences of the past for others. Each story was unique and informative.

The quantitative methods used in the previous papers provided data which highlighted the impacting and influencing variables across the age-groups. To enhance and capitalise upon this data, qualitative methods were required to discover further meaning. This may add the comprehension and completeness to a story which is minimally told with quantitative methods alone. For this paper, a qualitative interview schedule was utilised in one-on-one interviews with a self-selected sub-group of adult study participants. Adult study participants shared their life stories which offered them a voice to promote their preferences for change and enable others to understand the impact and meaning of having CL/P. This was also an opportunity to discuss the people who had made an impact in their lives, whether positive or not, and to discover the outcomes in the individual's lives. Participants were also encouraged to offer advice to younger CL/P patients based upon their personal experience.

Interviews were recorded and transcribed. Qualitative analysis methods of thematic analysis and word clouds were used to explore the psychosocial experience and support needs of the participants. The data collected provided an insightful complement to the previous papers for both to comprehend the impacts of CL/P and the effects and influences of the impacts which the participants had experienced.

7.2 Copy of Published Paper 4

Nicholls W, Persson M, Robinson S, Selvey L. Adult narratives of the psychosocial impact of cleft in a Western Australian cohort. *The Cleft Palate Craniofacial Journal*, May 2017 (in press).

Abstract

Background: Living with a cleft condition involves many years of multi-disciplinary therapy, treatment and surgical intervention. This complex process may have both physical and psychosocial long-term impacts. There is limited evidence of the psychosocial impact of cleft on individuals in Australia.

Aim: To obtain an understanding of the adult patient perception of having a cleft and explore the impact of the condition on their lives.

Design: Qualitative methodologies at one case study site in Western Australia.

Population of interest: Adults with a cleft lip and/or palate (CL/P) who had received treatment at Princess Margaret Hospital (PMH), the only treatment centre for cleft in Western Australia.

Methodology: Individual in-depth semi-structured qualitative interviews were conducted and recorded and transcribed for analysis.

Results: Fifteen adults with a cleft lip and/or palate. Two main themes were identified: lived experience, (with three sub-themes: normality; support networks and impacts in later life) and advice to others. The majority of participants reported social rejection and isolation which occurred mostly at school and in some instances at home, but did not often last into adulthood. The greatest protective factor was the support of family and friends, which if missing during their childhood, was desired and appreciated in adulthood.

Conclusion: Adults with CL/P may require psychosocial support from their Cleft Team including referral to clinicians in adult services. There is also the need for earlier psychological interventions and social programs to support those with appearance-related social difficulties.

Keywords: psychosocial, cleft lip and palate, qualitative review

Introduction

Living with a cleft of the lip and/or palate involves many years of multi-disciplinary therapy, treatment and surgical intervention. The range of treatment issues over the lifespan include visible facial and dental differences, as well as differences involving speech and hearing (Baker et al., 2009; Kapp-Simon, 2004; Kummer, Clark, Redle, Thomsen, & Billmire, 2012). Due to the complex nature of this condition, there are both medical and psychosocial implications to be considered (Cheung et al., 2007) including the burden of many years of treatment and surgical interventions and the potential accompanying emotional impacts.

The psychosocial impact on those with a cleft condition can be varied and may include appearance-related issues (Marcusson et al., 2002), low self-esteem (Sarwer et al., 1999), anxiety and depression (Mani et al., 2010; Ramstad et al., 1995a; Roberts & Mathias, 2012), and social anxieties concerning the perceived or actual responses of others (Rumsey et al., 2004), teasing and bullying (Hunt et al., 2006), and wider social discrimination and isolation (Sarwer et al., 1999). Recent research has emphasised the importance of incorporating measures of positive growth and resilience into studies of psychological adjustment to visible difference (Egan, Harcourt, & Rumsey, 2011; Stock et al., 2015).

Alansari et al. (2014) found that through the early years, patients with CL/P may experience teasing and low self-esteem, view treatment as a negative reminder of their cleft condition and experience accompanying feelings relating to not being 'normal'. The need not to be or be seen as different is more pressing during the school years and adolescence. As adults, improved self-esteem may in part be due to the realisation of treatment outcomes, however the feelings of not being 'normal' may still remain.

In contrast, other studies have reported adults with CL/P felt that their cleft did not affect their family or marital life and that, once in a relationship, the cleft had no impact whatsoever (Patel & Ross, 2003). People with CL/P have reported attracting good friends irrespective of their appearance (Eiserman, 2001) and have experienced positive outcomes including a sense of inner strength and resilience which may lead to developing coping techniques and confidence in dealing with life challenges.

The evolving life-process of developing coping techniques needed to assist with managing the challenges which accompany long-term treatment conditions may be difficult and complex. It is therefore necessary to use a research approach which will allow conceptual and contextual descriptions and provide opportunity to uncover meaning from those descriptions (Cresswell, 1997). The aim of this study is to utilise this approach to better understand the psychosocial impacts for adults with CL/P and how their perceptions and experiences have impacted their lives.

This study forms part of a broader mixed methods study investigating the psychosocial impact of CL/P (Nicholls, Harper, Hartig, et al., 2016; Nicholls, Harper, Robinson, Persson, & Selvey, 2016; Nicholls, Selvey, Harper, Persson, & Robinson, 2016) and adds to the growing body of international research in this area.

Methodology

Design

Qualitative methodologies have been used in other studies which have focused on chronic conditions which affect appearance including CL/P (Alansari et al., 2014; Chetpakdechit, Hallberg, Hagberg, & Mohlin, 2009; Stock et al., 2015, 2016). A case study approach was used which involved undertaking semi-structured interviews with a cohort of patients with CL/P. This qualitative approach allows for a greater understanding of an individual's lived experience (Kayle, 1996), and can provide a greater understanding of an individual's needs including the development of more appropriate and successful ways to support the individual (Bingley, Thomas, Brown, Reeve, & Payne, 2008).

An interview schedule was developed that covered a number of relevant themes from the literature and discussion with clinicians involved in treating CL/P, in particular, perceived or reported areas of psychosocial concern for patients with CL/P. This schedule of questions (see appendix 1) was used for the interviews with a varied order of questions in some instances to allow a natural flow to the interview. The broad questions developed around these themes related to:

1. The impact CL/P made on their lives.
2. The people that made an impact on their lives.
3. Things that could have been done differently.
4. Advice to give to a teenager with CL/P.

Guidelines for Theme Analysis

Thematic analysis was used to analyse the interview data. This is primarily a method for identifying and organizing patterns within a complete data set, but is also used to interpret various aspects of the subject matter (Howitt & Cramer, 2011). The guidelines from Braun and Clarke (2006) were followed: (1) data familiarisation; (2) identifying interesting data features; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) report production.

Saturation of information determines the minimum sample size in qualitative studies (Braun & Clarke, 2006), which, for this study occurred at interview twelve.

Participants

Participants were identified from a PMH CL/P database, and were residents in Western Australia, born between 1973 and 1993. Fifteen individuals agreed to be interviewed with ages ranging from 22 to 39 years, with a mean age of 30.4 years (see Table 1).

Ref No	Name Pseudonym	Gender	Age	Cleft Type	Occupational Industry	Residence Area	Negative Impact from CL/P?
1	Barbara	F	31	UCLP	Banking / Finance	Rural	Yes
2	Rena	F	32	CP	Postgrad Student	Metropolitan	Yes
3	Matthew	M	29	UCL	Marketing	Metropolitan	No
4	Brandon	M	37	BCLP	Kitchen Hand	Metropolitan	Yes
5	Zia	F	39	UCLP	Teacher/Mother	Rural	Yes
6	Paula	F	28	BCLP	Writer	Metropolitan	Yes
7	Tess	F	34	UCLP	Teacher/Mother	Rural	Yes
8	Justine	F	31	UCLP	Social Trainer	Metropolitan	Yes
9	Julia	F	30	BCLP	Hairdresser	Metropolitan	Yes
10	Marcus	M	28	BCL	Doctor/ Medical	Rural	No
11	Peta	F	29	BCLP	Accountant	Metropolitan	Yes
12	Emily	F	22	UCLP	Barista	Rural	Yes
13	Brian	M	34	BCLP	Rigger	Metropolitan	Yes
14	Andrew	M	22	UCL	Student Teacher	Rural	No
15	Rebecca	F	30	UCLP	Nurse	Rural	Yes

Table 1. Demographics of study participants.

This group had undergone many years of treatment from 1977 to 2014, with the majority (13) having been discharged from PMH between 1996 and 2010 due to completion of care or referral to adult services as per age-eligibility guidelines. Definitive CL/P treatment had been completed for 13 of the patients in their late teens and early twenties, and all patients had received comparable care regarding technique and technology. Ten participants were female and five were male, with the following CL/P breakdown; UCL/P(6); CP(1); UCL(2); BCL(1); and BCL/P(5). Two males reported having Attention Deficit Hyperactivity Disorder (ADHD) as an additional condition.

All participants identified as Caucasian, eight were either married or living with their partner, and all were employed at the time of interview in the following employment categories; Clerical and Administration (1); Community and Personal Service (4); Professionals (7); Students (2) and Technicians and Trades (1).

Seven participants lived in rural areas and eight lived in urban areas. Three participants had children of their own, with two having a child also born with CL/P. Participants had previously completed a quantitative questionnaire as part of the broader research program which included an invitation and consent form to further participate in a qualitative interview which formed this current study. At pre-arranged times, individual face to face, in-depth, semi-structured interviews were conducted by the first author in an interview room at the Hospital site with the 15 self-selected participants.

Data Analysis

Interviews were voice recorded and responses transcribed for subsequent thematic analysis. This technique identifies and organises patterns within a data set, and also interprets various aspects of the subject matter (Howitt & Cramer, 2011). Themes were identified in accordance with guidelines by Braun and Clarke (2006) and text mining and analysis was also undertaken using R statistical programming language version 3.3.0 (R Development Core Team, 2015).

Themes were chosen for both their repetition and impact with the research question and compared against the word cloud (see figure 1). This provided a cross-reference for the themes developed. The text cloud was developed using text mining using R functions and was used to identify the highest frequency key terms. Emerging themes were initially identified by the first author and were checked and discussed until agreement was reached between two authors. A summary of the resultant themes was also discussed in a follow-up telephone call to twelve of the participants (three could not be contacted) to confirm the accuracy of the analysis (Braun & Clarke, 2006; Yardley, 2000). The primary aim of this paper was to offer a representation of the participant's experience of having CL/P. In order to achieve this, participants' quotes are used to support the analysis and emergent themes. All participants have been given pseudonyms to protect their identity.

Ethical Considerations

Ethical approval was obtained from the Princess Margaret Hospital Research Ethics Committee (EC2014046) and Curtin University Research Ethics Committee. Participants were made aware of key interview issues including confidentiality and their right to withdraw and were advised that the researcher was not able to provide advice or counselling but could be directed to relevant organisations for information and support.

Results

The interviews produced a deep and emotive account of the lived experience of the participants from their early adolescent years to adulthood. This included their experience of treatment, family life, school and community, friendships and how they functioned in a social sense. Twelve of the fifteen participants reported a negative impact resulting from having CL/P. The three participants who did not report a negative impact were male and had the cleft type of lip-only. Two participants commented that they believed it likely that their emotional issues would have occurred irrespective of having CL/P. Two main themes were developed from the interviews; *lived experience* and *advice to others*.

Lived experience describes the impacts from having CL/P in terms of participants' life experience - what they experienced and what they learned from those experiences - and has three sub-themes of *normality*, *support networks* and *impacts in later life* which describe the significant concepts from the interviews.

Theme 1. Lived experience

1.1 Normality

Wanting a sense of normality was a recurring theme. Participants spoke of 'wanting to feel and to be seen as normal; wanting to fit in; and wanting to look physically normal'. In adolescence, in particular, many respondents referred to their inability to blend in and be accepted. Participants all spoke of the importance of having, and being seen to have, a normal life; one which included family, friends and a romantic partner which were described as crucial components for life satisfaction. The term 'different' was the most commonly used term by participants and had many representations. Participants felt different to their peers and these differences were most often perceived as equating to being negative and unwanted and gave a sense of being 'different', not feeling 'normal'. Being different gave rise to many negative emotions and feelings of rejection, exclusion and isolation, acknowledged both by those who had, and had not, experienced teasing and bullying.

"The way I saw it was that my cleft stood out. It was the first thing I would see when I looked in the mirror, when someone was mean to me, I assumed it was because of my cleft as well. I just felt different. I felt like I didn't look "normal" or like the other girls. I felt ugly." Justine

Having treatment also added to the perceived burden of being different. There was also the perception of treatment as both a cause of discomfort, inconvenience and a reminder of being different.

“I felt like going to the hospital was a constant reminder that I was different.” Peta

There was acknowledgement that having CL/P had made a substantial impact on participants' lives, especially during their school years. Participants commented that having CL/P had defined them and their outlook on life, making their lives harder as a consequence, even to the point of wishing they had not been born.

“A massive one! Having a cleft has defined me. People always say not to let it do so but of course it does, it has created the outlook I have, the appreciation and understanding I possess and it has made my skin a lot thicker. It has taken many years to get a thick skin and many years of hurt and feeling isolated and different, even ugly.” Emily

This was also demonstrated by the impact of appearance, the behaviour of others toward them, and participants' self-perception. Participants used strong emotive language when describing their imperfect appearance and the impact of the negative views of others. Participants were aware as children that their appearance was different from their school peers. Bullying was a common and negative influence and participants reported teasing and feeling humiliated about their facial appearance.

“I have always thought that I was attractive but having a cleft made me feel imperfect, not quite disfigured but certainly flawed. It has been very hard having a normal sister and mother who are really beautiful and being compared to them. I know that looks are not everything but that is easy for people to say who don't have uneven lips and a scar.” Julia

“I grew up being told that only a mother could love that face. This face ruined everything in my life” Brandon

Participants also reflected on the marked impact that bullying had on their lives and as a consequence, the need to camouflage their facial scarring. Female participants reflected the need for make-up to hide their scars and change the shape of their lip.

“I knew that my scarring was quite noticeable and I wasn't allowed to put on any make-up to cover it. This I understand for the school to not want girls to be trying to look older or getting caught up in the appearance barbie-doll thing – but this was not for attraction but just to try to look more normal. I think the school should have made an exception for me.” Peta

Participants reflected that their self-perception of being different negatively impacted their lives, which for some, became self-rejection. While some participants reported lacking self-confidence and feeling unattractive, others agreed that it was difficult but they were able to embrace their situation. Mostly it was how they felt about themselves and how they thought others judged them more than what others did.

For one participant, there was a sense of the people around her not acknowledging her life experience by not acknowledging her CL/P.

“But for me, no matter how many times someone said I was beautiful or anything like that I found it impossible to believe them. It took time. I felt that those who said they couldn’t tell [that I had a cleft] made me angry because they are negating a big part of my life. They don’t know what I went through or who I am.” Justine

1.2. Support networks

Many participants reflected on the importance of their parents and the support they had been given. Family support was seen as a protective factor which offered reassurance, understanding, and a guide to how they should feel about themselves and be treated by others. How parents reacted to their CL/P influenced how participants in turn reacted and responded.

“My parents were very supportive and loving and they ensured that I had a pretty happy upbringing. They did all that they could to ensure that I was both protected and could look after myself in the world.” Tess

Participants who had lacked family support suggested this had a negative impact on their life experience, leading to a sense of isolation. For some participants this was still felt in adulthood. When discussing families, some participants reflected on their experiences of rejection and blame by their family members. Participants talked about their parents being ashamed of them and embarrassed by their appearance. Discomfort and embarrassment was also felt by participants when comparisons of appearance were made by parents and family between siblings. There were instances of participants being blamed for parental relationship breakdown.

“We had some family turn their backs at birth but at the end of the day, they chose not to be a part of my life, even still now.” Emily

“People would comment, even family, when they thought that I couldn’t hear and also to my face, that it was a shame that I had a cleft and that my sister was so pretty.” Julia

Having friends at school was another significant factor, with some participants reporting a positive and supportive influence of friendships on their lives including the importance of friendships in protecting them from loneliness. Participants commented having a good friend at school influenced their ability to cope well and to offer a sense of belonging and as a buffer against difficult peers and isolation.

“I had one friend who stood up for me and actively tried to stop the bullying, more kids need to have the confidence to stand up for their friends rather than trying to fit in with the ‘cool kids’ and laughing at the bullying, or disappearing when it starts.” Paula

Participants had to attend many CL/P-related medical appointments – which led to them being absent from school on a regular basis. Participants commented that there were too many appointments, especially for those from rural areas who experienced an even greater number of absences from school due to being required to remain in the city to meet the treatment requirements.

“It made it hard to have a friend when you are away a lot.” Barbara

Problems with speech intelligibility and social discomfort resulted in participants being aloof and wary of others. Participants also commented on their lack of social skills and their discomfort with making any sort of informal conversation.

“I am a bit hard to understand and so I know why others would want to avoid the hassle but it still hurts”. Brian

There was acknowledgement of the importance of school programs for anti-bullying and student inclusion and the difference they believed these programs would have made to their lives. A major factor was that participants felt that the school administration could have done more to overcome the problems and deal with bullying. All of the participants who grew up or lived in smaller rural communities felt they had more positive support structures than those in larger urban communities. These participants also had difficulty when moving out to larger communities and towns.

“Coming from a small town and going to a small school really helped because people know you for who you are as well as so-and-so’s son and not just another kid who goes to the same school as someone else’s kid when you live in the larger towns. It was different at high school and then university as I had to go to a larger school and then to Uni in Perth. You become an outsider amongst strangers and that is hard.” Marcus

Participants experienced rejection at school and shared experiences of teasing and isolation, mostly by their peers, but also by a teacher and parent of a peer for one respondent. For some, changing schools improved their experience. Participants’ fear of being ignored by their peers or rejected prevented them from attempting to form friendships. There was a great impact felt by the reinforcement by adults of not being ‘normal’ when being rejected as an unsuitable friend for their child.

“I was teased and bullied and didn’t want to go to school. I was lonely and there was nobody who understood. I had a teacher that was a total arse and treated me really badly, making fun of how I spoke and just generally intimidating me. That was so hard. I would go home crying.” Zia

1.3 Impacts in later life

The impact of having CL/P during childhood and adolescence may greatly influence later life. The result of not addressing unresolved negative emotional impacts manifested as a crisis in later life and the opportunity for resolution of the earlier experiences. Participants acknowledged they also felt the fear of rejection as adults and spoke of using alcohol to help them feel more at ease in social situations. They also responded in other and varied ways including remaining aloof in social situations, avoiding social occasions or alternately, overcompensating and behaving in a more extroverted manner.

“I did drugs, alcohol and didn’t choose my friends wisely. You might say I was a bit wild trying to fit in and forget that I was different. Zia

Participants acknowledged that their CL/P had made them stronger and empathic and commented on the personal growth they achieved from the experience. With the help of hindsight participants saw the positive contribution that having CL/P had made, including how to support and defend others, and how less important appearance is in later life.

A difficult upbringing and the negative impacts of life experiences also influenced the outlook and responsibility of parenting. For some it gave the determination to do better than they had experienced from their parents. Participants reported becoming parents themselves as being 'life changing' and 'fulfilling'. However for others it was too daunting and extended from a position of not being able to cope with responsibility and for another, not wanting a child to experience the negative impacts and hardships of what they had experienced.

"It was only when I became pregnant that I realised that I could make a difference to someone else's life and from then on life became precious and I became important. I now spend each day being the best parent and partner that I can be. Zia

"Never feeling pretty, never feeling good enough, never fitting in, never believing that you would meet someone or that someone would ever love you. Being teased and made to feel ugly. I don't think I want to risk passing this to my children." Peta

For those who had a child with CL/P there was an empathy extended to their own children and the knowledge of how to help, that could only be appreciated by having CL/P themselves.

"But the biggest impact I think is having the experience so that I know how to help my daughter [who also has a cleft]. Without this knowledge I wouldn't be able to really understand what she is going through and will go through." Tess

Participants also conveyed that they had difficulty forming romantic relationships, often meeting their first partner late in their twenties. There were many reasons attributed to this, including the perception of aloofness due to being wary of others' reactions, lack of self-confidence, shyness and social discomfort. Many had never experienced a romantic relationship. Participants also suggested that they felt they had a lack of true friends until later in their life.

"I didn't have a girlfriend until I was 26 and this made me feel that I would never meet anyone." Marcus

However it was noted that support from a partner, friends and their own children was acknowledged as an important positive factor which offered encouragement and acceptance.

For many participants this was seen to be the greatest influence in their lives, one which allowed healing of both the old feelings from the past and many of the negative implications of their CL/P. Many reported the experience of feeling accepted, experiencing self-acceptance, and feeling the normality which was missing during their adolescent years.

“My husband and daughter have made the biggest difference – to have that love and acceptance is life-changing and feels wonderful.” Tess

“I never felt confident that I would meet anyone and it is nice to have someone. He says that he doesn’t see it [my scar] and even if he doesn’t 100% mean it – it doesn’t matter - it’s such a nice thing to say and to feel so accepted.” Julia

Participants realised the impact and value of the CL/P repair surgery. For those who had a minimal-impact CL/P, where their speech or teeth were not affected, their CL/P did not have a substantial impact in their lives.

“The surgeons gave me an appearance that was so close to being normal that I could in fact function without being obviously different. I think I have only come to this realisation within the last 6-8 years, as an adult and with the benefit of hindsight! That sort of care has also made me want to help others.” Marcus

The second main theme, advice to others, describes not only what life experience has taught the participants, but also holds advice and recommendation for improvement of both life and treatment experience for others. Although the original question was aimed at determining whether adolescence was a significant time in their lives, and whether or not this was due to having CL/P, many participants responded more broadly to also give advice in adulthood.

Theme 2. Advice to others

Participants indicated that their advice to a teenager concerning bullying would be to speak up rather than accept being bullied. Recommendations were made for asking for help from others including those in authority.

Speaking up was also the advice with respect to treatment, recommending to teenagers of today to take an interest in their treatment so they feel empowered and involved in the decision making process. This included having treatment which is the most suitable for them, and equally not having treatment if they feel it is not right for them.

“Take an interest in your treatment as the time comes really quickly when you have to make the decisions yourself and that is sometimes hard. Don’t wait for extra cosmetic surgery if you feel it would make a difference. Do it and enjoy your looks.”

Julia

There was also regret acknowledged for not having revision surgery performed at an earlier time. Participants also expressed concern at the lack of a transition to adult services and highlighted the need for information and guidance before they are discharged. Participants also felt they would have benefitted from speaking to a psychologist or counsellor throughout their treatment time, but especially during their adolescent years. Participants also reflected on the value of having contact with others with CL/P and their families.

“Having contact with other families or kids with clefts. I grew up knowing no one else who had a cleft and I felt quite alone with it.” Peta

The most repeated theme regarding advice to teenagers was to persevere – both with treatment and with their lives - with the sure knowledge that things do get better. When it came to finding some true friends, they advised not to worry if this takes some time - it is worth the wait.

“If you haven’t found your tribe yet – don’t worry because you will. Find some decent friends and be happy to be in your skin.” Andrew

Discussion

This paper has identified a number of factors which have impacted the participants’ experiences of CL/P from their reflections as adults. These factors will now be discussed within the context of the literature relating to psychosocial impacts of CL/P.

Theme 1. Lived experience

1.1 Normality

Nurmi (2004) describes the need for adolescents to be seen and accepted by their peers as typical or normal as a core measure of their well-being. For adolescents without CL/P, associations between appearance satisfaction and social behaviours have been reported (Paxton et al., 2006) with pressure from peers to meet appearance standards to allow inclusion in a peer group or develop a romantic relationship (Rumsey & Harcourt, 2005).

For adolescents with CL/P, this may be more difficult as appearance differences may impede the ability to fit in with their peers. Being denied methods to camouflage appearance differences also caused more discomfort.

The experience of having CL/P has many potential difficulties and challenges, especially during adolescence, including absence from school to attend appointments, appearance differences, unsatisfactory relationships and struggles with self-esteem and self-image (Tiemens et al., 2013). Richman, McCoy, Conrad, and Nopoulos (2012) described self-perception of being different from their peer-group to be an appreciable cause of stress for adolescents with CL/P and identified this to be a possible risk factor for difficult adjustment. For many participants in our study, negative self-perception had been influential during their lives, irrespective of their being teased about their CL/P. In contrast, the three participants who did not report a negative impact from having CL/P may have experienced a reduced burden of care associated with management of the cleft type of lip-only and the influence of being male. Although findings for gender differences within the studies of visible difference are limited, (Feragen, Kvaalem, Rumsey, & Borge, 2010) found that positive findings were more common within the group of boys with a visible cleft.

Teasing and bullying were reported by many participants in our study and were a major cause of distress. Teasing and perceived stigma leads individuals with CL/P to be more vulnerable to feeling different from their peers (Alansari et al., 2014; Tiemens et al., 2013). Many in our study feared teasing and rejection by others and advised that anti-bullying programs had not been available.

1.2. Support networks

Social support has been found to be an essential protective factor for psychological well-being, assisting adjustment in individuals with CL/P or visible appearance difference (Baker et al., 2009; Broder, 2001). Nelson, Kirk, Caress, and Glenny (2012) report that the level of support given by a family will impact a child's adjustment to their CL/P and life circumstance. Parental attitude has been shown to be the greatest support and a substantial influence for a child toward their CL/P (De Sousa et al., 2009) and was evidenced in our study as the greatest influence for participants with experiences of either rejection or support. Many participants in our study expressed gratitude for the people who had made a difference in their lives, by providing support and encouragement, both when growing up (mostly parents), and those currently making a difference (friends and partners). Some reflected that the importance of this support was essential and only realised as adults.

Feragen et al. (2015) found that having good friends could be a protective factor to counter difficult social concerns and that this protective factor may also extend to emotional difficulties. Those participants in our study who had friendships during their childhood expressed gratitude for the protection it offered from bullying and providing social acceptance by others. However many participants reflected on not having true friends, and the loneliness that accompanied this.

Gilligan (2000) reported that a sense of community or belonging may accompany an individual's sense of acceptance. For those participants in our study who grew up in small rural communities, there was a greater sense of acceptance, no reported bullying, and less isolation.

1.3 Impacts in later life

Participants in our study acknowledged that having CL/P had allowed them to develop empathy, strength and resilience as also reported by (Baker et al., 2009; Berger & Dalton, 2009; Feragen et al., 2010). However, it was often the difficult and sometimes painful experiences of many participants in their adolescent years which contributed to this development of resilience by being able to grow from these experiences to an appreciation of their current lives.

For those adults who may not be well adjusted to their own experiences of CL/P, starting a family may bring residual difficulties to light (O'Hanlon et al., 2012; Stock & Rumsey, 2015b). Where one respondent felt ill-equipped in his adult years to look after his child or himself sufficiently, for another this responsibility was more of an opportunity to provide a better upbringing for his child and for others it was the opportunity to help guide and buffer their child's experience from a place of firsthand knowledge.

Theme 2. Advice to others

The most constantly provided advice to others was: commitment to treatment; not to accept bullying; and perseverance in finding friends.

Study participants recommended psychological support throughout the treatment years, as also reported by (Stock et al., 2016) and also after treatment had been completed. Having contact with others with CL/P was identified as being beneficial to both parties, which supports a similar finding by (Egan et al., 2011).

Advice was also given for taking an active interest in treatment as also reported by (Best & Miller, 2010), to support preparation and readiness for future treatment decisions and access to services in adulthood. Advice was further given for having revision surgery at an earlier than recommended time to improve appearance as reported by (Byrne et al. (2014); (Lorot-Marchand et al., 2015) and self-confidence.

Perseverance was also advised with respect to life experiences and to encourage and reassure that life does get better. Participants in our study found that perseverance led to resilience, and was perceived as qualities to help to cope with difficult situations as also reported by R. Strauss and Fenson (2005) and Egan et al. (2011).

However, the situation to which participants in our study indicated as the most important with respect to perseverance, was finding *true* friends - those who can provide emotional stability and positive recognition, similar to findings by Stock et al. (2015) and Chetpakdechit et al. (2009). Participants from our study advised and reassured others with CL/P not to worry if they haven't found friends yet as this may take time, but to persevere in doing so.

Limitations

Sampling bias is inherent in self-selection and could not be controlled for with the restrictions for participant recruitment. Other limitations include the potential for recall bias from retrospective interviews and the many years from which to recall those experiences. Potential influence may arise when a relationship exists between participants and researchers during data collection for qualitative methods, however there was no clear evidence of this in the current study.

Conclusion

This study contributes to the limited qualitative literature for individuals with CL/P and furthers the understanding of life experience and accompanying self-perception. For many of the participants, having CL/P has been a lifelong challenge with the underlying recurring theme of wanting normality which influenced their self-perception, treatment compliance, life experiences and accompanying life satisfaction.

The majority of participants reported social rejection which occurred mostly at school, but often did not last into adulthood. The greatest protective factor reported was the support of family and friends, which if missing during childhood, was sought and appreciated in

adulthood. The key advice given was that for perseverance – that things do get better, and that people with find their ‘tribe’, even if it takes some time.

Recommendation

Educational and social programs may assist with social competence and achieving positive social experience for individuals with CL/P.

Training programs which address visible difference for professionals include Face Value (Face-Value, 2017) for health care professionals, Mirror, Mirror (Mirrorproject, 2014) for teachers and Changing Faces (Changing Faces, 2008) for youth.

Chapter 8 An international comparison of psychosocial support provision for patients with a cleft or other visible difference.

8.1 Introduction

This chapter describes the final research element of this study which provided an investigation of the perceptions of Health Care Professionals (HCPs) who treat individuals with CL/P (Objective 7). The interest was in HCPs regarding their confidence in supporting patients with a visible difference, and their training requirements to better understand the psychosocial needs of people with a visible difference. The chapter will begin by providing a brief background into the importance and relevance of the investigation before presenting methods, results, discussion and summary.

Background

For patients with CL/P, there are many years of appointments typically with the same treatment providers. This offers HCPs a unique opportunity to provide psychosocial support for their patients over an extended timeframe. However, HCPs may lack the knowledge and appreciation of the difficulties that individuals with a visible difference, such as CL/P may experience and need help to manage (Dahl, Wickman, & Wengstrom, 2012; Kornhaber, Wilson, Abu-Qamar, & McLean, 2014; Moi & Gjengedal, 2008). Clark (1997) reports the education and training of HCP's contributes to their mode of practice which either promotes or diminishes confident communication skills which are essential to providing effective care. A lack of confidence and inadequate time has been described by HCPs as barriers for being confident in meeting patients' support needs (Clarke & Cooper, 2001; Konradsen, Kirkevold, & Zoffmann, 2009; Persson, Rumsey, Spalding, & Partridge, 2008).

Oliveira and Oliveira (2015) state that it is crucial for HCPs to both respect and understand their patients' psychosocial needs. For this to occur, treatment providers must have the knowledge of the physical and psychosocial issues that may arise for patients with cleft-related differences or any other visible difference. It is essential for HCPs to feel confident and comfortable talking to patients so they may offer appropriate and timely support either directly or by subsequent referral. Grose, Freeman, and Skirton (2012) recommend training, a variety of resources for providing information to patients and knowledge and collaboration with referral services for those HCPs who feel they can provide psychosocial support to the patients. Where there are limited referral opportunities for hospital-based psychosocial support it is important to find other ways to ensure that people with CL/P have access to the support that may be required by themselves and their families. This implies that HCPs have knowledge of the appropriate external referral services available.

Targeted training and education are key tools for raising awareness and improving the psychosocial skills for HCPs so they may more effectively support their patients. This study aimed to discover how confident a diverse cross-section of HCPs from Australia and the European countries of Bulgaria, Latvia, Serbia and Turkey, were in supporting the psychosocial needs of their patients, what training they had received, and what further training was required. The partners from the European countries were also involved in a related study – ‘*Face Value: Optimising the psychosocial care for individuals with birth anomalies in Europe, by implementing an innovative training method for staff in health-care and NGO settings*’. This collaboration enabled the author to collect data from European HCPs with the view to proposed participation in a future *Face Value* initiative in Australasia.

8.2 Methods

Participants

For the European countries of Bulgaria, Latvia, Serbia and Turkey, a convenience sample of 15 HCP’s were recruited at each cleft centre, and in Australia, a convenience sample of 50 participants were recruited from five State based cleft centres (see below for centre information). All members of the respective cleft teams were invited to participate in the study resulting in a wide variety of roles including: plastic surgeons and nurses, oral surgeons, liaison nurses, feeding nurses, speech pathologists, neonatal nurses, outpatient nurses, orthodontists, ENT (Ear, Nose and Throat) surgeons, audiologists, physical therapists, unit coordinators, support service (administrative personnel) and dental surgeons.

Cleft centres participating in this study

Australia

Five cleft centres in Australia were included in this study:

Western Australia Princess Margaret Hospital for Children, Perth;

Victoria The Royal Children’s Hospital Melbourne;

Queensland Lady Cilento Children’s Hospital, South Brisbane; and

New South Wales The Children’s Hospital at Westmead; Sydney Children’s Hospital.

Bulgaria

The Plastic and Craniofacial Unit of the Medical University of Plovdiv, Bulgaria is the specialist centre for treatment of cleft lip and palate, treating 60-80 new cases per year. This Centre works in synergy with the Parent’s Association – ALA (Association of patients with facial anomalies and their parents), both founded in 1997.

Latvia

Riga Cleft Lip and Palate Centre at the Institute of Stomatology (under the Riga Stradins University) is the only referral unit for cleft children in Latvia. The Unit annually provides treatment to an average of 30 live cleft lip and palate births.

Serbia

The Clinic of Dentistry Nis is primarily concerned with orthodontic treatment of patients with cleft, with over 100 patients annually being treated at this clinic. Orthodontic treatment is carried out until growth completion, or longer.

Turkey

The Department of Physical Medicine and Rehabilitation of Marmara University Pendik Research and Training Hospital provides treatment to maximize the abilities of each patient, and provides information about their rehabilitation process.

Instrument

The Health Care Professional Questionnaire (HCPQ) used in this study was designed by the lead author with expert input from the *FaceValue* Team and Princess Margaret Hospital Cleft Team who also participated in a pilot to check formatting and provide face validity. A co-ordinator at each of the European cleft centres assisted with the administration of the HCPQ by translating the questionnaire from English to the native language of their country, and by translating participant responses back to English. The thesis author collated and analysed the English versions of the HCPQ responses.

The HCPQ collected demographic details such as country, gender, age, professional background, current role, and years of service in this current role. It also asked 14 questions related to a range of issues associated with patients who have a visible difference, with an invitation to comment on each question. Only the following questions were related to the thesis objective:

- To what extent do you feel confident in addressing the psychosocial needs of patients and their families?
- Have you received any training about the psychological impacts of disfigurement and how to meet the needs of patients?
- What would help you address the needs of patients and their families more effectively? (e.g. training – what sort; how should it be delivered; who needs it?)

Data Analysis

Microsoft Excel 2016, (Microsoft Corporation Albuquerque, New Mexico, United States) was used for data storage and creating tables for descriptive statistics.

Hypothesis tests were undertaken using Fisher’s Exact tests using the R statistical programming language version 3.4.1 (R Development Core Team, 2015). All p-values were compared against the alpha level of 0.05. To simplify comparisons the data were categorised as follows:

- Profession was grouped into five categories: Administration, Dental & Orthodontist, Nurse, Surgeon, and Therapist.
- Participant age (in years as at the time of the study) were grouped into five by 10-year intervals: 20-29, 30-39, 40-49, 50-59, and 60+.
- Years of service in current role were grouped into six by 5-year intervals: 0-4, 5-9, 10-14, 15-19, 20-24, and 25+.
- Extra training requirements free form text comments were interpreted for each participant and four binary variables were set accordingly: Formal Training, On-the-job Support, Written Materials, and Community Education.

8.3 Results

Demographics

The following table contains the demographic details of the 110 study participants.

Gender	Australia	Bulgaria	Latvia	Serbia	Turkey	Total	Total %
Male	23	8	3	7	3	44	40.0%
Female	27	7	12	8	12	66	60.0%
Profession	Australia	Bulgaria	Latvia	Serbia	Turkey	Total	Total %
Administration	2	0	2	0	0	4	3.6%
Dental & Ortho	12	1	5	4	0	22	20.0%
Nurse	5	2	4	2	7	20	18.2%
Surgeon	20	10	2	8	0	40	36.4%
Therapist	11	2	2	1	8	24	21.8%
Age-range (Years)	Australia	Bulgaria	Latvia	Serbia	Turkey	Total	Total %
20-29	1	0	4	0	9	14	12.7%
30-39	16	5	3	2	4	30	27.3%
40-49	16	2	4	8	2	32	29.1%
50-59	13	6	2	4	0	25	22.7%
60+	4	2	2	1	0	9	8.2%
Years of Service	Australia	Bulgaria	Latvia	Serbia	Turkey	Total	Total %
0-4	4	1	5	0	7	17	15.5%
5-9	7	3	3	2	6	21	19.1%
10-14	5	2	3	1	1	12	10.9%
15-19	7	1	1	8	0	17	15.5%
20-24	9	4	0	1	1	15	13.6%
25+	18	4	3	3	0	28	25.5%
Total	50	15	15	15	15	110	100.0%

Table 7. Participant Demographics

All 60 of the European participants were interviewed in person. Of the 50 Australian participants, 10 were interviewed by telephone, 20 were interviewed in person, and 20 returned emailed surveys. Surgeons were the highest surveyed profession in number, being over-represented in Australia and Bulgaria, but absent from the Turkey cleft centre sample which was limited to two professional groups: nurses and therapists.

Confidence in addressing patient psychosocial needs

Of 110 participants, 57 (52%) felt they were *not* confident in addressing the psychosocial needs of their patients (see Table 8). There was a significant difference in confidence by country ($p < 0.0001$) with 100% of Latvian participants and 74% of the Australian participants indicating they did not feel confident, whilst 100% of Serbians and 87% of Bulgarians indicating they did feel confident. There was also a significant difference in confidence between participants who reported they had received psychosocial training and those who had not ($p = 0.005$). Those who had received training were more likely to feel confident than those who had not.

	Confidence in addressing patient psychosocial needs			
Country	No	Sometimes	Yes	Total
Australia	37 (74%)	6 (12%)	7 (14%)	50 (100%)
Bulgaria	2 (13%)	0 (0%)	13 (87%)	15 (100%)
Latvia	15 (100%)	0 (0%)	0 (0%)	15 (100%)
Serbia	0 (0%)	0 (0%)	15 (100%)	15 (100%)
Turkey	3 (20%)	6 (40%)	6 (40%)	15 (100%)
Had received psychosocial training				
No	50 (60%)	6 (7%)	28 (33%)	84 (100%)
Yes	7 (27%)	6 (23%)	13 (50%)	26 (100%)
Total	57 (52%)	12 (11%)	41 (37%)	110 (100%)

Table 8. Confidence in addressing patient psychosocial needs by country and if participants had received psychosocial training. Percentages are by rows.

There were no significant differences in confidence by gender, age-group, service-years group or profession group ($p > 0.05$ in each case - see Appendix 5 for the detailed results for this analysis).

Psychosocial training history

Overall 26 of 110 study participants (24%) indicated that they had received some form of psychosocial training regarding the psychological impacts of disfigurement and how to meet the needs of such patients (see Table 9). There was a significant difference in training received by country ($p = 0.0204$) with 9 of 15 participants from Turkey (60%) indicating that they had received training, compared to 20% or less amongst the remaining countries.

Country	Had received psychosocial training		
	No	Yes	Total
Australia	40 (80%)	10 (20%)	50 (100%)
Bulgaria	12 (80%)	3 (20%)	15 (100%)
Latvia	13 (87%)	2 (13%)	15 (100%)
Serbia	13 (87%)	2 (13%)	15 (100%)
Turkey	6 (40%)	9 (60%)	15 (100%)
Total	84 (76%)	26 (24%)	110 (100%)

Table 9. Participants who had received psychosocial training by country. (Percentages are by rows).

There were no significant differences in training received by gender, age-group, service-years group or profession group ($p > 0.05$ in each case - see Appendix 5 for the detailed results for this analysis).

Of note, 13 of 15 Serbian participants (87%) had received no psychosocial training, yet 100% of the Serbian participants reported they were confident in their ability to address patient psychosocial needs.

Psychosocial training requirements

When asked what would help HCPs address the psychosocial needs of patients and their families more effectively, 96 (87%) of participants indicated that they would like to receive formal training such as lectures, workshops and/or a course (see Table 10). Only 3 (20%) of Turkish participants indicated they required formal training compared to 93% or more from the other countries. However 9 (60%) of Turkish participants had already received psychosocial training and hence 10 (67%) preferred on-the-job support.

Country	Psychosocial training requirements				
	Formal Training	On-the-Job Support	Written Materials	Community Education	Sample Size
Australia	49 (98%)	1 (2%)	2 (4%)	0 (0%)	50
Bulgaria	14 (93%)	0 (0%)	8 (53%)	0 (0%)	15
Latvia	15 (100%)	0 (0%)	0 (0%)	0 (0%)	15
Serbia	15 (100%)	0 (0%)	0 (0%)	4 (27%)	15
Turkey	3 (20%)	10 (67%)	0 (0%)	4 (27%)	15
Total	96 (87%)	11 (10%)	10 (9%)	8 (7%)	110

Table 10. Psychosocial training requirements by country. (Percentages are by sample size).

8.4 Discussion

There is a reported lack of expertise and poor levels of information provision from both a referral and multidisciplinary team perspective for the management of psychosocial needs in the community, and difficulties of patients with appearance concerns (Bessell, Dures, Semple, and Jackson (2012).

The results from this study support this premise with over half of all participants indicating they were not confident in addressing the psychosocial needs of patients with a visible difference.

As anticipated, it was found that participants who had received relevant psychosocial training were significantly more confident in meeting patient psychosocial needs than those who had not, although the efficacy of the support provided was not measured. The finding that only 26 of the 110 participants had received such training strongly suggests that this is an area for improvement for HCPs who work with patients who have a visible difference. There may also be cultural influences to overcome given that all the Serbian participants and 87% of the Bulgarian participants indicated they were confident in addressing patient needs and yet over 80% had not received any psychosocial training. Walters, Matson, Baer, and Ziedonis (2005) found in their review of workshop training for psychosocial addition treatments that new trainees may overestimate their skills and that self-ratings may not be a reliable indication of competence. By implication, for those who had not undertaken training at all, this inconsistency may be even more pronounced. That is, people may underestimate what they don't know.

There was very high agreement (87%) amongst the study participants that formal training such as lectures, workshops and/or courses would help HCPs address the psychosocial needs of patients. This may indicate a willingness to learn the skills to provide more effective care across a broad range of HCP roles and cultural backgrounds. Other areas of healthcare have found appropriate training has led to improved confidence, communication skills and management of difficult problems, including aged care (Clark, 1997), nursing of palliative care (Wilkinson, Roberts, and Aldridge (1998), substance addiction (Walters, Matson & Baer et al., 2005), and multiple sclerosis (Grose et al., 2012). This may be seen not only as a means for improving effective care but also as an opportunity for HCPs to experience competent and meaningful interactions with their patients.

A key finding was the lack of significant differences in confidence and completion of psychosocial training by gender, age-group, service-years group and profession group. This indicates that there was little bias amongst the HCPs in relation to supporting patients with a visible difference, and that relevant psychosocial training is required by all members of the treatment team regardless of their gender, age, role, or previous training.

Determining whether people with a cleft are at increased risk of developing psychosocial problems, and identifying the psychosocial impacts of cleft, are central to discovering and recommending appropriate actions and interventions to address these effects.

In particular, it is essential to determine the effects across the lifespan in order to offer targeted services which will support the individual at crucial times of their physical and emotional development and sequenced treatment interventions. The findings from this thesis are consistent with there being potential difficulties in psychosocial wellbeing within each age-group and across the lifespan for some individuals with CL/P. These difficulties are prevalent globally across age, gender and type of cleft. Just as the difficulties associated with CL/P are multi-faceted, the treatment and support provided must be multidisciplinary to ensure appropriate and satisfactory treatment and life outcomes. Paper 2 provided findings that the physical attributes of hearing and speech were reported to be of higher importance than facial and dental appearance across all three age-groups and that the support received from treatment providers was nearly as important as the support they received from their parents.

A key finding was the *lack* of significant differences in confidence and completion of psychosocial training by gender, age-group, service-years group and profession group. This indicates that there was little bias amongst the HCPs in relation to supporting patients with a visible difference, and that relevant psychosocial training is required by *all* members of the treatment team regardless of their gender, age, role, or previous training.

Determining whether people with a cleft are at increased risk of developing psychosocial problems, and identifying the psychosocial impacts of cleft, are central to discovering and recommending appropriate actions and interventions to address these effects. In particular, it is essential to determine the effects across the lifespan in order to offer targeted services which will support the individual at crucial times of their physical and emotional development and sequenced treatment interventions. The findings from this thesis are consistent with there being potential difficulties in psychosocial wellbeing within each age-group and across the lifespan for some individuals with CL/P. These difficulties are prevalent globally across age, gender and type of cleft. Just as the difficulties associated with CL/P are multi-faceted, the treatment and support provided must be multidisciplinary to ensure appropriate and satisfactory treatment and life outcomes. Paper 2 provided findings that the physical attributes of hearing and speech were reported to be of higher importance than facial and dental appearance across all three age-groups and that the support received from treatment providers was nearly as important as the support they received from their parents.

A key goal of any psychosocial research is to identify areas of impact and recommend improvements which will assist in the individual achieving positive sociological life outcomes in their education, employment, relationships and mental health.

Paper 3 provided findings which reported that 78% of adult study participants had experienced at least one psychosocial health issue and experienced anxiety and depression at four and six times the rate of the Australian general population respectively.

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8.5 Summary

Healthcare providers of patients with CL/P are often in a unique position of treating the same patients for many years, and as a consequence are able to provide support and guidance over that time. To be effective in providing the highest possible care, HCPs must not only have the knowledge of the physical component of the condition but also the psychosocial issues which may arise for patients. It is essential for HCPs to be capable, and feel confident and comfortable in supporting and guiding their patients. Undertaking appropriate training programmes to learn the skills and resources is essential in successfully achieving this outcome.

A limitation of this study was that the European countries included in the study were selected based on their participation in the European *Face Value* project. This limited the number of countries that could participate. Self-selection of respondents may not give a representative sample of the different types of healthcare professionals, and the sample size from each European country was small. However, the uniformity of findings provides valuable insight into confidence and training requirements. Future studies may include a greater range of participant countries with larger sample sizes to capture responses from all professional groups.

Chapter 9 Discussion

This thesis is the first investigation into the impact of CL/P on psychosocial health and treatment experience undertaken in Western Australia. It is also the first that has investigated impacts across three age-groups, to allow analysis of these impacts at different developmental time-points.

9.1 Psychosocial impact of CL/P

The main findings from this work identify the following key areas of psychosocial impact of CL/P for the study cohort.

Four domains of impact

The results from the literature review (chapter 2) indicated that children, adolescents and adults with CL/P do not appear to experience major psychological disorders, however, they are at a higher risk of developing specific psychosocial problems in four key domains: self-esteem and self-worth, social inhibition and isolation, anxiety and depression, and appearance dissatisfaction. Lee, Gibbon, and Spivey (2017) reported results similar to existing studies and noted an increased risk of individuals with CL/P developing psychosocial problems, in particular, the issues of stigma and prejudice. Stock, Feragen, & Rumsey, (2015) support the findings from the literature review and expand to report that the increased risk of developing such problems is diminished by adulthood. The findings from the studies in this thesis broadly support the first three domains from the literature review. The results from paper 3 indicated the most commonly reported impact of CL/P for adults was for self-esteem. Social inhibition and isolation was reported in all age-groups (papers 2, 3 and 4) - predominantly as shyness but also due to communication problems arising from cleft related speech and hearing issues. Self-reported rates for anxiety and depression for adults were nearly four and six times higher than the general Australian population respectively (paper 3). This is higher than previously published literature and may have been influenced by the larger sample size and difference in measurement methodology.

In contrast to that reported in the literature, there was mixed support for the domain of appearance dissatisfaction. Findings in paper 1 reported that BE-Appearance ratings between study participants and normative study scores were equivalent, and paper 3 found the importance of hearing and speech were rated more highly than facial appearance, with facial appearance satisfaction being highest for the children age-group, but lowest for the adult age-group. This finding is in contrast to other published literature which did not consider the aspects of importance and satisfaction of the variable as complementary

concepts. The findings from paper 4 indicated appearance dissatisfaction was associated with feeling humiliated and not fitting in as adolescents, but appearance became less important as study participants reached adulthood. Alansari et al., (2014) also found that self-perception may improve at adulthood, usually following completion surgery. However, this study also reported the issue of participants who sought further surgeries with the anticipation of finding emotional reconciliation from unresolved psychosocial issues.

Attribution

The findings from paper 1 indicated that the opinions of others were of concern in study participants' lives and was reported to have more of an impact and be of greater importance than either their appearance or their weight. Attribution is important as an influence of others in a social sense, especially during early adolescence where a sense of fitting in or having 'a tribe' factors very highly in the individual's life (Griffiths, Williamson, & Rumsey, 2012; Lioffi, 2003). The influence of attribution also enhances the already high importance reported for the support received from treatment providers. This influence may also be seen as intimidating for some patients in the context of multidisciplinary meetings where they receive highly focused attention. This has implications for changes to be made to treatment protocols to limit this effect.

Adult life outcomes

The findings from paper 3 indicated that adult study participants attained equivalent education and employment outcomes when compared to the general population. This is in agreement with Berg, Sivertsen, Ariansen, Filip, and Vindenes et al., (2016) who found that adult outcomes for education, income and socio-economic status were similar to those of the general population of Norway. However the results are at odds with most of the literature which reported that individuals with CL/P were typically not as successful in these areas. This may be due to the age of the studies, the influence of improved techniques and the support that is given by others. However, findings for delayed independent living and forming romantic relationships was similar to those from the literature (Danino et al., 2005; Ramstad, Ottem, & Shaw, 1995), which is related to the similar results for social inhibition. Conversely, the most concerning finding was that 78% of adult study participants self-reported that they had experienced at least one psychosocial health issue, in particular anxiety and/or depression. Although both Berg, Haaland, Feragen, Filip, and Vindenes et al., (2016) and Marcusson, Akerlind, and Paulin (2001) reported that adults with CL/P are at risk of experiencing poorer mental health, the very high reported rates from this thesis requires follow-up to verify these findings, and to determine potential causes with recommendations for appropriate support and potential intervention.

Treatment burden

The treatment burden involves many outpatient appointments and episodes of care which may impact the individual with CL/P in various ways including; treatment burn-out, a feeling of disempowerment, impact on school performance, and to add stress to the family (Baker, Owens, Stern, & Willmot, 2009). The time missed from school may also concern parents with respect to educational and social development (Nelson, Kirk, Caress, & Glenn, 2012). Findings from paper 4 indicated that adult and adolescent study participants identified the number of appointments and the experience of pain following surgery as the two most negative experiences of their cleft-related treatment, with some commenting that multi-disciplinary meetings were intimidating and overwhelming. Adult study participants recommended that teenagers take an interest in their treatment and become involved in the treatment decision-making process so they may feel empowered. This is noteworthy for those patients undergoing appearance altering surgery at growth completion. There may be many years spent in anticipation of this surgery which may dramatically alter facial appearance. Cadogan and Bennun (2011) reported that some adolescents may have unrealistic and naïve expectations of the facial changes anticipated from surgery but not have any concept of the emotional impact that may accompany facial altering surgery. Patients had difficulty in adjusting to the resulting changes.

These findings offer the following implications for HCPs; to minimise the number and duration of treatment events wherever possible, and involve patients in decision making where appropriate. This requires HCPs to ensure there are open lines of communication with patients concerning treatment. Cooperation between HCPs is also required to coordinate appointment scheduling, with consideration being given to outpatient services being sought closer to the home location to minimise travel for those from rural and remote areas.

Services post treatment

Stock, Feragen, and Rumsey (2015) found that adults who have been discharged from their child and adolescent treatment providers may feel reluctance or uncertainty as to how to contact adult health services for additional treatment. The need for instruction and support for the transitioning patient to access treatment in adult services is a global concern and provision for which is also a recommendation from this study.

Paper 3 reported speech intelligibility to be a factor which affected adult study participants in this thesis as an impact on their ability to work. This suggests a gap for provision of post-treatment services, in particular, those for speech therapy and ENT services as these are required for effective communication, and were especially noted in the workplace.

The findings from paper 3 also indicated that adult participants felt they would have benefitted from speaking to a psychologist or counsellor throughout their treatment time, and especially during their teenage years, but the service was not offered. This also suggests a gap for the provision of psychosocial services both during and after treatment has been completed and must be considered for instruction for transitioning patients. Thomas et al., (1997) recommends a discharge assessment for appearance satisfaction to determine the support issues with regard to adjustment and social issues. This assessment has the ability to be developed to encompass all areas of cleft treatment and recommend provision of services as required.

Teasing and bullying

Study participants in paper 3 reported teasing and bullying occurred most frequently from childhood through to late teenage years, then diminished rapidly in adulthood. Brand et al. (2009) also reported similar results with that the majority of problems for adolescents with CL/P relating to difficulties with peers, which included bullying, teasing, and name calling. Whilst there were no differences by gender, study participants with cleft lip and palate were more likely to have experienced teasing or bullying and to have lower self-reported self-esteem than lip-only or palate-only cleft types. This was also reported by Hearst (2007), who highlighted the higher levels of perceived peer harassment, particularly when the face is visibly affected. The implications for HCPs and parents is to be even more vigilant with patients with a cleft of the lip and palate than the other cleft types.

Investment in facial appearance

Crerand, Sarwer, Kazak, Clarke, and Rumsey (2017) take into consideration the level of investment (importance) with facial appearance in relation to satisfaction with facial appearance. This is an essential element to assist with understanding appearance, and requires consideration in all research which investigates appearance satisfaction, especially in our contemporary environment where appearance is pre-eminent. The concept of investment is a gap in the current literature and one which has also been considered and used in the CRQ instrument. The findings from paper 2 however, indicated that the physical attributes of hearing and speech were reported to be of higher importance than facial and dental appearance across all three age-groups. This is in contrast to existing literature but to elicit a more thorough understanding of individual investment and importance, all relevant physical attributes should be considered and not solely facial appearance.

Support from treatment providers

The support received from treatment providers was reported by study participants across all three age-groups in paper 2 to be nearly as important as the support they received from their parents.

However, the findings in chapter 8 indicated that half of the HCPs surveyed did not feel confident in dealing with the psychosocial needs of people with a visible difference, and only 24% had received appropriate training. The World Health Organisation (WHO, 2012) recognises the lack of adequate psychosocial care in healthcare organisations, primarily due to economics, and recommends in-service training in psychosocial support as an essential component for inclusion in care provision. The importance that patients placed on psychosocial support from HCPs and the accompanying lack of HCPs confidence in providing this support is a gap which requires further investigation.

Lack of available support

The psychosocial impact of CL/P on the individual is multifaceted, is subject to change over time and is influenced by the people who shared their experiences, in particular, parents and treatment providers. While there is ample evidence of psychosocial impacts associated with CL/P, there is a lack of conclusive comparable evidence of the effectiveness of psychological support available. Alansari et al., (2014) suggest that treatment should be guided by self-perception measures. This may also be appropriate to evaluate the need for service provision. The lack of recommended intervention programmes (and all but absent *trialled* intervention programmes) highlights the gaps in our current knowledge of how best to provide support, especially when there is such disparity in how individuals adjust to the condition. Where one individual may respond or adjust well, another may suffer difficulties throughout their lives or only at specific times in their lives.

In trying to find answers to the how and why of the manner in which an individual responds, and how this may also be of benefit to others, it is reasonable to anticipate that results must also influence the policy and protocols of treatment providers, and the psychosocial skills and attitudes of treatment providers themselves.

9.2 Contribution and significance of the research

This thesis contributes to the existing quantitative and qualitative work investigating the psychosocial impact of CL/P. This is the first study of psychosocial outcomes of patients with cleft across three age-groups in a Western Australian cohort. The participant samples are larger than much of the comparable research in this field of enquiry. The broad participant age-groups enables unique comparison of impacts.

The findings from this thesis demonstrated the considerable patient perceived impact of CL/P on psychosocial adjustment and life outcomes and are significant for the people of Western Australia as they are from comprehensive local data. The findings also have relevance for other comparable cleft teams in other countries.

This thesis has also illustrated the perceptions of confidence and training requirements of healthcare providers who treat and support patients with CL/P. Appropriate training will provide the knowledge and skills required to improve the confidence of HCPs in treating and supporting patients with CL/P, and also for those with other visible difference, with the aim of achieving optimal psychosocial outcomes.

This thesis has made the following contribution to the knowledge base of literature relevant to individuals with CL/P and those who provide treatment in this area as follows:

- The first use of the BES in a cohort with CL/P;
- The first study with an international collaboration to assess treatment provider confidence and training requirements;
- Validation of an instrument specific to CL/P but with potential to be used across conditions with appearance difference and related conditions;
- Expanded the knowledge base across three age-groups;
- Provided findings from patient perceptions to influence policy, clinical practice and give a voice to people with CL/P.

The literature review underpinning this thesis uncovered gaps in knowledge, methodological shortfalls and differences in research focus across three age-groups. Most studies undertook an approach based on a negative impact of cleft, with only a few having a positive approach. This thesis aimed to take a more balanced research approach, examining both positive and negative impacts.

The use of a mixed methods approach with this patient group enabled greater exploration and understanding of the impact of CL/P. Liddle, Baker, Smith, and Thompson (2015) support the mixed methods approach as one which ensures depth of knowledge. This thesis used a mixed methods approach with included a comprehensive investigation of body esteem (paper 1) as opposed to solely facial appearance in patients with CL/P, the psychosocial impacts using both quantitative (papers 2 and 3) and qualitative methodologies (paper 4), a current investigation of sociological outcomes for adults (paper 3) and the self-assessment of health care professionals and their attitudes and confidence in treating their patients with CL/P (chapter 9).

The value of employing mixed methods provided a comprehensive approach with quantitative measures identifying psychosocial impacts, and a qualitative approach to more fully evaluate the impact and provide an opportunity to explore the impact from the patient's perspective, including how and why this was significant. It gave a voice to participants to express their experience and influence change in a safe and anonymous capacity. This approach also allows for information to be collected which may be out of the original scope of inquiry, and which may offer a greater understanding of an individual's lived experience. It may also provide a greater appreciation of an individual's needs and how best to offer support. The principal study instrument was rated at a high level of face validity and reliability, and may be adapted for other medical conditions and in other national and international contexts, including multicentre comparison, either as a stand-alone instrument or to complement other instruments.

These findings provide an understanding of patient perceived impacts of CL/P on psychosocial adjustment and sociological life outcomes across three age-groups and the contextual base upon which policy decisions regarding the practices and protocols for treating individuals with cleft and other craniofacial conditions should be made. The findings also provide insight into the perceptions of healthcare professionals who treat individuals with CL/P, and the foundation for the training required for these professionals to adequately understand and confidently support the psychosocial needs of people with CL/P and other craniofacial or visible difference. Although the data collection for this thesis occurred in Western Australia, the findings are both timely and relevant to other CL/P centres, both in Australasia and internationally. The findings may be built upon using the study instruments and expanded into use for multi-centre studies.

The findings from this research offer an understanding of the patient perceived impacts and will be used to influence and help improve the quality of current and future care of patients with CL/P at PMH and to minimise adverse psychosocial impacts of CL/P. The results from this thesis may be translatable to other units of similar demographics and cultures and for other related conditions. Determining whether people with a cleft are at increased risk of developing psychosocial problems, and identifying the psychosocial impacts of cleft, are central to discovering and recommending appropriate actions and interventions to address these effects. In particular, it is essential to determine the effects across the lifespan in order to offer targeted services which will support the individual at crucial times of their physical and emotional development and sequenced treatment interventions.

A key contribution of any psychosocial research is to identify areas of impact and recommend improvements which will assist the individual in achieving positive sociological life outcomes in their education, employment, relationships and mental health.

This thesis investigated these important factors and offered a perspective from a Western Australian cohort.

9.3 Limitations

This thesis acknowledges the following limitations. The conditions under which the questionnaires were completed during clinic appointments were not controlled. Completion of questionnaires as a convenience sample in a busy hospital waiting-room may not have offered privacy, adequate time for completion, or an environment conducive to the task. This may have had an adverse impact on responses, and provision for access to a private room or sectioned area which is in close proximity to the waiting area is recommended for future studies.

The use of non-standardised measures (i.e. the CRQ) restricted the ability to provide definitive comparison with published standardised measures. Although standardised measures provide reliability, validation and rigor, at the time of the study, there were no relevant standardised cleft-related measures available which specifically targeted Australian participants, and therefore existing measures were potentially not suitable for the study cohort. Some standardised measures were used in this thesis: the BES which is a validated standardised questionnaire, and the adult-specific comparison data to the ABS data, whereby many of the questions in the CRQ were comparable to the questions in the ABS surveys.

The limitations of using self-reported data are well documented. Hoskins (2012) suggests self-reported questionnaires have the potential to impact the validity of study results in the following ways: honesty of participants, level of introspective ability, level of understanding and interpretation, response bias, and lack of control over the instrument. In this study, response bias may have been present whereby the more motivated and engaged parents may have been more likely to assist their child to complete the questionnaire. Participants may have exhibited uncontrolled bias, including memory and social bias which may have influenced the veracity of the information provided. In particular, there was potential for recall bias for the adult age-group as they have experienced many years of treatment and for some, many years since completion of treatment.

The format of the study instruments was influenced by patient inputs to be at an agreed acceptable level of enquiry. The CRQ was not as burdensome as the use of separate psychometric tests but was also not as comprehensive for the individual areas of enquiry.

A psychometric measure for assessing quality of life (e.g. the Health Related Quality of Life) may have offered more insight into participants' general outlook, in particular between cleft types, and between age-groups.

Paper 1 used normative BES scores from participants from Canada and were from 1996 for the children age-group and 2001 for the adolescent and adult age-groups (18 and 13 years prior to the data collection for this study respectively). A further limitation was that the age ranges from this study were not identical with those in the comparative studies. The age-groups were not matched as the BES questionnaires in this study formed part of a broader research undertaking that required the study age-groups to be based on CL/P protocol treatment milestones.

A limitation for all papers was sampling bias for age (children and adolescent age-groups), gender (adult age-group), cleft type (adolescent age-group) and area of residence (adult age-group). Using postal self-administered questionnaires for the adult age-group, and convenience sampling for the other age-groups, enhanced the risk of selection bias. The majority of respondents were Caucasian which reduces the inclusion of ethnic influences. Further, the study sample was drawn from a Western Australian cohort which may limit generalisation to other populations. Non-participation bias has limited the response from rural areas and which may have offered more information and an indication of the inconvenience with service provision in these areas. A control group without cleft from the same catchment areas in Western Australia may have provided more context for findings, and may have provided a better comparison than using population census data. Certain questions in the CRQ were not standardised to official surveys of the Australian population which may enhance the risk of misclassification bias. However this was not possible due to resource constraints. A further limitation was that sample size was relatively small once broken down into subgroups, but is consistent with or larger than most condition-similar studies.

Sampling bias is inherent in self-selection and could not be controlled for in paper 4 with the restrictions placed for participant recruitment.

The European countries included in chapter 8 were based on their participation in the European *Face Value* project, and consequently limited the choice of participating countries. However, this is the first study to undertake this form of multi-country comparison and may encourage other studies to follow. Self-selection of respondents may have reduced the representative sample of the different types of healthcare professionals who participated in the study.

The sample size of participants in this thesis was large compared to many of the previous studies in this field. The questionnaire was formulated to provide a comprehensive instrument in place of many different instruments with which to collect similar range of data. The questions were formulated from three relevant sources, the current literature, clinicians working in the field and patients/parents. The instrument has face validation and the suitability for use for future research would require evaluation of the psychometric properties. These early findings are positive but further investigation is required to test and refine.

Chapter 10 Conclusion and Recommendations

For many of the adult participants, having CL/P has been a lifelong challenge with the underlying recurring theme of wanting normality which influenced their self-perception, treatment compliance, life experiences and accompanying life satisfaction. The majority of participants reported social rejection which occurred mostly at school, but invariably did not last into adulthood. While study participants attained positive education, income, home-ownership and employment outcomes when compared to the Australian general population, they did not report positive relationship and psychosocial outcomes. The reported rates of anxiety and depression at four and six times the rate of the Australian general population levels, requires further investigation to verify this finding, and to determine potential causes and provide appropriate support and/or intervention.

Health care practice

Health care professionals (HCPs) hold a position of high influence and must ensure all interactions minimise the potential negative impact of attribution. HCPs need the skills to recognise those individuals with negative attribution and other psychosocial issues, and be able to offer appropriate referral to services and access to resources whether they be on-line or a community programme. In particular, discussions concerning appearance requires sensitive handling. They also need to be aware of the importance of their support for patients, and the potentially intimidating nature of multidisciplinary meetings.

This has implications for clinical practice as frequent appointments over years of treatment offers the opportunity for clinicians to provide support and to instil confidence in patients, and to make changes to the clinical process. To ensure appropriate and effective care is delivered, adequate psychosocial training is required for treatment providers to confidently and effectively assist patients and their families, both with effective interpersonal skills and a knowledge base of relevant support agencies.

Clinicians and support staff need to be aware that the attribution aspect of body-esteem has a greater negative impact on patients than their appearance and body weight. The Cleft Team are one of the groups that has an influence in their patients' lives - what is said and how it is said is important. Emphasis on being appearance-supportive instead of appearance-focussed is required to encourage patients to look to other areas of their lives beyond their appearance for confidence and interest. Clinicians and staff should also have knowledge of how patients may access resources to assist with issues of teasing and appearance dissatisfaction.

Cleft and craniofacial teams should raise awareness with parents, educators, other clinicians, and employers of the impact of CL/P across the lifespan and promote programmes which improve self-esteem, social skills, confidence in public speaking and appearance dissatisfaction. Available programmes for promotion which address visible difference for professionals include: Face Value for health care professionals (Face-Value, 2017); Mirror, Mirror for teachers (Mirrorproject, 2014); and Changing Faces for youth (Changing Faces, 2008).

Health care policy

Providing services to improve social support both for family and work-related situations may positively influence outcomes for education, employment opportunities and mental health. In particular, the transition to adult services requires relevant individual treatment and/or maintenance planning to ensure an appropriate level of treatment standard is maintained following discharge. Post-treatment services and referrals should be made available to patients to address hearing and speech difficulties due to their negative impact on communication. The interest from the adult age-group for psychological support in this thesis highlights the importance and need for these services, both during and post-treatment.

Research

Further quantitative and qualitative investigation is required to determine causes for the markedly higher rates of anxiety and depression identified in this study, and also to provide greater understanding of participant choices that underpin sociological outcomes. The basic treatment-related factors of fear of the dentist, fear of having an anaesthetic, satisfaction with smile, and ability to chew properly are benchmarks for functional and aesthetic outcome measures and inclusion in further studies will determine their value.

Future research should incorporate long-term psychosocial outcomes as part of overall treatment assessment. Where possible, participation in multi-centre studies will facilitate assessment of a wide range of participants, factors and situations. This will also increase sample size and power in relation to the results. Consistent instruments and methodology are the basis for comparable research. This is also a focus of the Global Taskforce into Holistic Outcomes in Cleft (GlobalForce, 2016), a current collaboration of international HCPs and academics working to provide a holistic tiered approach to CL/P outcome measures across cultures and countries.

This framework should be completed in 2021 and provide a comprehensive set of standardised measures for audit and research. A recommendation is for relevant components of the study approach, instruments and findings from this thesis be considered for incorporation into the Global Taskforce framework.

The study instruments and approach used in this thesis may also be revised for use with other conditions involving craniofacial and other visible differences. By including other comparable conditions, it may also promote resource-sharing between support groups and facilitate consumer participation. The lack of trialled interventions for psychosocial impacts of CL/P reported in the literature is a gap that future research must address to assist in detailing and directing successful supportive measures, and to provide an informed base from which to develop future work. Other areas of psychosocial research and associated conditions which result in visible difference may provide interventions which have potential to be adapted for use in CL/P. One example is the study by Lovegrove and Rumsey (2005) which provided a structured and detailed intervention and results from the trialled intervention. This study was also noteworthy in its development of the intervention which included programme input from patients.

Future research must be more inclusive and recognise the value of patient contribution. Patient participation in the audit and feedback of the treatment process and experience is essential to be able to provide patient-focused care and patient empowerment. It is after all their journey. Patient participation in the development and content of intervention strategies and content may provide concepts and context with which the researcher may be unfamiliar or unacquainted. Consumer participation is also essential to be able to raise awareness and promote education programmes to reduce stigma and bullying, as well as provide the opportunity to form caring communities.

Ideal programmes

In an ideal world, patients with CL/P, craniofacial and other conditions resulting in visible difference would be offered programmes to assist in self-esteem and self-confidence. Such programmes would be created and managed to reflect the ideals and qualities of the individual and focus on their positive attributes. Components of the programme may include: a professional photo shoot to build appearance confidence and to find a photo with which the individual would feel comfortable to display (Lowenstein et al., 2008); a public speaking opportunity; a buddy system with either another peer or from an age group with which the individual is comfortable, and group team-building opportunities for both physical fitness and problem-solving. Another option would be to volunteer in an organisation or institution where

the individual may feel that their contribution would make a difference to others in either a material or emotional way. This would include opportunities to mentor or just speak with other people with CL/P either through a recognised support group or through the cleft team and may be face to face or through closed social media groups. Another volunteering opportunity is to assist others to overcome bullying (DoSomething.Org, 1993), which encourages participation in campaigns to reduce bullying.

The value of such programmes may be measured with pre and post survey instruments but the greatest worth would be measured with the individual's attitudes, opinions and stories.

References

- Australian Broadcasting Commission. (2014). *WA unemployment rate jumps to highest level in a decade*. 13 Mar 2014. Retrieved from <http://www.abc.net.au/news/2014-03-13/undemployment-jumps-in-wa/5319212>
- Australian Bureau of Statistics. (2009). 4102.0 - *Australian Social Trends, March 2009. Couples in Australia*. Retrieved from [http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/LookupAttach/4102.0Publication25.03.093/\\$File/41020_Couples.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/LookupAttach/4102.0Publication25.03.093/$File/41020_Couples.pdf)
- Australian Bureau of Statistics. (2011). *Registered Marital Status by Age By Sex*. Retrieved from http://stat.data.abs.gov.au/Index.aspx?DataSetCode=ABS_CENSUS2011_T04
- Australian Bureau of Statistics. (2013). *Employee Earnings, Benefits and Trade Union Membership Australia*. Retrieved from <http://www.abs.gov.au/ausstats/abs@.nsf/mf/6310.0>
- Australian Bureau of Statistics. (2014a). 4125.0 - *Gender Indicators, Australia, Feb 2014*. Retrieved from <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4125.0~Feb%202014~Main%20Features~Welcome%20from%20the%20Director~2>
- Australian Bureau of Statistics. (2014b). *Employed persons by Occupation (ANZSCO major group), State and Territory, Sex, Age and Actual hours worked, August 1991 onwards*, data cube: SuperTABLE, cat. No. 6291.0.55.003. Retrieved from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/6291.0.55.003May%202014?OpenDocument#Data>
- Australian Bureau of Statistics. (2015a). *Housing Occupancy and Costs, 2013-14*. Retrieved from <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4130.0>
- Australian Bureau of Statistics. (2015b). *Labour force Australia by sex report*. Retrieved from <http://www.abs.gov.au/ausstats/meisubs.NSF/log?openagent&6202001.xls&6202.0&Time%20Series%20Spreadsheet&A7147A4C0D1FE34FCA257E60007CAAB9&0&May%202015&11.06.2015&Latest>
- Australian Bureau of Statistics. (2015c). *National Health Survey: First Results, 2014-15*. Retrieved from

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4364.0.55.0012014-15?OpenDocument>

Australian Bureau of Statistics. (2016). ANZSCO: *Australian and New Zealand Standard Classification of Occupations, First Edition, Revision 1*. Retrieved from <http://www.abs.gov.au/ausstats/abs@.nsf/0/7437179C7B7C1EEEECA2575DF002DA5D8?opendocument>

Abyholm, F. E., Bergland, O., & Semb, G. (1981). Secondary bone grafting of alveolar clefts. A surgical/orthodontic treatment enabling a non-prosthetic rehabilitation in cleft lip and palate patients. *Scandinavian Journal of Plastic and Reconstructive Surgery*, 15(2), 127-140. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/7041248>

Australian Institute for Family Studies. (2013). *Marriage in Australia source data*. Retrieved from <https://aifs.gov.au/facts-and-figures/marriage-australia/marriage-australia-source-data#median>

Australian Institute for Family Studies. (2016). *Household, Income and Labour Dynamics in Australia (HILDA) Survey Wave 11 and Wave 14*. Retrieved from <https://aifs.gov.au/cfca/2016/07/25/report-hilda-survey-selected-findings-waves-1-14-2016>

Alansari, R., Bedos, C., & Allison, P. (2014). Living with cleft lip and palate: the treatment journey. *Cleft Palate-Craniofacial Journal*, 51(2), 222-229. <http://dx.doi.org/10.1597/12-255>.

Alen, F. (2015). Prospective Associations between Childhood Victimization and Body Image in Early Adulthood. Retrieved from https://gupea.ub.gu.se/bitstream/2077/38744/1/gupea_2077_38744_1.pdf

Ames, J. R., Ryan, D. E., & Maki, K. A. (1981). The autogenous particulate cancellous bone marrow graft in alveolar clefts. A report of forty-one cases. *Oral Surgery, Oral Medicine, Oral Pathology*, 51(6), 588-591. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/7019804>

Armfield, J. M., Spencer, A. J., & Stewart, J. F. (2006). Dental fear in Australia: who's afraid of the dentist? *Australian Dental Journal*, 51(1), 78-85. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16669482>

Australian Institute of Health and Welfare. (2015). *Overweight and obesity*. Retrieved from <http://www.aihw.gov.au/overweight-and-obesity/>

- Baker, S. R., Owens, J., Stern, M., & Willmot, D. (2009). Coping strategies and social support in the family impact of cleft lip and palate and parents' adjustment and psychological distress. *Cleft Palate-Craniofacial Journal*, 46, 229-236.
- Beaune, L., Forrest, C., & Keith, T. (2004). Adolescents' perspectives on living and growing up with Treacher Collins Syndrome: a qualitative study. *Cleft Palate-Craniofacial Journal*, 41, 343-350.
- Berg, E., Haaland, O.A., Feragen, K.B., Filip, C., Vindenes, H.A., Moster, H., Lie, T.L., and Sivertsen, A. (2016). Health status among adults born with an oral cleft in Norway. *JAMA Pediatrics*, published online September 26, 2016.
doi:10.1001/jamapediatrics.2016.1925
- Berg, E., Sivertsen, A., Ariansen, A.M.S., Filip, C., Vindenes, H.A., Feragen, K.B., Moster, H., Lie, T.L., and Haaland, O.A. (2016). Population-based cohort study in Norway. *PLoS ONE*, 11(9), e0162196. doi:10.1371/journal.pone.0162196
- Berger, Z. E., & Dalton, L. J. (2009). Coping with a cleft: psychosocial adjustment of adolescents with a cleft lip and palate and their parents. *Cleft Palate-Craniofacial Journal*, 46(4), 435-443. <http://dx.doi.org/10.1597/08-093.1>
- Berger, Z. E., & Dalton, L. J. (2011). Coping with a cleft II: Factors associated with psychosocial adjustment of adolescents with a cleft lip and palate and their parents. *Cleft Palate-Craniofacial Journal*, 48(1), 82-90. <http://dx.doi.org/10.1597/08-094>
- Bergland, O., Semb, G., & Abyholm, F. E. (1986). Elimination of the residual alveolar cleft by secondary bone grafting and subsequent orthodontic treatment. *Cleft Palate Journal*, 23(3), 175-205. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3524905>
- Berk, N. W., Cooper, M. E., Liu, Y. E., & Marazita, M. L. (2001). Social anxiety in Chinese adults with oral-facial clefts. *Cleft Palate-Craniofacial Journal*, 38(2), 126-133.
[http://dx.doi.org/10.1597/1545-1569\(2001\)038<0126:SAICAW>2.0.CO;2](http://dx.doi.org/10.1597/1545-1569(2001)038<0126:SAICAW>2.0.CO;2)
- Berkowitz, S., Mejia, M., & Bystrick, A. (2004). A comparison of the effects of the Latham-Millard procedure with those of a conservative treatment approach for dental occlusion and facial aesthetics in unilateral and bilateral complete cleft lip and palate: part I. Dental occlusion. *Plastic and Reconstructive Surgery*, 113(1), 1-18.
<http://dx.doi.org/10.1097/01.PRS.0000096710.08123.93>
- Bernstein, N. R., & Kapp, K. (1981). Adolescents with cleft palate: body-image and psychosocial problems. *Psychosomatics*, 22(8), 697-703.
[http://dx.doi.org/10.1016/S0033-3182\(81\)73469-8](http://dx.doi.org/10.1016/S0033-3182(81)73469-8)

- Berscheid, E., & Gangestad, S. (1982). The social psychological implications of facial physical attractiveness. *Clinics in Plastic Surgery*, 9, 289-296.
- Bessell, A., Dures, E., Semple, C., & Jackson, S. (2012). Addressing appearance-related distress across clinical conditions. *British Journal of Nursing*, 21(19), 1138-1143. <http://dx.doi.org/10.12968/bjon.2012.21.19.1138>
- Best, J. R., & Miller, P. H. (2010). A developmental perspective on executive function. *Child Development*, 81, 1641-1660.
- Bilboul, M. J., Pope, A. W., & Snyder, H. T. (2006). Adolescents with craniofacial anomalies: psychosocial adjustment as a function of self-concept. *Cleft Palate-Craniofacial Journal*, 43(4), 392-400. <http://dx.doi.org/10.1597/05-084.1>
- Bingley, A. F., Thomas, C., Brown, J., Reeve, J., & Payne, S. (2008). Developing narrative research in supportive and palliative care: the focus on illness narratives. *Palliative Medicine*, 22(5), 653-658. <http://dx.doi.org/10.1177/0269216308089842>
- Bjornsson, A., & Agustsdottir, S. (1987). A psychosocial study of Icelandic individuals with cleft lip or cleft lip and palate. *Cleft Palate Journal*, 24(2), 152-157. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3472689>
- Boes, A. D., Murko, V., Wood, J. L., Langbehn, D. R., Canady, J., Richman, L., & Nopoulos, P. (2007). Social function in boys with cleft lip and palate: relationship to ventral frontal cortex morphology. *Behavioural Brain Research*, 181(2), 224-231. <http://dx.doi.org/10.1016/j.bbr.2007.04.009>
- Boyne, P. J., & Sands, N. R. (1972). Secondary bone grafting of residual alveolar and palatal clefts. *Journal of Oral Surgery*, 30(2), 87-92. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/4550446>
- Brand, S., Blechschmidt, A., Muller, A., Sader, R., Schwenzler-Zimmerer, K., Zeilhofer, H. F., & Holsboer-Trachsler, E. (2009). Psychosocial functioning and sleep patterns in children and adolescents with cleft lip and palate (CLP) compared with healthy controls. *Cleft Palate-Craniofacial Journal*, 46(2), 124-135. <http://dx.doi.org/10.1597/07-165.1>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Broder, H. L. (2001). Using psychological assessment and therapeutic strategies to enhance well-being. *Cleft Palate-Craniofacial Journal*, 38(3), 248-254. [http://dx.doi.org/10.1597/1545-1569\(2001\)038<0248:UPAATS>2.0.CO;2](http://dx.doi.org/10.1597/1545-1569(2001)038<0248:UPAATS>2.0.CO;2)

- Broder, H. L., Smith, F. B., & Strauss, R. P. (1994). Effects of visible and invisible orofacial defects on self-perception and adjustment across developmental eras and gender. *Cleft Palate-Craniofacial Journal*, 31(6), 429-436. [http://dx.doi.org/10.1597/1545-1569\(1994\)031<0429:EOVAIO>2.3.CO;2](http://dx.doi.org/10.1597/1545-1569(1994)031<0429:EOVAIO>2.3.CO;2)
- Broder, H. L., & Strauss, R. P. (1989). Self-concept of early primary school age children with visible or invisible defects. *Cleft Palate Journal*, 26(2), 114-117; discussion 117-118. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/2706780>
- Broder, H. L., Richman, L. C., & Matheson, P. B. (1998). Learning disabilities, school achievement, and grade retention among children with cleft: a two-center study. *Cleft Palate-Craniofacial Journal*, 35(2), 127-131.
- Bruce, I., Harman, N., Williamson, P., Tierney, S., Callery, P., Mohiuddin, S., O'Brien, K. (2015). The management of Otitis Media with Effusion in children with cleft palate (mOMEnt): a feasibility study and economic evaluation. *Health Technology Assessment*, 19(68), 1-374. <http://dx.doi.org/10.3310/hta19680>
- Bull, R., & Rumsey, N. (1988). The social psychology of facial disfigurement. *Journal of Cross-Cultural Psychology*, 17, 99-108.
- Burtaverde, V. (2012). Self-esteem, body esteem and quality of life among obese people in Romania. *Romanian Journal of Experimental Applied Psychology*, 3(4), 245-251.
- Byrne, M., Chan, J. C., & O'Broin, E. (2014). Perceptions and satisfaction of aesthetic outcome following secondary cleft rhinoplasty: evaluation by patients versus health professionals. *Journal of Cranio-Maxillo-Facial Surgery*, 42(7), 1062-1070. <http://dx.doi.org/10.1016/j.jcms.2014.01.031>
- Cadogan, J., & Bennun, I. (2011). Face value: an exploration of the psychological impact of orthognathic surgery. *British Journal of Oral and Maxillofacial Surgery*, 49(5), 376-380.
- Child and Adolescent Health Service. (2015). *Child and Adolescent Health Service – Service Agreement 2015-16*. Retrieved from http://healthywa.wa.gov.au/~/_/media/Files/Corporate/general%20documents/Service%20Agreements/PDF/ServAgree-CAHS-updated.ashx
- Carmichael, S. L., Shaw, G. M., Ma, C., Werler, M. M., Rasmussen, S. A., Lammer, E. J., & National Birth Defects Prevention Study. (2007). Maternal corticosteroid use and orofacial clefts. *American Journal of Obstetrics and Gynecology*, 197(6), 585 e581-587; discussion 683-584, e581-587. <http://dx.doi.org/10.1016/j.ajog.2007.05.046>

- Center for Generational Kinetics. (2015). *Millennial women living at home in record numbers*. Retrieved from <http://genhq.com/millennial-women-living-at-home-in-record-numbers/>.
- Chan, R. K. K., McPherson, B., Whitehil, & L., T. (2006). Chinese Attitudes toward Cleft lip and palate: Effects of Personal Contact. *Cleft Palate-Craniofacial Journal*, 43, 731-739.
- Changing Faces. (2008). *Public Attitudes Survey*. London: C. Faces.
- Chen, X. K., Wen, S. W., Fleming, N., Yang, Q., & Walker, M. C. (2007). Teenage pregnancy and congenital anomalies: which system is vulnerable? *Human Reproduction*, 22(6), 1730-1735. <http://dx.doi.org/10.1093/humrep/dem043>
- Chetpakdeechit, W., Hallberg, U., Hagberg, C., & Mohlin, B. (2009). Social life aspects of young adults with cleft lip and palate: Grounded theory approach. *Acta Odontologica Scandinavica*, 67, 122-128.
- Cheung, L. K., Loh, J. S. P., & Ho, S. M. Y. (2007). Psychological Profile of Chinese with Cleft Lip and Palate Deformities. *Cleft Palate-Craniofacial Journal*, 44(1), 79-86.
- Cheung, L. K., Loh, J. S. P., & Ho, S. M. Y. (2007). Psychological Profile of Chinese with Cleft Lip and Palate Deformities. *Cleft Palate-Craniofacial Journal*, 44(1), 79-86.
- Christensen, K., Juel, K., Herskind, A. M., & Murray, J. C. (2004). Long term follow up study of survival associated with cleft lip and palate at birth. *British Medical Journal*, 328(7453), 1405. <http://dx.doi.org/10.1136/bmj.38106.559120.7C>
- Chuacharoen, R., Ritthagol, W., Hunsrisakhun, J., & Nilmanat, K. (2009). Felt needs of parents who have a 0- to 3-month-old child with a cleft lip and palate. *Cleft Palate-Craniofacial Journal*, 46(3), 252-257. <http://dx.doi.org/10.1597/07-099.1>
- Cleft Lip and Palate Association. (2017). *Cleft Lip and Palate UK*. Retrieved from <https://www.clapa.com/>
- Clark, P. G. (1997). Values in health care professional socialization: implications for geriatric education in interdisciplinary teamwork. *Gerontologist*, 37(4), 441-451. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9279032>
- Clarke, A., & Cooper, C. (2001). Psychosocial rehabilitation after disfiguring injury or disease: investigating the training needs of specialist nurses. *Journal of Advanced Nursing*, 34(1), 18-26. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11430602>
- Cleft Palate Foundation. (2014). *Cleft Craniofacial Awareness and Prevention Month*. Retrieved from <http://www.cleftline.org/who-we-are/what-we-do/cleft-craniofacial-awareness-and-prevention-month/>

- CleftPALS WA. (2016). *Cleft Lip and Palate Society WA*. Retrieved from <http://www.cleftpalswa.org.au/>
- Clifford, E., Walster, E., & Pope, B. A. (1973). The effects of physical attractiveness on teacher expectation. *Sociology of Education*, 46(2), 248-258.
- Clifford, E., Walster, E., & Pope, B. A. (1978). Psychological findings in the adulthood of 98 cleft lip and palate children. *Plastic and Reconstructive Surgery*, 50, 234-237.
- Cohen, M. S. (1999). Families coping with childhood chronic illness: a research review. *Family Systems and Health*, 17, 149-164.
- Collett, B. R., & Speltz, M. L. A. (2007). A developmental approach to mental health for children and adolescents with orofacial clefts. *Orthodontics & Craniofacial Research*, 10(3), 138-148.
- Collett, B. R., Wehby, G. L., Barron, S., Romitti, P. A., Ansley, T. N., & Speltz, M. L. (2014). Academic achievement in children with oral clefts versus unaffected siblings. *Journal of Pediatric Psychology*, 39(7), 743-751. <http://dx.doi.org/10.1093/jpepsy/jsu049>
- Confalonieri, E., Gatti, E., Ionio, C., & Traficante, D. (2008). Body Esteem Scale: A validation on Italian adolescents. *Testing, Psychometrics, Methodology in Applied Psychology*, 15(3), 153-165.
- Crawley, M. J. (2014). *The R Book, Second Edition*: John Wiley & Sons, Ltd.
- Crerand, C. E., Sarwer, D. B., Kazak, A. E., Clarke, A., & Rumsey, N. (2017). Body image and quality of life in adolescents with craniofacial conditions. *Cleft Palate-Craniofacial Journal*, <http://dx.doi.org/10.1597/15-167>
- Cresswell, J. W. (1997). *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks, CA: Sage Publications.
- Dahl, O., Wickman, M., & Wengstrom, Y. (2012). Adapting to life after burn injury--reflections on care. *Journal of Burn Care Research*, 33(5), 595-605. <http://dx.doi.org/10.1097/BCR.0b013e31823d0a11>
- Damiano, P. C., Tyler, M. C., Romitti, P. A., Momany, E. T., Canady, J. W., Karnell, M. P., & Murray, J. C. (2006). Type of oral cleft and mothers' perceptions of care, health status, and outcomes for preadolescent children. *Cleft Palate-Craniofacial Journal*, 43(6), 715-721. <http://dx.doi.org/10.1597/05-206>
- Danino, A., Gradell, J., Malka, G., Moutel, G., Herve, C., & Rosilio, C. (2005). Social adjustment in French adults from who had undergone standardised treatment of

- complete unilateral cleft lip and palate. *Annales de Chirurgie Plastique et Esthétique*, 50(3), 202-205.
- Davalbhakta, A., & Hall, P. N. (2000). The impact of antenatal diagnosis on the effectiveness and timing of counselling for cleft lip and palate. *British Journal of Plastic Surgery*, 53(4), 298-301. <http://dx.doi.org/10.1054/bjps.2000.3330>
- De Sousa, A., Devare, S., & Ghanshani, J. (2009). Psychological issues in cleft lip and cleft palate. *Journal of Indian Association of Pediatric Surgeons*, 14, 55-58.
- Demir, T., Karacetin, G., Baghaki, S., & Aydin, Y. (2011). Psychiatric assessment of children with nonsyndromic cleft lip and palate. *General Hospital Psychiatry*, 33(6), 594-603. <http://dx.doi.org/10.1016/j.genhosppsych.2011.06.006>
- Dion, K., Berscheid, E., & Walster, E. (1972). What is beautiful is good. *Journal of Personality and Social Psychology*, 24(3), 285-290. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/4655540>
- DoSomething.Org. (1993). Volunteer for social change: anti-bullying campaign Retrieved from <https://www.dosomething.org/us/campaigns/i-beat-bullying/pages/faqs-facts>
- Duncan, M. J., Al-Nakeeb, Y., & Nevill, A. M. (2004). Body esteem and body fat in British school children from different ethnic groups. *Body Image*, 1(3), 311-315. <http://dx.doi.org/10.1016/j.bodyim.2004.03.002>
- Duncan, M. J., Al-Nakeeb, Y., & Nevill, A. M. (2013). Establishing the optimal body mass index - body esteem relationship in young adolescents. *BMC Public Health*, 13, 662. <http://dx.doi.org/10.1186/1471-2458-13-662>
- Edwards, T. C., Patrick, D. L., Topolski, T. D., Aspinall, C. L., Mouradian, W. E., & Speltz, M. L. (2005). Approaches to craniofacial-specific quality of life assessment in adolescents. *Cleft Palate-Craniofacial Journal*, 42, 19-24.
- Egan, K., Harcourt, D., & Rumsey, N. (2011). The Appearance Research Collaboration. A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference. *Journal of Health Psychology*, 16, 739-749.
- Eide, M. G., Skjærven, R., Irgens, L. M., Bjerkedal, T., & Oyen, N. (2006). Associations of birth defects with adult intellectual performance, disability and mortality: Population-based cohort study. *Pediatric Research*, 59(6), 848-853.
- Eiserman, W. (2001). Unique outcomes and positive contributions associated with facial difference: expanding research and practice. *Cleft Palate-Craniofacial Journal*, 38, 236-244.

- Endriga, M. C., & Kapp-Simon, K. A. (1999). Psychological issues in craniofacial care: state of the art. *Cleft Palate-Craniofacial Journal*, 36, 3-11.
- Face-Value. (2017). *Face Value*. Retrieved from <http://www.facevalue.cc/News>
- Feragen, K. B., & Borge, A. I. (2010). Peer harassment and satisfaction with appearance in children with and without a facial difference. *Body Image*, 7(2), 97-105.
<http://dx.doi.org/10.1016/j.bodyim.2009.12.001>
- Feragen, K. B., & Stock, N. M. (2014). When there is more than a cleft: psychological adjustment when a cleft is associated with an additional condition. *Cleft Palate-Craniofacial Journal*, 51(1), 5-14. <http://dx.doi.org/10.1597/12-328>
- Feragen, K. B., & Stock, N. M. (2016). A longitudinal study of 340 young people with or without a visible difference: The impact of teasing on self-perceptions of appearance and depressive symptoms. *Body Image*, 16, 133-142.
<http://dx.doi.org/10.1016/j.bodyim.2016.01.003>
- Feragen, K. B., Kvaalem, I. L., Rumsey, N., & Borge, A. I. (2010). Adolescents with and without a facial difference: The role of friendships and social acceptance in perceptions of appearance and emotional resilience. *Body Image*, 7(4), 271-279.
<http://dx.doi.org/10.1016/j.bodyim.2010.05.002>
- Feragen, K. B., Stock, N. M., & Kvaalem, I. L. (2015). Risk and Protective Factors at Age 16: Psychological Adjustment in Children with a Cleft Lip and/or Palate. *Cleft Palate-Craniofacial Journal*, 52(5), 555-573. <http://dx.doi.org/10.1597/14-063>
- Fisher, S., & Cleveland, S. E. (1968). *Body image and personality*. New York: Dover.
- Folkman, S. (2008). The case for positive emotions in the stress process. *Anxiety Stress and Coping*, 21, 3-14.
- Foo, P., Sampson, W., Roberts, R., Jamieson, L., & David, D. (2012). General health-related quality of life and oral health impact among Australians with cleft compared with population norms; age and gender differences. *Cleft Palate-Craniofacial Journal*, 49(4), 406-413. <http://dx.doi.org/10.1597/10-126>
- Frederickson, M. S., Chapman, K. L., & Hardin-Jones, M. (2006). Conversational skills of children with cleft lip and palate: a replication and extension. *Cleft Palate-Craniofacial Journal*, 43(2), 179-188. <http://dx.doi.org/10.1597/04-086.1>
- Friede, H., & Katsaros, C. (1998). Current knowledge in cleft lip and palate treatment from an orthodontist's point of view. *Journal of Orofacial Orthopedics*, 59(6), 313-330.
Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9857601>

- Frisen, A., Lunde, C., & Berg, A. I. (2015). Developmental patterns in body-esteem from late childhood to young adulthood: A growth curve analysis. *European Journal of Developmental Psychology*, 12(1), 99-115.
- George, D., & Mallery, P. (2003). *SPSS for Windows step by step guide: A simple guide and reference*. 11.0 update (4th Edition). Boston: Allyn and Bacon.
- Georgiade, N. G., & Latham RA Maxillar. (1975). Arch alignment in the bilateral cleft lip and palate infant, using pinned coaxial screw appliance. *Plastic and Reconstructive Surgery*, 56(1), 52-60.
- Gilligan, R. (2000). Adversity, resilience and young people: the protective value of positive school and spare time experiences. *Children and Society*, 14(1), 37-47.
- Gkantidis, N., Papamanou, D. A., Karamolegkou, M., & Dorotheou, D. (2015). Esthetic, Functional, and Everyday Life Assessment of Individuals with Cleft Lip and/or Palate. *Biomedical Research International*, 2015, 510395.
<http://dx.doi.org/10.1155/2015/510395>
- GlobalForce. (2016). *Global taskforce in holistic outcomes in cleft*. Retrieved from <https://www.cleft2017.org/task-forces-update-jan-2016>
- Grant, H. R., Quiney, R. E., Mercer, D. M., & Lodge, S. (1988). Cleft palate and glue ear. *Archives of Disease in Childhood*, 63(2), 176-179. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3348665>
- Grieve, R., & Helmick, A. (2008). The Influence of Men's Self-Objectification on the Drive for Muscularity: Self-Esteem, Body Satisfaction and Muscle Dysmorphia. *International Journal of Men's Health*, 7(3), 288-298.
- Griffiths, C., Williamson, H., & Rumsey, N. (2012). The romantic experiences of adolescents with a visible difference: exploring concerns, protective factors and support needs. *Journal of Health Psychology*, 17(7), 1053-1064.
<http://dx.doi.org/10.1177/1359105311433909>
- Grose, J., Freeman, J., & Skirton, H. (2012). Value of a confidant relationship in psychosocial care of people with multiple sclerosis. *International Journal of Multiple Sclerosis Care*, 14(3), 115-122. <http://dx.doi.org/10.7224/1537-2073-14.3.115>
- Grunwell, P. (2001). *Management of Cleft lip and palate*. London: Whurr Publishing.
- Gussy, M., & Kilpatrick, N. (2006). The self-concept of adolescents with cleft lip and palate: a pilot study using a multidimensional/hierarchical measurement instrument.

- International Journal of Paediatric Dentistry*, 16(5), 335-341.
<http://dx.doi.org/10.1111/j.1365-263X.2006.00754.x>
- Hall, M. J., Gibson, B. J., James, A., & Rodd, H. D. (2013). Children's and adolescent's perspectives on cleft lip and/or palate. *Cleft Palate-Craniofacial Journal*, 50(2), e18-26.
<http://dx.doi.org/10.1597/10-193>
- Hamlet, C., & Harcourt, D. (2015). Older Adults' Experiences of Living with Cleft lip and palate: A qualitative study exploring aging and appearance. *Cleft Palate-Craniofacial Journal*, 52(2), 32-40.
- Harrison, K. (2000). The body electric: Thin-ideal media and eating disorders in adolescents. *Journal of Communication*, 50, 119-143.
- Havstam, C., Laakso, K., Lohmander, A., & Ringsberg, K. C. (2011). Taking charge of communication: adults' descriptions of growing up with a cleft-related speech impairment. *Cleft Palate-Craniofacial Journal*, 48(6), 717-726.
<http://dx.doi.org/10.1597/10-033>
- Hearst, D. (2007). Can't they like me as I am? Psychological interventions for children and young people with congenital visible disfigurement. *Developmental Neurorehabilitation*, 10(2), 105-112. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17687983>
- Hearst, D., Shearer, J., & Ranger, M. (2005). *Monitoring satisfaction with appearance an important contribution to intervention and outcome?* Paper presented at the 10th International congress of cleft palate and related craniofacial anomalies, Durban, South Africa.
- Heller, A., Tidmarsh, W., & Pless, I. B. (1981). The psychosocial functioning of young adults born with cleft lip or palate. A follow-up study. *Clinical Pediatrics*, 20(7), 459-465. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/7237883>
- Hens, G., Picavet, V. A., Poorten, V. V., Schoenaers, J., Jorissen, M., & Hellings, P. W. (2011). High patient satisfaction after secondary rhinoplasty in cleft lip patients. *International Forum Allergy Rhinology*, 1(3), 167-172.
<http://dx.doi.org/10.1002/alr.20023>
- Hester, T. R., Jr., Jurkiewicz, M. J., Meyer, R., Cunningham, S., & Eros, T. (1985). Total reconstruction of the "end-stage" cleft lip and palate deformity. *Plastic and Reconstructive Surgery*, 76(4), 539-553. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/4034773>

- Holdsworth, W. G. (1954). Early treatment of cleft-lip and cleft-palate. *British Medical Journal*, 1(4857), 304-308. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/13115704>
- Hoskins, R. (2012). The dangers of self-report. www.sciencebrainwaves.com. Accessed 20/1/2018.
- Howitt, D., & Cramer, D. (2011). *Introduction to Research Methods in Psychology*. (4th. ed.). Essex, England: Pearson Education Limited.
- Huang, J. S., Norman, G. J., Zabinski, M. F., Calfas, K., & Patrick, K. (2007). Body image and self-esteem among adolescents undergoing an intervention targeting dietary and physical activity behaviors. *Journal of Adolescent Health*, 40(3), 245-251. <http://dx.doi.org/10.1016/j.jadohealth.2006.09.026>
- Hunt, O., Burden, D., Hepper, P., & Johnston, C. (2005). The psychosocial effects of cleft lip and palate: a systematic review. *European Journal of Orthodontics*, 27(3), 274-285. <http://dx.doi.org/10.1093/ejo/cji004>
- Hunt, O., Burden, D., Hepper, P., Stevenson, M., & Johnston, C. (2006). Self-reports of psychosocial functioning among children and young adults with cleft lip and palate. *Cleft Palate-Craniofacial Journal*, 43(5), 598-605. <http://dx.doi.org/10.1597/05-080>
- Hunt, O., Burden, D., Hepper, P., Stevenson, M., & Johnston, C. (2007). Parent reports of the psychosocial functioning of children with cleft lip and/or palate. *Cleft Palate-Craniofacial Journal*, 44(3), 304-311. <http://dx.doi.org/10.1597/05-205>
- Husain, W., & Aziz, N. (2014). The levels of body esteem among veiled and unveiled women. *FWU Journal of Social Sciences*, 8(1), 46-49.
- Hutchinson, K., Wellman, M. A., Noe, D. A., & Kahn, A. (2011). The psychosocial effects of cleft lip and palate in non-Anglo populations: a cross-cultural meta-analysis. *Cleft Palate-Craniofacial Journal*, 48(5), 497-508. <http://dx.doi.org/10.1597/09-046>
- Howitt D, Cramer D. (2011). *Introduction to Research Methods in Psychology*. 4th. ed. Essex, England: Pearson Education Limited.
- Jiang, R., Bush, J. O., & Lidral, A. C. (2006). Development of the upper lip: morphogenetic and molecular mechanisms. *Developmental Dynamics*, 235(5), 1152-1166. <http://dx.doi.org/10.1002/dvdy.20646>
- Kapp-Simon, K. A. (1995). Psychological interventions for the adolescent with cleft lip and palate. *Cleft Palate Journal*, 32(2), 104-108.

- Kapp-Simon, K. A. (2004). Psychological issues in cleft lip and palate. *Clinics in Plastic Surgery*, 31(2), 347-352. [http://dx.doi.org/10.1016/S0094-1298\(03\)00134-2](http://dx.doi.org/10.1016/S0094-1298(03)00134-2)
- Kapp-Simon, K. A., Simon, D. J., & Kristovich, S. (1992). Self-perception, social skills, adjustment, and inhibition in young adolescents with craniofacial anomalies. *Cleft Palate-Craniofacial Journal*, 29(4), 352-356.
- Kapp-Simon, K. A., Simon, D. J., & Kristovich, S. (1992). Self-perception, social skills, adjustment, and inhibition in young adolescents with craniofacial anomalies. *Cleft Palate-Craniofacial Journal*, 29(4), 352-356. [http://dx.doi.org/10.1597/1545-1569\(1992\)029<0352:SPSSAA>2.3.CO;2](http://dx.doi.org/10.1597/1545-1569(1992)029<0352:SPSSAA>2.3.CO;2)
- Kasten, E. F., Schmidt, S. P., Zickler, C. F., Berner, E., Damian, L. A., Christian, G. M., Hicks, T. L. (2008). Team care of the patient with cleft lip and palate. *Current Problems in Pediatric and Adolescent Health Care*, 38(5), 138-158. <http://dx.doi.org/10.1016/j.cppeds.2008.02.003>
- Kayle, S. (1996). *InterViews: An Introduction to Qualitative Research Interviewing*. London: Sage.
- Knight, J., Cassell, C., Meyer, R., & Strauss, R. (2015). Academic Outcomes of Children With Isolated Orofacial Clefts Compared With Children Without a Major Birth Defect. *Cleft Palate-Craniofacial Journal*, 52(3), 259-268.
- Konradsen, H., Kirkevold, M., & Zoffmann, V. (2009). Surgical facial cancer treatment: the silencing of disfigurement in nurse-patient interactions. *Journal of Advanced Nursing*, 65(11), 2409-2418. <http://dx.doi.org/10.1111/j.1365-2648.2009.05102.x>
- Kornhaber, R., Wilson, A., Abu-Qamar, M. Z., & McLean, L. (2014). Adult burn survivors' personal experiences of rehabilitation: an integrative review. *Burns*, 40(1), 17-29. <http://dx.doi.org/10.1016/j.burns.2013.08.003>
- Kosowski, T. R., Weathers, W. M., Wolfswinkel, E. M., & Ridgway, E. B. (2012). Cleft palate. *Seminars in Plastic Surgery*, 26(4), 164-169. <http://dx.doi.org/10.1055/s-0033-1333883>
- Kramer, F. J., Gruber, R., Fialka, F., Sinikovic, B., & Schliephake, H. (2008). Quality of life and family functioning in children with nonsyndromic orofacial clefts at preschool ages. *Journal of Craniofacial Surgery*, 19(3), 580-587. <http://dx.doi.org/10.1097/SCS.0b013e31816aaa43>
- Kramer, F. J., Gruber, R., Fialka, F., Sinikovic, B., Hahn, W., & Schliephake, H. (2009). Quality of life in school-age children with orofacial clefts and their families. *Journal of*

Craniofacial Surgery, 20(6), 2061-2066.

<http://dx.doi.org/10.1097/SCS.0b013e3181be8892>

- Kummer, A. W., Clark, S. L., Redle, E. E., Thomsen, L. L., & Billmire, D. A. (2012). Current practice in assessing and reporting speech outcomes of cleft palate and velopharyngeal surgery: a survey of cleft palate/craniofacial professionals. *Cleft Palate-Craniofacial Journal*, 49(2), 146-152. <http://dx.doi.org/10.1597/10-285>
- Lansdown, R., Lloyd, J., & Hunter, J. (1991). Facial deformity in childhood: severity and psychological adjustment. *Child: Care, Health and Development*, 17(3), 165-171. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/2070504>
- Lee, A., Gibbon, F. E., & Spivey, K. (2017). Children's Attitudes Toward Peers With Unintelligible Speech Associated With Cleft Lip and/or Palate. *Cleft Palate-Craniofacial Journal*, 54(3), 262-268. <http://dx.doi.org/10.1597/15-088>
- Liddle, M. J., Baker, S. R., Smith, K. G., & Thompson, A. R. (2015). Psychosocial Outcomes in Orthognathic Surgery: A Review of the Literature. *Cleft Palate-Craniofacial Journal*, 52(4), 458-470. <http://dx.doi.org/10.1597/14-021>
- Lidral, A. C., & Murray, J. C. (2004). Genetic approaches to identify disease genes for birth defects with cleft lip/palate as a model. Birth Defects Research. Part A: *Clinical and Molecular Teratology*, 70(12), 893-901. <http://dx.doi.org/10.1002/bdra.20096>
- Lilja, J., Mars, M., Elander, A., Enocson, L., Hagberg, C., Worrell, E., Friede, H. (2006). Analysis of dental arch relationships in Swedish unilateral cleft lip and palate subjects: 20-year longitudinal consecutive series treated with delayed hard palate closure. *Cleft Palate-Craniofacial Journal*, 43(5), 606-611. <http://dx.doi.org/10.1597/05-069>
- Lioffi, C. (2003). *Clinical health psychology: a textbook*. London: Sage Publications.
- Lo, L. J. (2006). Primary correction of the unilateral cleft lip nasal deformity: achieving the excellence. *Chang Gung Medical Journal*, 29(3), 262-267. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16924887>
- Locker, D., Jokovic, A., Stephens, M., Kenny, D., Tompson, B., & Guyatt, G. (2005). Family impact of child oral and oro-facial conditions. *Community Dentistry and Oral Epidemiology*, 30, 438-448.
- Lorot-Marchand, A., Guerreschi, P., Pellerin, P., Martinot, V., Gbaguidi, C. C., Neiva, C., Francois-Fiquet, C. (2015). Frequency and socio-psychological impact of taunting in school-age patients with cleft lip-palate surgical repair. *International Journal of*

- Pediatric Otorhinolaryngology*, 79(7), 1041-1048.
<http://dx.doi.org/10.1016/j.ijporl.2015.04.024>
- Lovegrove, E., & Rumsey, N. (2005). Ignoring it doesn't make it stop: adolescents, appearance, and bullying. *Cleft Palate-Craniofacial Journal*, 42(1), 33-44.
<http://dx.doi.org/10.1597/03-097.5.1>
- Lowenstein, J., Sutton, E., Guidotti, R., Shapiro, K., McLean, D., & Biesecker, D. (2008). The art of coping with a craniofacial difference: helping others through "positive experience". *American Journal of Medical Genetics*, 146(12), 1547-1557.
- Lozano, R. (2012). Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet*, 380(9859), 2095-2128.
- Macias, M. M., Saylor, C. F., Haire, K. B., & Bell, N. L. (2007). Predictors of paternal versus maternal stress in families of children with neural tube defects. *Children's Health Care*, 36, 99-115.
- Mangold, E., Ludwig, K. U., Birnbaum, S., Baluardo, C., Ferrian, M., Herms, S., Nothen, M. M. (2010). Genome-wide association study identifies two susceptibility loci for nonsyndromic cleft lip with or without cleft palate. *Nature Genetics*, 42(1), 24-26.
<http://dx.doi.org/10.1038/ng.506>
- Mani, M., Carlsson, M., & Marcusson, A. (2010). Quality of life varies with gender and age among adults treated for unilateral cleft lip and palate. *Cleft Palate-Craniofacial Journal*, 47, 491-498.
- Marcusson, A. (2001). Adult patients with treated complete cleft lip and palate. Methodological and clinical studies. *Swedish Dental Journal. Supplement*,(145), 1-57. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11400538>
- Marcusson, A., Akerlind, I., & Paulin, G. (2001). Quality of life in adults with repaired complete cleft lip and palate. *Cleft Palate-Craniofacial Journal*, 38(4), 379-385.
- Marcusson, A., Paulin, G., & Ostrup, L. (2002). Facial appearance in adults who had cleft lip and palate treated in childhood. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 32(1), 16-23.
- Martin, V. (1995). Helping parents cope. *Nursing Times*, 91(31), 38-40. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/7638074>

- Masarei, A. G., Sell, D., & Wade, A. (2003). *An investigation of pre-surgical orthopedic treatment on feeding and speech outcomes in cleft lip and palate*. (Dissertation). University College London, London.
- McComb, H. (1975). Treatment of the unilateral cleft lip nose. *Plastic and Reconstructive Surgery*, 55(5), 596-601. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/1144536>
- McComb, H. (1985). Primary correction of unilateral cleft lip nasal deformity: a 10-year review. *Plastic and Reconstructive Surgery*, 75(6), 791-799. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/4001197>
- McComb, H., & Coghlan, B. A. (1996). Primary repair of the unilateral cleft lip nose: completion of a longitudinal study. *Cleft Palate-Craniofacial Journal*, 33(1), 23-30; discussion 30-21. [http://dx.doi.org/10.1597/1545-1569\(1996\)033<0023:PROTUC>2.3.CO;2](http://dx.doi.org/10.1597/1545-1569(1996)033<0023:PROTUC>2.3.CO;2)
- McKinney, B., & Peterson, R. A. (1987). Predictors of stress in parents of developmentally disabled children. *Journal of Pediatric Psychology*, 12, 133-149.
- McWilliams, B. J., & Paradise, L. P. (1973). Educational, occupational, and marital status of cleft palate adults. *Cleft Palate Journal*, 10, 223-229.
- Mendelson, B. K., & White, D. R. (1993). Manual for the body-esteem scale for children. *Concordia University Research Bulletin*, 12, 1-10.
- Mendelson, B. K., & White, D. R. (1993). Manual for the body-esteem scale for children. *Concordia University Research Bulletin*, 12(2), 1-10.
- Mendelson, B. K., Mendelson, M. J., & White, D. R. (2001). Body-esteem scale for adolescents and adults. *Journal of Personality Assessment*, 76(1), 90-106. http://dx.doi.org/10.1207/S15327752JPA7601_6
- Mendelson, B. K., White, D. R., & Mendelson, M. J. (1996). Self-esteem and body esteem: effects of gender, age, and weight. *Journal of Applied Developmental Psychology*, 17, 321-246.
- Mendelson, B. K., White, D. R., & Mendelson, M. J. (1996). Self-esteem and body esteem: effects of gender, age, and weight. *Journal of Applied Developmental Psychology*, 17, 321-346.
- Mendelson, B. K., White, D. R., & Mendelson, M. J. (1997). Manual for the body-esteem scale for adolescents and adults. *Concordia University Research Bulletin*, 16, 1-12.
- Mendelson, B. K., White, D. R., & Mendelson, M. J. (1997). Manual for the body-esteem scale for adolescents and adults. *Concordia University Research Bulletin*, 16(2), 1-12.

- Meyer-Marcotty, P., Gerdes, A. B., Reuther, T., Stellzig-Eisenhauer, A., & Alpers, G. W. (2010). Persons with cleft lip and palate are looked at differently. *Journal of Dental Research*, 89(4), 400-404. <http://dx.doi.org/10.1177/0022034509359488>
- Mental Health Council of Australia. (2007). Fact Sheet – Statistics on mental health. Retrieved from https://mhaustralia.org/sites/default/files/imported/component/rsfiles/factsheets/statistics_on_mental_health.pdf.
- Millar, K., Bell, A., Bowman, A., Brown, D., Lo, T. W., Siebert, P., Ayoub, A. (2013). Psychological status as a function of residual scarring and facial asymmetry after surgical repair of cleft lip and palate. *Cleft Palate-Craniofacial Journal*, 50(2), 150-157. <http://dx.doi.org/10.1597/10-222>
- Millard, T., & Richman, L. C. (2001). Different cleft conditions, facial appearance and speech: relationship to psychological variables. *Cleft Palate-Craniofacial Journal*, 35, 68-75.
- Mirrorproject. (2014). *Mirror Mirror*. Retrieved from www.mirrorproject.eu
- Mizuno, K., Ueda, A., Kani, K., & Kawamura, H. (2002). Feeding behaviour of infants with cleft lip and palate. *Acta Paediatrica*, 91(11), 1227-1232. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12463323>
- Moi, A. L., & Gjengedal, E. (2008). Life after burn injury: striving for regained freedom. *Qualitative Health Research*, 18(12), 1621-1630. <http://dx.doi.org/10.1177/1049732308326652>
- Moore, I. J., Moore, G. F., & Yonkers, A. J. (1986). Otitis media in the cleft palate patient. *Ear, Nose, and Throat Journal*, 65(7), 291-295. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3743473>
- Moore, K., & Persaud, T. (2008). *The developing human: clinically oriented embryology* (8th ed.). Philadelphia: Saunders Elsevier.
- Mossey, P. A., Davies, J. A., & Little, J. (2007). Prevention of orofacial clefts: does pregnancy planning have a role? *Cleft Palate-Craniofacial Journal*, 44(3), 244-250. <http://dx.doi.org/10.1597/06-002>
- Mossey, P. A., Little, J., Munger, R. G., Dixon, M. J., & Shaw, W. C. (2009). Cleft lip and palate. *Lancet*, 374(9703), 1773-1785. [http://dx.doi.org/10.1016/S0140-6736\(09\)60695-4](http://dx.doi.org/10.1016/S0140-6736(09)60695-4)

- Munz, S. M., Edwards, S. P., & Inglehart, M. R. (2011). Oral health-related quality of life, and satisfaction with treatment and treatment outcomes of adolescents/young adults with cleft lip/palate: an exploration. *International Journal of Oral and Maxillofacial Surgery*, 40(8), 790-796. <http://dx.doi.org/10.1016/j.ijom.2011.03.002>
- Murray, L., Arteché, A., Bingley, C., Hentges, F., & Bishop, D. V. (2010). The effect of cleft lip on socio-emotional functioning in school-aged children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 51(1), 94-103. <http://dx.doi.org/10.1111/j.1469-7610.2009.02186.x>
- Nelson, P. A. (2009). Qualitative approaches in craniofacial research. *Cleft Palate-Craniofacial Journal*, 46(3), 245-251. <http://dx.doi.org/10.1597/08-121.1>
- Nelson, P. A., Kirk, S. A., Caress, A. L., & Glenny, A. M. (2012). Parents' emotional and social experiences of caring for a child through cleft treatment. *Qualitative Health Research*, 22(3), 346-359. <http://dx.doi.org/10.1177/1049732311421178>
- Nicholls, W. (2016). Dental anomalies in children with cleft lip and palate in Western Australia. *European Journal of Dentistry*, 10(2), 254-258. <http://dx.doi.org/10.4103/1305-7456.178317>
- Nicholls, W., Harper, C., Hartig, G., Robinson, S., Selvey, L., & Persson, M. (2016). Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups. *Cleft Palate-Craniofacial Journal*,
- Nicholls, W., Harper, C., Robinson, S., Persson, M., & Selvey, L. (2016). Adult specific life outcomes of cleft lip and palate in a Western Australian cohort. *Cleft Palate-Craniofacial Journal*,
- Nicholls, W., Jennings, R., Yeung, Y., Walters, M., & Hewitt, B. (2017). Antenatal Ultrasound Detection of Cleft in Western Australia from 2003 to 2012: A Follow-Up Study. *Cleft Palate-Craniofacial Journal*, 54(3), 321-326. <http://dx.doi.org/10.1597/15-127>
- Nicholls, W., Selvey, L., Harper, C., Persson, M., & Robinson, S. (2016). The psychosocial impact of cleft in a Western Australian cohort across three age-groups. *Cleft Palate-Craniofacial Journal*,
- Nicholls, W., Singer, S. L., Southall, P. J., & Winters, J. C. (2014). The Assessment of Digital Study Models Using the GOSLON Yardstick Index. *Cleft Palate-Craniofacial Journal*, 51(3), 264-269. <http://dx.doi.org/10.1597/12-163>

- Nilsson, S., Merlo, J., Lyberg-Ahlander, V., & Psouni, E. (2015). Psychotropic drug use in adolescents born with an orofacial cleft: a population-based study. *British Medical Journal Open*, 5(4), e005306. <http://dx.doi.org/10.1136/bmjopen-2014-005306>
- Noar, J. H. (1991). Questionnaire survey of attitudes and concerns of patients with cleft lip and palate and their parents. *Cleft Palate-Craniofacial Journal*, 28(3), 279-284. [http://dx.doi.org/10.1597/1545-1569\(1991\)028<0279:QSOAAC>2.3.CO;2](http://dx.doi.org/10.1597/1545-1569(1991)028<0279:QSOAAC>2.3.CO;2)
- Noor, S. N., & Musa, S. (2007). Assessment of patients' level of satisfaction with cleft treatment using the Cleft Evaluation Profile. *Cleft Palate-Craniofacial Journal*, 44(3), 292-303. <http://dx.doi.org/10.1597/05-151>
- Norman, A., Persson, M., Stock, N., Rumsey, N., Sandy, J., Waylen, A., Ness, A. (2015). The Effectiveness of Psychosocial Intervention for Individuals with Cleft Lip and/or Palate. *Cleft Palate-Craniofacial Journal*, 52(3), 301-310. <http://dx.doi.org/10.1597/13-276>
- Nurmi, J. E. (2004). *Socialization and self-development. Channeling, selection, adjustment, and reflection.* (Lerner RM, Steinberg L. ed.). Hoboken, NJ: Wiley & Sons.
- Nyberg, D. A., Sickler, G. K., Hegge, F. N., Kramer, D. J., & Kropp, R. J. (1995). Fetal cleft lip with and without cleft palate: US classification and correlation with outcome. *Radiology*, 195(3), 677-684. <http://dx.doi.org/10.1148/radiology.195.3.7753993>
- O'Dea, J. A. (2006). Self-concept, self-esteem and body weight in adolescent females: a three-year longitudinal study. *Journal of Health Psychology*, 11, 599-611.
- Ogden, J. (2015). *Are we normalising obesity?* Retrieved from <http://www.independent.co.uk/life-style/health-and-families/features/are-we-normalising-obesity-10313776.html>
- O'Hanlon, K., Camic, P. M., & Shearer, J. (2012). Factors associated with parental adaptation to having a child with a cleft lip and/or palate: the impact of parental diagnosis. *Cleft Palate-Craniofacial Journal*, 49(6), 718-729. <http://dx.doi.org/10.1597/10-018>
- Oliveira, M., & Oliveira, L. (2015). *Management of patients with facial disfigurement.* Retrieved from <https://pocketdentistry.com/22-management-of-patients-with-facial-disfigurement/>
- Online Mendelian Inheritance in Man. (2009). *Online Mendelian Inheritance in Man.* Retrieved from <http://www.ncbi.nlm.nih.gov/sites/entrez?db=omim>

- Oosterkamp, B. C., Dijkstra, P. U., Rimmelink, H. J., van Oort, R. P., Goorhuis-Brouwer, S. M., Sandham, A., & de Bont, L. G. (2007). Satisfaction with treatment outcome in bilateral cleft lip and palate patients. *International Journal of Oral and Maxillofacial Surgery*, 36(10), 890-895. <http://dx.doi.org/10.1016/j.ijom.2007.07.008>
- Parrotta, A., & Corrias, G. (2010). *Orofacial Clefts - oral pathology*. Retrieved from <http://flipper.diff.org/app/items/2927>
- Patel, Z., & Ross, E. (2003). Reflections on the cleft experience by South African adults: use of qualitative methodology. *Cleft Palate-Craniofacial Journal*, 40, 471-480.
- Patrick, D. L., Topolski, T. D., Edwards, T. C., Aspinall, C. L., Kapp-Simon, K. A., Rumsey, N. J., . . . Thomas, C. R. (2007). Measuring the quality of life of youth with facial differences. *Cleft Palate-Craniofacial Journal*, 44, 538-547.
- Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family Counseling*, 64(2), 349-360.
- Paxton, S. J., Neumark-Sztainer, D., Hannan, P. J., & Eisenberg, M. E. (2006). Body dissatisfaction prospectively predicts depressive mood and low self-esteem in adolescent girls and boys. *Journal of Clinical Child and Adolescent Psychology*, 35(4), 539-549. http://dx.doi.org/10.1207/s15374424jccp3504_5
- Pedersen, D. A., Wehby, G. L., Murray, J. C., & Christensen, K. (2016). Psychiatric Diagnoses in Individuals with Non-Syndromic Oral Clefts: A Danish Population-Based Cohort Study. *PloS One*, 11(5), e0156261. <http://dx.doi.org/10.1371/journal.pone.0156261>
- Persson, M., Becker, M., & Svensson, H. (2007). Physical characteristics of young men with cleft lip, with or without cleft palate, and cleft palate only. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 41(1), 6-9. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17484178>
- Persson, M., Becker, M., & Svensson, H. (2008). General intellectual capacity of young men with cleft lip with or without cleft palate and cleft palate alone. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 42(1), 14-16. <http://dx.doi.org/10.1080/02844310701694472>
- Persson, M., Becker, M., & Svensson, H. (2012). Academic Achievement in Individuals with Cleft: A Population-Based Register Study. *Cleft Palate-Craniofacial Journal*, 49(2), 153-159.

- Persson, M., Rumsey, N., Spalding, H., & Partridge, J. (2008). *Bridging the gap between current care provision & the psychological standards of burn care: Staff perceptions of current psycho-social care provision and the way forward*. British Burns Association: Retrieved from http://www.britishburnassociation.org/downloads/psychosocial_sig/NBCG_Final_Report_300908.pdf
- Pertschuk, M. J., & Whitaker, L. A. (1982). Social and psychological effects of craniofacial deformity and surgical reconstruction. *Clinics in Plastic Surgery*, 9(3), 297-306.
- Peter, J. P., & Chinsky, R. R. (1974). Sociological aspects of cleft palate adults. I. Marriage. *Cleft Palate Journal*, 11, 295-309.
- Peter, J. P., Chinsky, R. R., & Fisher, M. J. (1975). Sociological aspects of cleft palate adults. III. Vocational and economic aspects. *Cleft Palate Journal*, 12, 193-199.
- Phillips, J. H., Nish, I., & Daskalogiannakis, J. (2012). Orthognathic surgery in cleft patients. *Plastic and Reconstructive Surgery*, 129(3), 535e-548e. <http://dx.doi.org/10.1097/PRS.0b013e31824128e6>
- Pillemer, F. G., & Cook, K. V. (1989). The psychosocial adjustment of paediatric craniofacial patients after surgery. *Cleft Palate-Craniofacial Journal*, 26, 201-207.
- Pinquart, M., & Shen, Y. (2010). Depressive symptoms in children and adolescents with chronic physical illness: an updated meta-analysis. *Journal of Pediatric Psychology*, 36(4), 375-384. <http://dx.doi.org/10.1093/jpepsy/jsq104>
- Pisula, E., Lukowska, E., & Fudalej, P. S. (2014). Self-esteem, coping styles, and quality of life in polish adolescents and young adults with unilateral cleft lip and palate. *Cleft Palate-Craniofacial Journal*, 51(3), 290-299. <http://dx.doi.org/10.1597/13-002>
- Pope, A. W., & Snyder, H. T. (2005). Psychosocial adjustment in children and adolescents with a craniofacial anomaly: age and sex patterns. *Cleft Palate-Craniofacial Journal*, 42(4), 349-354. <http://dx.doi.org/10.1597/04-043R.1>
- Pope, A. W., & Ward, J. (1997). Factors associated with peer social competence in preadolescents with craniofacial anomalies. *Journal of Pediatric Psychology*, 22(4), 455-469.
- Pope, A. W., Klein, T. P., & Bergman, A. J. (2016). A Qualitative Study of Children's Perspectives on Their Peer Relationships in the Context of Living with a Craniofacial Anomaly. *Cleft Palate-Craniofacial Journal*, 53(5), 527-538. <http://dx.doi.org/10.1597/15-060>

- Pope, A. W., Tillman, K., & Snyder, H. T. (2005). Parenting stress in infancy and psychosocial adjustment in toddlerhood: a longitudinal study of children with craniofacial anomalies. *Cleft Palate-Craniofacial Journal*, 42(5), 556-559. <http://dx.doi.org/10.1597/04-066R.1>
- Porterfield, H. W. (1988). Feeding infants with cleft lip, cleft palate, or both. *Cleft Palate Journal*, 25(1), 80. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3422606>
- Price, M., Hides, L., Cockshaw, W., Staneva, A. A., & Stoyanov, S. R. (2016). Young Love: Romantic Concerns and Associated Mental Health Issues among Adolescent Help-Seekers. *Behavioural Science (Basel)*, 6(2) <http://dx.doi.org/10.3390/bs6020009>
- R Development Core Team. (2015). *R: A language and environment for statistical computing* (Version 3.2.3). Vienna, Austria: R Foundation for Statistical Computing. Retrieved from <https://www.R-project.org>.
- Ramstad, T., Ottem, E., & Shaw, W. C. (1995). Psychosocial adjustment in Norwegian adults who had undergone standardised treatment of complete cleft lip and palate. I. Education, employment and marriage. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 29(3), 251-257. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/8539569>
- Ramstad, T., Ottem, E., & Shaw, W. C. (1995). Psychosocial adjustment in Norwegian adults who had undergone standardised treatment of complete cleft lip and palate. II. Self-reported problems and concerns with appearance. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 29(4), 329-336. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/8771260>
- Ramstad, T., Ottem, E., & Shaw, W. C. (1995a). Psychosocial adjustment in Norwegian adults who had undergone standardised treatment of complete cleft lip and palate. I. Education, employment and marriage. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 29(3), 251-257. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/8539569>
- Ramstad, T., Ottem, E., & Shaw, W. C. (1995b). Psychosocial adjustment in Norwegian adults who had undergone standardised treatment of complete cleft lip and palate. II. Self-reported problems and concerns with appearance. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 29(4), 329-336. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/8771260>
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists. (2016). *Prenatal assessment of fetal structural conditions*. Retrieved from

[https://www.ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical-Obstetrics/Prenatal-assessment-of-fetal-structural-conditions-\(C-Obs-60\)-Amended-May-2016_1.pdf?ext=.pdf](https://www.ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical-Obstetrics/Prenatal-assessment-of-fetal-structural-conditions-(C-Obs-60)-Amended-May-2016_1.pdf?ext=.pdf)

Reichman, N. E., Corman, H., & Noonan, K. (2008). Impact of child disability on the family. *Maternal and Child Health Journal*, 12, 679-683.

Reid, J., Reilly, S., & Kilpatrick, N. (2007). Sucking performance of babies with cleft conditions. *Cleft Palate-Craniofacial Journal*, 44(3), 312-320.
<http://dx.doi.org/10.1597/05-173>

Ribeiro, L. L., DasNeves, L. T., Costa, B., & Gomide, M. R. (2003). Dental anomalies of the permanent lateral incisors and prevalence of hypodontia outside the cleft area in complete unilateral cleft lip and palate. *Cleft Palate-Craniofacial Journal*, 40, 172-175.

Richman, L. C. (1983). Self-reported social, speech, and facial concerns and personality adjustment of adolescents with cleft lip and palate. *Cleft Palate Journal*, 20(2), 108-112. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/6573978>

Richman, L. C., & Eliason, M. (1982). Psychological characteristics of children with cleft lip and palate: Intellectual, achievement, behavioral, and personality variables. *Cleft Palate Journal*, 19, 249-257.

Richman, L. C., & Millard, T. (1997). Brief report: cleft lip and palate: longitudinal behavior and relationships of cleft conditions to behavior and achievement. *Journal of Pediatric Psychology*, 22(4), 487-494. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9302846>

Richman, L. C., McCoy, T. E., Conrad, A. L., & Nopoulos, P. C. (2012). Neuropsychological, behavioral, and academic sequelae of cleft: early developmental, school age, and adolescent/young adult outcomes. *Cleft Palate-Craniofacial Journal*, 49(4), 387-396.
<http://dx.doi.org/10.1597/10-237>

Richman, L. C., McCoy, T. E., P, D., Conrad, A. L., & Nopoulos, P. C. (2012). Neuropsychological, Behavioral, and Academic Sequelae of Cleft: Early Developmental, School Age, and Adolescent/Young Adult Outcomes. *Cleft Palate-Craniofacial Journal*, 49(4), 387-396.

Rigby, K. (2016). *Bullying in schools: how well is it being addressed?* Retrieved from www.unisa.edu.au/Media-Centre/Releases/2016-Media-releases/Bullying-in-schools-how-well-is-it-being-addressed/#.WPOLtGwdjo

- Roberts, R. M., & Mathias, J. L. (2012). Psychosocial functioning in adults with congenital craniofacial conditions. *Cleft Palate-Craniofacial Journal*, 49(3), 276-285.
<http://dx.doi.org/10.1597/10-143>
- Robson, A. K., Blanshard, J. D., Jones, K., Albery, E. H., Smith, I. M., & Maw, A. R. (1992). A conservative approach to the management of otitis media with effusion in cleft palate children. *Journal of Laryngology and Otology*, 106(9), 788-792. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/1431515>
- Ross, R. B., & MacNamera, M. C. (1994). Effect of presurgical infant orthopedics on facial esthetics in complete bilateral cleft lip and palate. *Cleft Palate-Craniofacial Journal*, 31(1), 68-73. [http://dx.doi.org/10.1597/1545-1569\(1994\)031<0068:EOPIOO>2.3.CO;2](http://dx.doi.org/10.1597/1545-1569(1994)031<0068:EOPIOO>2.3.CO;2)
- Rumsey, N., & Harcourt, D. (2012). *The Oxford handbook of the psychology of appearance*. Oxford: Oxford University Press.
- Rumsey, N., & Harcourt, D. (2005). *The Psychology of Appearance* (Vol. 1). Maidenhead: Open University Press.
- Rumsey, N., & Harcourt, D. (2007). Visible difference amongst children and adolescents: issues and interventions. *Developmental Neurorehabilitation*, 10(2), 113-123. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17687984>
- Rumsey, N., Clarke, A., White, P., Wyn-Williams, M., & Garlick, W. (2004). Altered body image: appearance-related concerns of people with visible disfigurement. *Journal of Advanced Nursing*, 48, 443-453.
- Salyer, K. E. (1992). Early and late treatment of unilateral cleft nasal deformity. *Cleft Palate-Craniofacial Journal*, 29(6), 556-569.
- Sarwer, D., Barlett, S., Whitaker, L., Paige, K., Pertschuk, M., & Wadden, T. (1999). Psychological functioning of individuals born with craniofacial anomalies. *Plastic and Reconstructive Surgery*, 103, 412-418.
- Schaaf, N. G., Casey, D. M., & McLean, T. R. (1995). *Maxillofacial prosthetics. Craniofacial Anomalies: An Interdisciplinary Approach*. St Louis: Mosby Year Book.
- Scheuerle, J., Guilford, A., & Garcia, S. (1982). Employee bias associated with cleft lip/palate. *Journal Applied Rehabilitation Counsel*, 13, 6-8.
- Semb, G. (1991). A study of facial growth in patients with unilateral cleft lip and palate treated by the Oslo Cleft Lip and Palate Team. *Cleft Palate-Craniofacial Journal*, 28, 1-21.

- Sharif, M. O., Callery, P., & Tierney, S. (2013). The perspectives of children and young people living with cleft lip and palate: a review of qualitative literature. *Cleft Palate-Craniofacial Journal*, 50(3), 297-304. <http://dx.doi.org/10.1597/12-054>
- Sharp, H. M., Canady, J. W., Ligot, F. A., Hague, R. A., Gutierrez, J., & Gutierrez, J. (2008). Caregiver and patient reported outcomes after repair of cleft lip and/or palate in the Philippines. *Cleft Palate-Craniofacial Journal*, 45(2), 163-171. <http://dx.doi.org/10.1597/06-230.1>
- Shaw, W. C., Brattstrom, V., Molsted, K., Pahl-Andersen, B., Roberts, C. T., & Semb, G. (2005). The Eurocleft study: intercenter study of treatment outcome in patients with complete cleft lip and palate. Part 5: discussion and conclusions. *Cleft Palate-Craniofacial Journal*, 42(1), 93-98. <http://dx.doi.org/10.1597/02-119.5.1>
- Sinko, K., Jagsch, R., Prechtel, V., Watzinger, F., Hollmann, K., & Baumann, A. (2005). Evaluation of esthetic, functional, and quality-of-life outcome in adult cleft lip and palate patients. *Cleft Palate-Craniofacial Journal*, 42(4), 355-361.
- Sivertsen, A., Wilcox, A. J., Skjaerven, R., Vindenes, H. A., Abyholm, F., & Harville, E. (2008). Familial risk of oral clefts by morphological type and severity: population based cohort study of first degree relatives. *British Medical Journal*, 336(7641), 432-434.
- Slifer, K. J., Amari, A., Diver, T., Hilley, L., Beck, M., Kane, A., & McDonnell, S. (2004). Social interaction patterns of children and adolescents with and without oral clefts during a videotaped analogue social encounter. *Cleft Palate-Craniofacial Journal*, 41(2), 175-184. <http://dx.doi.org/10.1597/02-084>
- Slifer, K. J., Pulbrook, V., Amari, A., Vona-Messersmith, N., Cohn, J. F., & Ambadar, Z. (2006). Social acceptance and facial behavior in children with oral clefts. *Cleft Palate-Craniofacial Journal*, 43(2), 226-235.
- Smolak, L., & Levine, M. P. (2001). Body image, eating disorders, and obesity in youth: assessment, prevention, and treatment. Washington DC: American Psychological Association.
- Snyder, H. T., Bilboul, M. J., & Pope, A. W. (2005). Psychosocial adjustment in adolescents with craniofacial anomalies: a comparison of parent and self-reports. *Cleft Palate-Craniofacial Journal*, 42(5), 548-555. <http://dx.doi.org/10.1597/04-078R.1>
- Snyder, H., & Pope, A. W. (2010). Psychosocial adjustment in children and adolescents with a craniofacial anomaly: diagnosis-specific patterns. *Cleft Palate-Craniofacial Journal*, 47(3), 264-272. <http://dx.doi.org/10.5555/08-227.1>

- Speltz, M. L., Greenberg, M. T., Endriga, M. C., & Galbreath, H. (1994). Developmental approach to the psychology of craniofacial anomalies. *Cleft Palate-Craniofacial Journal*, 31(1), 61-67.
- Stock, N. M., & Rumsey, N. (2015a). Parenting a child with a cleft: the father's perspective. *Cleft Palate-Craniofacial Journal*, 52(1), 31-43. <http://dx.doi.org/10.1597/13-035>
- Stock, N. M., & Rumsey, N. (2015b). Starting a Family: The Experience of Parents with Cleft Lip and/or Palate. *Cleft Palate-Craniofacial Journal*, 52(4), 425-436. <http://dx.doi.org/10.1597/13-314>
- Stock, N. M., Feragen, K. B., & Rumsey, N. (2015). "It Doesn't All Just Stop at 18": Psychological Adjustment and Support Needs of Adults Born with Cleft Lip and/or Palate. *Cleft Palate-Craniofacial Journal*, 52(5), 543-554. <http://dx.doi.org/10.1597/14-178>
- Stock, N. M., Feragen, K. B., & Rumsey, N. (2016). Adults' Narratives of Growing up with a Cleft Lip and/or Palate: Factors Associated with Psychological Adjustment. *Cleft Palate-Craniofacial Journal*, 53(2), 222-239. <http://dx.doi.org/10.1597/14-269>
- Strauss, R. P., Broder, H. L., & Helms, R. W. (1988). Perceptions of appearance and speech by adolescent patients with cleft lip and palate and by their parents. *Cleft Palate Journal*, 25(4), 335-342. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3203464>
- Strauss, R., & Fenson, C. (2005). Experiencing the good life: literary views of craniofacial conditions and quality of life. *Cleft Palate-Craniofacial Journal*, 42, 14-18.
- Swan, M. C., Goodacre, T. E., Czernuszka, J. T., & Bucknall, D. G. (2008). Cleft palate repair with the use of osmotic expanders: a response. *Journal of Plastic, Reconstructive and Aesthetic Surgery*, 61(2), 220-221. <http://dx.doi.org/10.1016/j.bjps.2007.10.007>
- Thomas, P. T., Turner, S. R., Rumsey, N., Dowell, T., & Sandy, J. R. (1997). Satisfaction with facial appearance among subjects affected by a cleft. *Cleft Palate-Craniofacial Journal*, 34(3), 226-231. [http://dx.doi.org/10.1597/1545-1569\(1997\)034<0226:SWFAAS>2.3.CO;2](http://dx.doi.org/10.1597/1545-1569(1997)034<0226:SWFAAS>2.3.CO;2)
- Thompson, A., & Broom, L. (2009). Positively managing intrusive reactions to disfigurement: an interpretative phenomenological analysis of naturalistic coping. *Diversity in Health and Care*, 6, 171-180.
- Thompson, J. K., & Atabe, M. N. (1991). Psychometric qualities of the Figure Rating Scale. *International Journal of Eating Disorders*, 10, 615-691.

- Thompson, S. C., Thomas, C., Rickabaugh, C. A., Tantamjarik, P., Otsuki, T., Pan, D., Sinar, E. (1998). Primary and secondary control over age-related changes in physical appearance. *Journal of Personality*, 66, 583-605.
- Tiemens, K., Nicholas, D., P, D., & Forrest, C. (2013). Living with Difference: Experiences of Adolescent Girls with Cleft Lip and Palate. *Cleft Palate-Craniofacial Journal*, 50(2), e27-e34.
- Tripplett, I. (2007). *The Blame Game: A first glimpse at the socially acceptable causes of female fatness*. International Communications Association, held in San Francisco, California, (pp. 1-27).
- Turner, S. R., Rumsey, N., & Sandy, J. R. (1998). Psychological aspects of cleft lip and palate. *European Journal of Orthodontics*, 20(4), 407-415. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9753822>
- Turner, S. R., Thomas, P. W., Dowell, T., Rumsey, N., & Sandy, J. R. (1997). Psychological outcomes amongst cleft patients and their families. *British Journal of Plastic Surgery*, 50(1), 1-9. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9038507>
- University of California, Los Angeles. (2015). *R Data Analysis Examples: Ordinal Logistic Regression*. Retrieved from <http://www.ats.ucla.edu/stat/r/dae/ologit.htm>
- Van Demark, D. R., & Van Demark, A. A. (1970). Speech and socio-vocational aspects of individuals with cleft lip and palate. *Cleft Palate Journal*, 7, 284-299.
- van der Plas, E., Caspell, C. J., Aerts, A. M., Tsalikian, E., Richman, L. C., Dawson, J. D., & Nopoulos, P. (2012). Height, BMI, and pituitary volume in individuals with and without isolated cleft lip and/or palate. *Pediatric Research*, 71(5), 612-618. <http://dx.doi.org/10.1038/pr.2012.12>
- Van Lierde, K. M., Dhaeseleer, E., Luyten, A., Van De Woestijne, K., Vermeersch, H., & Roche, N. (2012). Parent and child ratings of satisfaction with speech and facial appearance in Flemish pre-pubescent boys and girls with unilateral cleft lip and palate. *International Journal of Oral and Maxillofacial Surgery*, 41(2), 192-199. <http://dx.doi.org/10.1016/j.ijom.2011.10.030>
- Vanz, A. P., & Ribeiro, N. R. (2011). Listening to the mothers of individuals with oral fissures. *Revista da Escola de Enfermagem da USP*, 45(3), 596-602.
- Verhoeven, A., Kilpatrick, N., Heavey, L., & Reilly, S. (2013). *Prevalence of different types of speech, language and communication disorders and speech pathology services in Australia*. Canberra:

- Walters, S. T., Matson, S. A., Baer, J. S., & Ziedonis, D. M. (2005). Effectiveness of workshop training for psychosocial addiction treatments: a systematic review. *Journal of Substance Abuse Treatment*, 29(4), 283-293. <http://dx.doi.org/10.1016/j.jsat.2005.08.006>
- Watkins, S. E., Meyer, R. E., Strauss, R. P., & Aylsworth, A. S. (2014). Classification, epidemiology, and genetics of orofacial clefts. *Clinics in Plastic Surgery*, 41(2), 149-163. <http://dx.doi.org/10.1016/j.cps.2013.12.003>
- Watterson, T., Mancini, M., Brancamp, T. U., & Lewis, K. E. (2013). Relationship between the perception of hypernasality and social judgments in school-aged children. *Cleft Palate-Craniofacial Journal*, 50(4), 498-502. <http://dx.doi.org/10.1597/11-126>
- Wehby, G. L., Collet, B., Barron, S., Romitti, P. A., Ansley, T. N., & Speltz, M. (2014). Academic achievement of children and adolescents with oral clefts. *Pediatrics*, 133(5), 785-792. <http://dx.doi.org/10.1542/peds.2013-3072>
- Wehby, G. L., Goco, N., Moretti-Ferreira, D., Felix, T., Richieri-Costa, A., Padovani, C., Murray, J. C. (2012). Oral cleft prevention program (OCPP). *BMC Pediatrics*, 12, 184. <http://dx.doi.org/10.1186/1471-2431-12-184>
- Weigel MT, P. M., Goldsmith, M. M., Postma, D. S., & Pilsbury, H. C. (1989). A prospective randomised study of four commonly used tympanostomy tubes. *Laryngoscope*, 99, 252-256.
- West Australian Department of Education and Training. (2015). *Safe and Supportive Schools*. Retrieved from <http://det.wa.edu.au/studentsupport/behaviourandwellbeing/detcms/navigation/safe-and-supportive-schools/>
- World Health Organisation. (2012). *World Health Organisation Psychosocial support for individuals with HIV*. Retrieved from <http://www.who.int/hiv/topics/psychosocial/support/en/>
- World Health Organisation. (2007). *World Health Organization Early Child Development Knowledge Network (WHO ECDKN). Early Child Development: A Powerful Equalizer. Final Report of the Early Childhood Development Knowledge Network of the Commission on Social Determinants of Health*. Geneva.
- Wilkinson, S., Roberts, A., & Aldridge, J. (1998). Nurse-patient communication in palliative care: an evaluation of a communication skills programme. *Palliative Medicine*, 12(1), 13-22. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9616455>

- Williams, A. C., Bearn, D., Mildinhal, S., Murphy, T., Sell, D., Shaw, W. C., Sandy, J. R. (2001). Cleft lip and palate care in the United Kingdom--the Clinical Standards Advisory Group (CSAG) Study. Part 2: dentofacial outcomes and patient satisfaction. *Cleft Palate-Craniofacial Journal*, 38(1), 24-29. [http://dx.doi.org/10.1597/1545-1569\(2001\)038<0024:CLAPCI>2.0.CO;2](http://dx.doi.org/10.1597/1545-1569(2001)038<0024:CLAPCI>2.0.CO;2)
- Williams, L., Dures, E., Waylen, A., Ireland, T., Rumsey, N., & Sandy, J. (2012). Approaching parents to take part in a cleft gene bank: a qualitative pilot study. *Cleft Palate-Craniofacial Journal*, 49(4), 425-436. <http://dx.doi.org/10.1597/10-086>
- Wong, F. K., & Hagg, U. (2004). An update on the aetiology of orofacial clefts. *Hong Kong Medical Journal*, 10(5), 331-336.
- Wood, R. J., & Jurkiewicz, M. J. (1999). *Plastic and reconstructive surgery* (7th ed.). New York: McGraw-Hill.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215-228.
- Yttri, J. (2011). Reproductive patterns among Danish women with oral clefts. *Cleft Palate-Craniofacial Journal*, 48, 601-607.

Appendices

Appendix 1. Terminology

A

Alveolar: Part of the jaw or jaw-ridge which contain the bony sockets of the teeth

Alveolar Ridge: The bony ridge of the gingiva or gum-line containing the teeth.

Articulation: Movements of the mouth and airway that produce speech.

Articulation Test: An evaluation which provides information about how speech sounds are formed.

Audiogram: A record of hearing levels or sensitivity.

Audiologist: A person with a degree, license, and certification in audiology (science of hearing) who measures hearing, identifies hearing loss, and participates in rehabilitation of hearing impairment.

B

Bilateral cleft: Cleft on both sides of the lip or palate

Bone graft (alveolar): Insertion of cancellous bone into the alveolar ridge to reconstruct the bony defect.

C

Cleft: Failure of fusion of parts.

Columella: The central, lower portion of the nose which divides the nostrils into right and left.

Communication Disorder: An interference with a person's ability to comprehend others or express themselves (usually in verbal form).

Congenital: A disease, deformity, or deficiency existing at the time of birth.

Craniofacial Anomaly: A visible, structural and/or functional difference affecting the head (cranium) and/or face.

Crossbite: A dental condition where the upper teeth are behind the lower teeth rather than in front of them.

D

Dental Arch: The curved structure formed by the teeth in their normal position.

Dental Extraction: Dental procedures performed to remove damaged, malformed, or malpositioned teeth.

E

Eardrum: Tympanic membrane which vibrates and transmits sound to the middle ear.

E.N.T.: The abbreviation for ear, nose, and throat.

Eustachian Tube: The air duct which connects the nasopharynx (back of the throat) with the middle ear; usually closed at one end, opens with yawning and swallowing; allows ventilation of the middle ear cavity and equalization of pressure on two sides of the eardrum.

F

Fistula: An abnormal opening, usually referring to a hole in the palate after repair.

G

Genetics: The science of heredity (how things pass from one generation to the next).

Grommet: Drainage tube for the ear drum

H

Hard Palate: The front part of the roof of the mouth containing bone covered by mucosa (pink "skin").

Hearing Impairment: A loss in hearing which may range from mild loss to complete deafness.

Heredity: The total of the physical characteristics, abilities, and potentialities genetically derived from one's ancestors.

Hypernasality: Speech that sounds overly "nasal," as if the person is "talking through his/her nose" where an excess amount of air escaping through the nose during speech

Hyponasality: Denasality. A lack of normal nasal resonance during speech.

L

Language Disorder or Impairment: Inability to communicate normally and effectively due to problems with comprehension or expression of language.

Lateral: Side

M

Malocclusion: A deviation from normal occlusion, that is, incorrect positioning of the upper teeth in relation to the lower teeth.

Mandible: The lower jaw.

Maxilla: The upper jaw.

Microform cleft: a very slight cleft (split or opening) in the lip or muscle of the lip

Micrognathia: Small size of mandible

Middle Ear: The portion of the ear behind the eardrum. It contains three small bones which transfer sound from the eardrum to the inner ear.

Mixed dentition: period of time when children have both deciduous teeth and permanent teeth.

Myringotomy: A minor surgical procedure in which a small incision is made in the ear-drum to allow fluid to drain from the middle ear.

Multidisciplinary Team: A group of professionals who work together to help plan and carry out treatment for patients with cleft lip, cleft palate, and related disorders. The group usually includes surgeons, dental specialists, speech pathologist, and other specialists and staff who meet regularly to evaluate and discuss the patients under their care.

N

Nasal Air Emission or Nasal Escape: An abnormal flow of air through the nose during speech. Usually indicative of an incomplete seal between oral and nasal cavities.

Nasality: The quality of voice that lacks normal nasal resonance for /m /n/ ng (“head cold” sound).

Nasal regurgitation: food or liquids leaking out through the nose.

Nasal septum: internal structure that divides the nasal cavity into halves. It normally joins the roof of the hard palate.

Nasendoscopy: A diagnostic procedure in which a small camera is inserted through the nose to look at palate and throat movement during speech.

Nasopharyngoscope: A lighted telescopic instrument used for examining the passages in the back of the throat. Useful in assessing velopharyngeal function.

O

Obturator: retainer-like device placed in the roof of the mouth to cover the cleft (split or opening); helps with feeding and speech development

Occlusion: Relationship between upper and lower teeth when they are in contact. Refers to the alignment of teeth as well as relationship of dental arches.

Oral Cavity: The mouth bounded by the teeth in front and the soft palate at the back.

Orthognathic surgery: (Jaw) surgery to move forward the whole of the upper jaw, or to move the mandible (lower jaw)

Orthodontics: The specialty of dentistry concerned with the correction and prevention of irregularities and malocclusion of the teeth and jaws. The aim of orthodontics is to move the teeth into better alignment with one another to improve chewing, oral hygiene, and appearance.

Otitis Media: Inflammation and/or infection of the middle ear with accumulation of thick, mucous-like fluid.

Otolaryngologist: An ear, nose and throat clinician specialising in the diagnosis and management of head and neck disorders.

P

Palatal Insufficiency: A lack or shortness of tissue preventing the soft palate from contacting the back of the throat (pharynx).

Palate: The roof of the mouth including the front portion, or hard palate, and the back portion, or the soft palate (also called the velum).

Paediatric Dentistry: The specialty of dentistry concerned with the care of children's teeth.

Pharyngeal Flap: Surgical procedure designed to minimize hypernasality. A flap of skin creates a "bridge" between the soft palate and the back of the throat.

Pharyngoplasty: Surgical procedure designed to minimize hypernasality.

Premaxilla: The small bone in the upper jaw which contains the upper four front teeth. Normally connected with the side segments of the upper jaw (maxilla) but separated in some clefts.

Primary palate: (Premaxilla) – Developing lip anterior hard palate and alveolus. Triangular area of the anterior hard palate. Formed between the 4th and 7th weeks of gestation.

Prolabium: The central area of the upper lip beneath the centre of the nose (columella) and between the philtral columns.

Prosthodontist: A dentist who specialises in providing prosthetic appliances for oral structures.

R

Resonance: Vocal quality associated with the vibration of air in the oral and nasal cavities.

Rhinoplasty: Nasal correction

S

Secondary palate: Posterior part of the hard palate and soft palate. Formed between the 6th and 9th weeks of gestation.

Soft Palate: The back part of the roof of the mouth containing muscles and mucosa (pink “skin”). The Latin name for the soft palate is “velum”.

Speech-Language Pathologist: An individual with the necessary academic training and experience to be certified or licensed to diagnose and treat disorders of speech, language, and communication.

Speech Defect: Deviation of speech from the range of normal.

Speech Videofluoroscopy: A tape recorded x-ray examination of the speech mechanism during function, focusing on the soft palate (velum) and walls of the throat (pharynx). Useful in assessing velopharyngeal function.

Submucous cleft: Although surface layers of the palate are complete, muscle beneath not joined.

Supernumerary teeth Tiny, extra teeth – also known as denticles.

T

U

Unilateral cleft: One sided cleft

Uvula: Small, cone-shaped muscular process hanging at the back of the soft palate.

V

Velopharyngeal Closure: The closing of the nasal cavity from the oral cavity which directs air used in speech through the mouth rather than the nose. It requires interaction of the muscles in the palate and the back of the throat.

Velopharyngeal Insufficiency (VPI): A structural or functional disorder resulting in the inability to achieve adequate separation of the nasal and oral cavities. This occurs during speech without a good seal between the nose and the mouth; resulting in hypernasal speech as air escapes from the back of the throat

Vermillion border: where the red portion of the lip meets the lighter skin portion of the lip

References:

<http://www.cleftline.org/parents-individuals/glossary-of-terms/>

http://www.cleft.ie/?page_id=58

Appendix 2. Table of Articles for Literature Review

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Alansari et al, 2014	QoL. Qualitative - grounded theory	Canada	11			X	Convenience sample from AboutFace Int. Semi-structured interview. Perception of experience changes over time. Self-perception is an important tool during and after the treatment progression.		Future studies should develop self-perception measures relative to cleft. Treatment should be guided by and tempered with the inclusion of self-perception.	X	
Beaune et al., 2004	Lived experience. Qualitative - thematic response	Canada	6		X		Semi-structured long interview technique. Themes central to the adolescents' experiences were balancing sameness and difference and the journey toward social and self-acceptance. Challenges of social stigma, finding a good fit in school and in meeting unique needs.		Very small sample size. Value of using qualitative research approaches for understanding lived experience.	X	
Berger & Dalton, 2009	Psychosocial adjustment. Quantitative – cross-sectional	UK	145		X		Patient and parent postal questionnaire (37% response), monetary incentive to participate, The Strengths and Difficulties Questionnaire (SDQ), The General Well-being Scale (GWBS), KIDCOPE, Brief COPE, Satisfaction With Appearance Questionnaire (SWA), Childhood Experience Questionnaire (CEQ). Comparison with normative data for the measures. Findings do not support cleft patients or their mothers suffering difficulty with		Recommend further study of factors which influence self-reporting measures.		X

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
							psychosocial adjustment. A lack of father participation.				
Berger & Dalton, 2011	Psychosocial adjustment. Quantitative – cross-sectional	UK	91		X		Patient and mothers postal questionnaire (34% response). Some data from 2009 study. The Strengths and Difficulties Questionnaire (SDQ), KIDCOPE, The Satisfaction With Appearance questionnaire (SWA), Childhood Experience Questionnaire (CEQ), Family Support Scale (FSS), Parenting Stress Index Life Stress subscale (PSI). Adolescent adjustment was predicted by social experience and wellbeing of mother; – maternal adjustment was predicted by coping methods.		Authors recommend provision of targeted social skills workshops and coping effectiveness training to reduce anxiety, increase confidence, and coping in difficult situations.	X	
Berk et al. 2001	Social anxiety. Quantitative – cross-sectional case matched	China	85		X		Patients, siblings and control group, gender and age-match but not for area of residence or educational level. Social Avoidance and Distress Scale, Fear of Negative Evaluation, Rosenberg Self-Esteem Scale, Interpersonal Support Evaluation List. Subjects in the cleft group reported significantly more anxiety in social situations and reported lower levels of support and self-esteem.	X	Authors recommend cross-cultural comparisons and have expanded the study to include data from USA.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Bernstein & Kapp, 1981	Body image. Quantitative – longitudinal	USA	60	X			Observation. No comparison group		Authors promote that co-ordinated cleft team care can assist in developing a satisfactory self-image and self-identity.	X	
Bilboul et al, 2006	Self-concept. Quantitative – cross-sectional	USA	49		X		Patient chart review. Patient and parent report: Child Behavior Checklist, Self-Perception Profile for Adolescents. Adjustment problems in psychosocial health may be linked to appearance issues only when there is a negative self-view.		Longitudinal studies are required to identify Causation of psychosocial adjustment issues. Future studies should investigate the factors that could impact self-concept and adjustment, including number of surgeries, parenting, and associated medical conditions.	X	
Bjornsson et al., 1987	QoL. Quantitative – cross-sectional	Iceland	63			X	Postal questionnaire using a comparison group from a previous study. Overall subjects did not feel that their cleft had greatly influenced their lives, however very few were married. Females were more conscious of their facial appearance than males.		Longitudinal studies needed.		X
Boes et al., 2007	Social and brain functioning. Mixed Methods.	USA	30	X			Self-report questionnaire-1 (SDQ-1) and MRI measures. Cleft group – males only with cleft lip and palate. Results indicate the cleft group had	X	Further study required to isolate gene relationship. Previous	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
							abnormal frontal cortex measures causing of social inhibition.		study with adult males with similar results.		
Brand et al., 2009	Sleep and psychosocial assessment. Quantitative – cross-sectional	Switzerland	32	X	X		Strength and Difficulties Questionnaire (SDQ) international competencies (PIELCQ). Children with cleft were six times more likely to have difficulty with social interaction. Sleep results were inconclusive.	X	Further study in assessing sleep-disordered breathing and the role in amount and quality of sleep and its association with psychosocial difficulties.	X	
Broder and Strauss, 1989	Self concept. Quantitative – cross-sectional	USA	58	X			Primary Self-Concept Inventory (PSCI) pictorial report. Results indicated that children with cleft lip and palate (both a visible and invisible condition) had lowest scores in self-concept.	X	Further studies should consider each cleft type as an entity. More longitudinal studies are required.	X	
Broder et al., 1994	Satisfaction with facial appearance. Mixed Methods.	USA	341		X		Retrospective interviews and self-reports. Those with visible clefts rated a higher appearance dissatisfaction and social inhibition but also a higher problem solving ability. This group may be deemed to be at risk of not developing adequate social skills and positive concept of self.	X	Replication and social skills research required.	X	
Broder et al., 1998	School achievement. Quantitative – cross-sectional	USA	84	X	X		Cross sectional two centre study of matched subjects IQ test, school reporting. Findings include learning difficulties affected 46%, low education scores development 47% and grade repeating 27%.		Multi-centre and cross-centre studies to increase comparability and sample sizes.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
							Males with isolated cleft palate had lowest school scores and highest learning problems.				
Cadogan & Bennun, 2011	Lived surgical experience. Qualitative - phenomenology	UK	7		X	X	Digital recordings of face to face or telephone semi-structured interviews. Social rejection, prejudice and feeling different were common feelings. There was negative reactions to society's body image ideals.		Breaking the link between body image from physical appearance requires further investigation.	X	
Chetpakdechit et al. 2009	Social life aspects. Qualitative - grounded theory	Sweden	12			X	Telephone interviews. Seven main themes. Higher self-esteem and lower social inhibition were reported by those who were given recognition and support from the significant persons in their lives		Non-verbal clues missed.		X
Cheung et al., 2007	Psychosocial wellbeing. Quantitative – cross-sectional	China	94	X	X	X	Questionnaires: Social Avoidance and Distress Scale, Satisfaction With Life Scale. Cultural-Free Self-Esteem Inventory, Chinese Miller Behavioral Style Scale. Main finding was the cleft group had lower self- esteem.	X	Longitudinal studies required to track across main ages.	X	
Christensen et al., 2004	Survival. Registry Study	Denmark	5331	X	X	X	Observed and expected deaths in three intervals: first year of life; 1-17 and 18-55 years		Expected number of deaths was 259 but 402 were observed. Increased risk of death from all major causes.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Clifford et al., 1973	Attractiveness. Quantitative – cross-sectional	USA	504	X			Materials and rating sheet. Subjective ratings by teachers of appearance and expectations of subjects.		Attractiveness influenced teacher's perceptions including education, social and parental educational interest.	X	
Danino et al., 2005	QoL. Registry Study	France	82		X	X	Age, gender and region Comparison group. Marriage, higher education, income and living independently were significantly lower in the cleft group.		Further comparative studies with larger sample sizes required.	X	
Dion et al., 1972	Physical attractiveness and stereotyping. Quantitative – cross-sectional	Canada	60			X	Subjective rating of photographs. Findings show that there is the existence of stereotyping based on facial appearance.		Physical attractiveness may have implications in social settings.	X	
Edwards et al., 2005	QoL. Qualitative - grounded theory	USA	33	X	X		In-depth interview, focus group and panel outcome. Adolescent and parent. Domains from grounded theory and development of Youth Quality of Life Instrument		Issues such as missed life opportunities or pain have impact but are not usually measured. Further studies should include these aspects.	X	
Eide et al., 2006	Birth defects and mortality. Registry study	Norway	9186			X	Population-based cohort study. Males only, good sample size. Military draft records linked to Medical Birth Registry of Norway (1967–1979). Outcome measures of disability, mortality and IQ scores.		Males with birth defects had a relative risk of 6.0 compared to general population. Cleft palate	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
									was a subgroup that indicated lower intellectual performance.		
Eiserman, 2001	Psychosocial deficits. Qualitative - thematic response	USA	22			X	Questionnaire and interview. Contributional perspective and framework – thematic analysis to explore positive meanings. Patient and parent input. Eleven cleft adults and eleven parents - convenience sample. Almost half of the subjects and parents found life meaning including helping others and questioning societal norms. Living with a cleft or appearance difference may offer the experience to develop coping techniques and confidence in dealing with life challenges, including a sense of inner strength and resilience. Also found that people who have a cleft attracted good friends irrespective of their appearance difference.		Bias toward finding positive outcome. Contributional framework to influence further studies, practice and intervention and has implications for policy considerations.		X
Feragen and Borge, 2010	Peer harassment appearance satisfaction. Quantitative – cross-sectional	Norway	661	X			Semi-standardised interview and questionnaire. Dissatisfaction with appearance was found to be related to peer harassment. Low report of negative social experience.		Addressing positive and negative social experiences and their impact on appearance satisfaction should be a factor in clinical interventions.		X

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Feragen et al., 2010	Social acceptance. Quantitative – cross-sectional	UK	289		X		Questionnaire Self-Perception Profile for Adolescents, (SPPA) to compare gender and visible/nonvisible cleft. Girls with a visible cleft rated appearance satisfaction lowest, boys with a visible difference rated more positive perception of friendship and facial appearance. Ratings of appearance, social acceptance and depression were significant in all groups.		Interventions should be directed at developing social competence.	X	
Foo et al., 2012	QoL. Mixed Methods.	Australia	88		X	X	HRQoL was measured by the Short Form (SF)-36 questionnaire. Questionnaire rating of photographs. Oral health impact was measured by the Oral Health Impact Profile (OHIP)-14 questionnaire. State-based and national norms were used for comparative purposes. Difference in perception of attractiveness and aesthetics between professionals and non-professionals and between surgical and non-surgical professionals. Non-cleft non-professionals rated attractiveness lower and need for further surgery higher than cleft non-professionals.		Studies lack uniformity and consistency in their approaches and instruments.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Gussy & Kilpatrick, 2006	Self-concept. Quantitative – cross-sectional	Australia	23	X	X		Pilot questionnaire Self-Description Questionnaire II (SDQII). Low sample size. Normative comparison group. Findings suggest that children with a cleft have a self concept which is normative. Study suggests that cleft of the lip and palate has specific link with psychosocial adjustment and requires the use of instruments which measure specific areas of self-concept.		The SDQ may be used in addition to other instruments for auditing clinical outcomes.		X
Hearst et al., 2007	Psychology. Case Study	UK	5	X	X		Challenge in cleft care is to deliver psychological intervention which takes the focus away from pathologizing the condition and to satisfy the needs at different developmental times		Outcomes need to be re-defined away from a surgical quality focus to resilience and psychosocial well-being		X
Heller et al., 1981	Adjustment. Quantitative – cross-sectional	Canada	96			X	Telephone follow-up study 10-33% of participants felt psychosocial problems. No comparison group. Dissatisfaction was high with appearance, hearing, speech, teeth, social integration. Prolonged dependence on family low levels of social integration 50% had few leisure activities and 25% had few friends. Psychological support needs to be offered in adolescence and adulthood.		Cleft treatment services need to be extended into early adulthood.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Hunt et al., 2006	Psychological. Mixed Methods.	Ireland	160	X	X	X	Questionnaires; State Trait Anxiety Inventory for Children (STAIC), State Trait Anxiety Inventory (STAI) Children's Depression Inventory (CDI), Beck Depression Inventory (BDI), Self-Esteem Index (SEI), Rosenberg Self-Esteem Scale (RSE), Youth Self-Report (YSR), Young Adult Self-Report (YASR), visual analog scale, and semi-structured interview. No difference between groups for self-esteem and anxiety but significant issues of teasing, depression, facial appearance and speech for the cleft group.	X	Prevalence and type of teasing should form a major component of any psychological evaluation. As a minimum, psychological assessment and intervention should be aimed at those children who are being teased/bullied.	X	
Kapp-Simon et al., 1992	Social skills. Quantitative – intervention program	USA	45	X	X		Twelve session group program. Questionnaire; Self Perception Profile for Children, Personality Inventory for Children, Revised Behavior Problem Checklist. Findings indicate children with cleft are similar to others with chronic conditions and have problems with psychological adjustment.		Programs are recommended which teach social skills and measure the outcomes from these skills to social integration and psychosocial adjustment.	X	
Knight et al., 2015	Academic outcomes. Quantitative – cross-sectional	USA	112	X			Postal questionnaire. Very low response rate. Parents of cleft group reported more issues with speech, hearing and development than from control group. Cleft group reported more days missed from school and lower grades than the control group.	X	Further studies need to link longitudinal academic and medical chart information to evaluate variables to predict academic outcomes.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Kramer et al., 2009	Impact Study and QoL. Quantitative – cross-sectional	Germany	132	X			Questionnaires: Impact on Family Scale and KINDL. There were several limitations on QoL which affected social functioning. Boys more affected in self-esteem and psychological health.		Special psychological support should be available to children with clefts and their families.	X	
Locker et al., 2005	HRQoL. Mixed Methods.	Canada	39		X		Family Impact Scale (FIS); development of Child Oral Health Quality of Life Questionnaire (COHQoL). Comparison group from pool requiring dental care. Problems with speech, missing school and being teased were higher in the cleft group		Methodological issues – comparison group suitability convenience sample, suitability of questionnaire for cleft population, appearance not measured, small sample size. Study is descriptive only, and further studies should include the measurement of factors.	X	
Lowenstein et al., 2008	Experience of stigma. Mixed Methods.	Canada	35	X	X	X	State Self Esteem (SSE), Perceived Stigma (PS), State Hope (SH) Questionnaires, participant photographic session and video interview. Many participants had negative experiences of stigma. Age and life experience had taught them coping skills for teasing and stigma.		More diverse age of participants – problems at worse when younger than the study group. Intervention study.	X	
Mani et al., 2010	HRQoL. Quantitative – cross-sectional	Sweden	86			X	Long term follow-up 35 years, Normative data comparison group. Questionnaire: HRQoL SF-36 Lower mental health sub scores were noted. Women rated higher in the positive emotional role		Further studies need to assess the factors that negatively affect people with cleft.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
							function than men. Younger patients were more negatively affected than older patients.				
Marcusson et al., 2001	QoL. Quantitative – cross-sectional case matched	Sweden	68			X	Self-report questionnaire; Generic Quality of Life, Health-related Quality of Life. Well-being and social life were affected but not the more practical and tangible aspects of their daily living. Generally, the quality of life for the cleft group was only slightly lower than controls.	X	Further adult studies are required to assess and improve the effectiveness of cleft treatment and management teams.	X	
Marcusson et al., 2002	QoL. Quantitative – cross-sectional case matched	Sweden	68			X	Questionnaire: body image, QoL, HRQoL, somatisation, and depression. Cleft group reported significantly more dissatisfaction with their facial appearance. Satisfaction with facial appearance was significantly correlated with a better quality of life in both groups, and significantly correlated with a better health-related QoL and a lower anxiety in the cleft group. Dissatisfaction with facial appearance was the most significant predictor of depression in both groups. 47% of patients wanted more surgery. Four professionals recommended further surgery for 59%.	X	More insight is required into the lived experience of adults with a cleft.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
McWilliams & Paradise, 1973	Adjustment. Quantitative – cross-sectional	USA	115		X	X	Parent telephone interview. Comparison of educational and vocational level to parent and non-cleft sibling group. Hollingshead and Redlich Occupational Scale. Both groups had a higher education level to their parents. The cleft group dropped out of school at a higher rate and married less frequently.		Preventive intervention needs to be offered early to improve life outcome.	X	
Meyer-Marcotty et al., (2010)	Appearance. Quantitative – cross-sectional case matched	Germany	30			X	Media recruitment. Photos of 18 cases with complete unilateral cleft lip and palate and photos of 18 controls. More direct eye movements to the mouth and nose areas and more negative ratings with the cleft photos.	X	Clinicians must be open-minded to patient's self-perception and request for further treatment.	X	
Millard & Richman, 2001	Adjustment and learning characteristics. Mixed Methods.	USA	65	X	X		Child and parent. Pediatric Behavior Scale (Parent and Teacher Form), Revised Children's Manifest Anxiety Scale (RCMAS), Reynolds Child Depression Scale (RCDS) and Adolescent Depression Scale (RADS), Self-Perception Interview Form. The cleft type of isolated cleft palate had highest signs of depression and anxiety. Speech and appearance are also risk factors.		Genetic and neurocognitive models are recommended to clarify cleft-type and cleft-related risk factors. Alternative research strategies: syndromic and non-syndromic, risk factors and psychological aspects of face, speech, and learning.	X	
Murray et al., 2010	Socioemotional function.	UK	93	X			Has control group, doll play observation by Mother and Teacher. Reported increased risk for social and emotional problems with the cleft group.	X	Clinical interventions need to focus on communication problems and offering support to	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
	Quantitative – longitudinal								parents. The transition to school may require support.		
Noar, 1991	Attitudes and concerns. Quantitative – cross-sectional	UK	32		X	X	Patients and parents. Having a cleft affected relations with opposite sex and school results. Report of teasing and dissatisfaction with specific appearance features.		Longitudinal studies required to determine when intervention is best suited.	X	
O'Dea, 2006	Self concept. Quantitative – longitudinal	Australia	80	X			Non-cleft, body image. Longitudinal over three years. BMI measures and Physical Appearance and Close Friendship Scale. Self-image was seen to be detrimentally affected by high BMI status.		Further and multi-centre studies required to determine how when intervention programs would be most effective.	X	
Oosterkam p et al., 2007	Appearance and QoL. Mixed Methods.	Netherlands	43			X	BCL/P only. HRQL and qualitative interview -eight domains. Patients were dissatisfied with their lip, nose and nasal breathing. Low response rate (58%).	X	Disparity of results between assessment types qualitative highlighted issues that could not be measured by quantitative evaluation. Quantitative measures of a satisfied patient do not automatically equate to objective outcome .	X	
Patel and Ross, 2003	Perceptions. Qualitative - exploratory	South Africa	20		X	X	Exploratory descriptive semi-structured interviews in participant's homes. The most important finding was the negative impact of society's judgements in the cleft group. However, adults reported cleft did not		Implications for policy; emphasis on strengths, counselling and education, culturally sensitive	X	X

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
							affect their family or marital life and that, once in a relationship, the cleft had no impact whatsoever.		education and further longitudinal studies.		
Persson et al, 2008	IQ. Registry Study	Sweden	503		X		Males only. Registry comparison group. The cleft type with significantly lower scores for general intelligence was isolated cleft palate.	X	Further studies required for outcomes in the isolated cleft palate subtype.	X	
Persson et al, 2012	Academic achievement. Registry Study	Sweden	1992	X	X		Registry comparison group. Large sample sizes. The odds of the cleft group receiving a high school certificate was lower than the comparison group. The group with the worst outcome was isolated cleft palate.	X	Implications for teachers and educational providers.	X	
Pertschuk & Whitaker, 1982	Psychosocial surgical adjustment. Quantitative – cross-sectional	USA	12	X	X		Small sample size, pre and post operative questionnaire. Presurgically younger patients, those between 6 and 13, fare better than those 14 years and over. The former, for the most part, appear to be functioning adequately and test within normal range on standardized psychometric measures. Children over 14 years do not appear to cope as well as the younger patients due to issues with mood, social inhibition and self-concept. Findings indicate that improved psychosocial adjustment is correlated with improved appearance after surgery.		Multi-centre studies are needed to improve sample size.	X	X

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Peter and Chinsky, 1974	Social functioning. Quantitative – cross-sectional	USA	195			X	Postal questionnaire. Patients, siblings and comparison group. Study areas of travel confidence, friendship formation and participation, family co-and inter –dependence and level of social confidence. Findings showed a high level of reliance on family for social and living arrangements, had less friendships, and less social confidence.		Intervention earlier would assist the social confidence of cleft adults.	X	
Peter et al., 1975	Socioeconomic. Quantitative – cross-sectional	USA	196			X	Siblings and random comparison group. Socioeconomic scales. Employment remuneration was found to be lower in the cleft group.			X	
Pillemer and Cook, 1989	Adjustment post surgical. Quantitative – cross-sectional	USA	25	X	X		Patient, Teacher and parent reports. Findings include low self esteem, problems with peer interactions and a higher dependency on significant adults. Greater physical and facial attractiveness correlated to greater psychological adjustment		More supportive services are recommended for surgical patients.	X	
Pisula et al., 2013	QoL self-esteem. Quantitative – cross-sectional	Poland	48		X	X	Questionnaire: Multidimensional Self-Esteem Inventory, Coping Inventory for Stressful Situations, WHOQOL-BREF. Males with cleft scored lower than controls but not in females. Areas of correlation were QoL, self-esteem and coping styles.	X	There is a need for instruments to assess social approval in psychosocial adjustment research for cleft patients. Longitudinal studies may offer role of self-esteem and coping styles		X

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Pope & Snyder, 2005	Psychosocial adjustment. Quantitative – longitudinal	USA	305	X	X		Retrospective chart review. Longitudinal. Questionnaires: Parenting Stress Index, Child Behaviour Checklist. Increased risk for certain social adjustment issues but not for overall adjustment.		More fine-tuned descriptive studies are required, focusing on narrower age-groups and specific diagnostic categories, with more varied methodologies. Interventions to have focus of family and parenting, school/educational issues, the peer group as a source of stress and support.	X	
Pope and Ward, 1997	Social competence. Quantitative – cross-sectional	USA	24	X	X		Patient self report and parent report. Low sample size. Parental Involvement Checklist, Self-Perception Profile for Children (pre-adolescents), Child Behavior Checklist, Network of Relationships Inventory, Loneliness Questionnaire, Social Anxiety and Social Avoidance Questionnaire. Results indicate low social competence and risk for social rejection by peers.		Boys were over-represented. Low father response. Analysis may have inflated the relationships reported. Further studies to include more expansive methodologies, including teacher and peer ratings and reports.	X	
Ramstad et al., 1995	Appearance concerns. Mixed Methods.	Norway	233			X	Questionnaire based on existing lifestyle study with additional questions. Comparison group taken from a national lifestyle (Bureau of Statistics) study. Appearance concerns were associated with palpitations and reported twice the number of the		Methodological issue – some participants had self-reports and others were interviewed. Not standardised questions for cleft research. Research enquiry must reach beyond present	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
							control group. Higher rates of anxiety and depression in the cleft group.		strategies looking to alternative designs and methods.		
Rumsey et al., 2004	Psychological. Mixed Methods.	UK	458		X		Convenience sample 15 clinics. Measures; Hospital Anxiety and Depression Scale, Derrisford Appearance Scale short-form and World Health Organization Quality of Life Brief Scale, semi-structured interview and staff focus group. High levels of psychological distress in social situations, compared with normative values. Patient satisfaction with care high; but 71% require appropriately trained personnel to help with appearance concerns. Nursing staff felt unable to do this.		Psychosocial goals should be assessed with biomedical goals. Multidisciplinary teams should be trained with basic standards of psychosocial care and have a psychosocial specialist as a member of the team. Questions about psychosocial issues should be included as part of the assessment and identification of current problems.	X	
Scheuerle et al., 1982	Employment stigma. Quantitative – cross-sectional	USA	37			X	Video-taped review with visible and speech difference. A speech disorder with an orofacial cleft anomaly was more negatively related to employer judgments than was the visible difference alone.		Further studies concerning the importance of pathological correction and normalising of appearance and speech in employment are required. Low sample size not diverse sample.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Sinko et al, 2005	QoL. Quantitative – cross-sectional	Austria	70			X	HRQoL, MOS Short-Form 36 and visual analog scale.. Expert panel rated the aesthetic outcome better than patients. Patients may not be satisfied with treatment but do not seek further treatment. Patients with unrealistic expectations should be referred for psychological support. In most subscales of health-related quality of life, patients who desired further treatment had significantly lower scores than did patients who desired no further treatment.		Bias toward finding positive outcome. Detailed assessment of outcome of treatment is required for the length of patient treatment by both the patient and treatment providers.	X	X
Slifer et al., 2004	Social behaviours. Quantitative – cross-sectional	USA	34	X	X		Video of facial expression and scale. Facial expressions based on responses from scales. Harter Self-Perception Profile, Social Acceptance subscale. Cleft group made fewer choices and failed to respond to peer questions more often. Cleft group and parents reported higher dissatisfaction with the child's facial appearance and rated them as less competent with social interaction.	X	Future studies to develop early intervention strategies to encourage and support social development and adjustment	X	
Slifer et al., 2006	Social and facial behaviours . Quantitative – cross-sectional case matched	USA	24	X	X		Observation and coding from videotaped sessions Coding of videotaped specified facial expressions. Harter Self-Perception Profile, Social Acceptance subscale. Social acceptance was negatively correlated with gaze inhibition in the cleft group whom also displayed low social confidence.	X	Multi-centre studies with case-matched controls and larger sample sizes are required. Neuropsychological assessment is needed to note any observed deficiency in social skills to	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
									determine whether social competence problems are the result of organically based neuropsychological differences or the social reactions of others to the cleft facial appearance.		
Snyder et al., 2005	Psycho-social adjustment. Quantitative – retrospective	USA	64		X		Retrospective chart review. Patient and parent report. Compared with published norms. Child Behavior Checklist, Youth Self-Report. Parents report higher risk for academic and relationship problems for their child compared with the patient self report..		Clinical assessment should recognise the importance to use information from adolescents themselves as well as their parents.	X	
Thomas et al., 1997	Satisfaction. Quantitative – cross-sectional	UK	111	X	X		Patients and parents. Prospective across 3 age-groups and nine centres. Social evaluation. Cleft Satisfaction Profile (CSP) and Childhood Experience Questionnaire (CEQ). Disagreement between parent and child appearance rating. Overall cleft patients with visible difference were more dissatisfied with their appearance and adults were more satisfied than adolescents.		Patient satisfaction with their appearance needs to be assessed prior to their discharge to counter social and adjustment issues.	X	

Author and year	Study focus	Country	Sample size	Children	Teens	Adults	Methods and major findings	Control Group	Recommendations and outcomes	Negative effect	Positive effect
Thompson and Broom, 2009	Coping. Qualitative - phenomenology	UK	8			X	Semi-structured interviews of six women and two men. Purposive sampling and media recruitment of those successfully managing intrusive reactions of others to their disfigurement. Two processes developed impacts of internal and external effect and strategies of coping.		Bias to positive coping. Self-selected participants – self-reported for inclusion criteria. Questionable definition of coping style in some participants. Small sample. More diverse age of participants needed – harder to cope at younger ages. Recommend social skills training and self-development.	X	X
Tiemens et al., 2013	Experience strain. Qualitative - phenomenology	Canada	7		X		Females only. Semi structured interviews pre surgery. All participants reported receiving negative social reactions and felt some degree of concern about their facial difference when in public situations. Strategies to reduce impact.		Post-surgical follow-up interview required and further follow-up. Small sample. Females only.	X	
Yttri, 2011	Reproductive patterns. Registry Study	Denmark	1931			X	Population-based historic cohort study. Danish women with a cleft are more often are childless (55% / 44%) or have their first child later (27.3 years / 24.7) , but if they children, have as many as the population background.	X	Social, psychological, and biological reasons are suggested for these results.	N/A	N/A

Appendix 3. Thesis Instruments

Cleft Research Questionnaire (CRQ) – Children version

PMH CLEFT LIP & PALATE PATIENT QUESTIONNAIRE (6 to 12 years)

Your completion of this confidential questionnaire will contribute to a better understanding of what it is like to have a Cleft lip and/or Palate and how we may improve the experience.

Please place the completed questionnaire in the box provided on the reception desk in the Dental Department. If you wish to discuss any concerns please contact Wendy Ph: 9340 8342 or ask at Dental Reception

1. Life details What is your gender?: Male Female What is your age?:

What is your racial heritage?: Caucasian Asian Aboriginal /TSI Other:
please specify

What is your type of cleft?: Lip Palate Lip & Palate Other:
please specify

Has all of your treatment taken place at PMH?: Yes No:
please specify

.....

What is your area of residence?: Perth metro WA Country Postcode:

Do you a currently live with your parent/s?: Yes No:
please specify

Are they?:
 Single Married/de facto Widowed Separated/divorced

With which hand do you write?: Left Right

2. Does having a cleft make an impact on your life ?

Please indicate whether having a cleft makes an impact in your life in the following areas:

Participation in school Yes No Academic achievements Yes No
please comment

Participation in sport Yes No Friendships with people your own age Yes No
please comment

Physical health Yes No Your attitude to life Yes No
please comment

Physical restriction of any kind Yes No Your independence Yes No
please comment

Public speaking Yes No Being photographed Yes No
please comment

.....

On a scale of 0 to 10, please circle your rating of how happy you are:

0 1 2 3 4 5 6 7 8 9 10

Not usually happy Not happy but not unhappy Usually always happy

PMH CLEFT LIP & PALATE PATIENT QUESTIONNAIRE 6 to12 years

Using the scale of 1 = Extremely to 5 = Not at all, please circle your rating to the following issues

1 Extremely 2 Very 3 Somewhat 4 Not very 5 Not at all

Importance of your facial appearance	1	2	3	4	5	Satisfaction with your facial appearance	1	2	3	4	5
Importance of the appearance of your teeth	1	2	3	4	5	Satisfaction with the appearance of your teeth	1	2	3	4	5
Importance of your hearing	1	2	3	4	5	Satisfaction with your hearing	1	2	3	4	5
Importance of your clarity of speech	1	2	3	4	5	Satisfaction with your clarity of speech	1	2	3	4	5
Support from your parents	1	2	3	4	5	Satisfaction with support from parents	1	2	3	4	5
Support from your sisters and brothers	1	2	3	4	5	Satisfaction with support from sisters and brothers	1	2	3	4	5
Support from teacher	1	2	3	4	5	Satisfaction with support from teacher	1	2	3	4	5
Support from treatment givers	1	2	3	4	5	Satisfaction with support from treatment givers	1	2	3	4	5

Who has given you the most support?

Who has given you the least support?

Have you ever been teased or bullied because of your cleft condition? Yes No

If yes please answer : Where? At what age?

How did you respond to being teased?

Have you ever stayed home to avoid being teased?

What advice would you give to a child who is being teased?

.....

Would you like more help or information on coping with teasing or other issues? No Yes please select as required

- | | | |
|---|-----------------------------------|--|
| <input type="checkbox"/> Teasing and bullying | <input type="checkbox"/> Pamphlet | <input type="checkbox"/> Talk to: councillor / nurse / support staff/ friend |
| <input type="checkbox"/> Self esteem | <input type="checkbox"/> Pamphlet | <input type="checkbox"/> Talk to: councillor / nurse / support staff/ friend |
| <input type="checkbox"/> Social skills | <input type="checkbox"/> Pamphlet | <input type="checkbox"/> Talk to: councillor / nurse / support staff/ friend |
| <input type="checkbox"/> Appearance issues | <input type="checkbox"/> Pamphlet | <input type="checkbox"/> Talk to: councillor / nurse / support staff/ friend |

As a result of your treatment –

Do you feel scared /anxious to go to the dentist? Yes No Are you happy with your smile? Yes No

Do you feel scared/ anxious to have a general anaesthetic? Yes No Are you able to chew properly? Yes No

please comment

PMH CLEFT LIP & PALATE PATIENT QUESTIONNAIRE 6 to 12 years

2

3. Appearance Questions Ages 6 to 12 years

Please circle the most appropriate answer to each statement

1.	I like what I look like in pictures	Yes	No
2.	Kids my own age like my looks	Yes	No
3.	I'm pretty happy about the way I look	Yes	No
4.	Most people have a nicer body than I do	Yes	No
5.	My weight makes me unhappy	Yes	No
6.	I like what I see when I look in the mirror	Yes	No
7.	I wish I were thinner	Yes	No
8.	There are lots of things I'd change about my looks if I could	Yes	No
9.	I'm proud of my body	Yes	No
10.	I really like what I weight	Yes	No
11.	I wish I looked better	Yes	No
12.	I often feel ashamed of how I look	Yes	No
13.	Other people make fun of the way I look	Yes	No
14.	I think I have a good body	Yes	No
15.	I'm looking as nice as I'd like to	Yes	No
16.	I often wish I looked like someone else	Yes	No
17.	My looks upset me	Yes	No
18.	I'm as nice looking as most people	Yes	No
19.	My parents like my looks	Yes	No
20.	I worry about the way I look	Yes	No

What is your body weight?: Underweight Normal weight A little overweight Quite overweight

How would you rate your experience of the service provided by PMH?:

Excellent Good Average Poor

please comment

How can we improve the service at PMH or the experience here?

please comment

Suggestions

Thank you for completing this questionnaire.

Cleft Research Questionnaire (CRQ) – Adolescent version

**PMH CLEFT LIP & PALATE
PATIENT QUESTIONNAIRE
(13 to 21 years)**

Your completion of this confidential questionnaire will contribute to a better understanding of what it is like to have a Cleft Lip and/or Palate and how we may improve the experience.

Please place the completed questionnaire in the box provided on the :
reception desk in the Dental Department

1. Life details What is your gender?: Male Female What is your age?:

What is your racial heritage? Caucasian Asian Aboriginal /TSI Other:
please specify

What is your type of cleft?: Lip Palate Lip & Palate Other:.....
please specify

Has all of your treatment taken place at PMH?: Yes No:
please specify

.....

What is your area of residence?: Perth metro WA Country Postcode:

Are you currently studying or working?: Studying fulltime Working fulltime Studying & working
(please select as appropriate): Studying part time Working part time Not studying or working

Do you a currently live with your parent/s?: Yes No:.....
please specify

Are they?:
 Single Married/de facto Widowed Separated/divorced

With which hand do you write?: Left Right

2. Does having a cleft make an impact on your life ?

Please indicate whether having a cleft makes an impact in your life in the following areas:

Participation in school/work Yes No Academic achievements Yes No
please comment

Participation in sport Yes No Friendships with people your age Yes No
please comment

Physical health Yes No Your attitude to life Yes No
please comment

Physical restriction of any kind Yes No Relationships with special people
eg partner, boyfriend/ girlfriend Yes No
please comment

Public speaking Yes No Getting work Yes No
please comment

Being photographed Yes No Your independence Yes No
please comment

PMH CLEFT LIP & PALATE PATIENT QUESTIONNAIRE 13 to 21 years

Using the scale of 1 = Extremely to 5 = Not at all, please circle your rating to the following issues

1 Extremely 2 Very 3 Somewhat 4 Not very 5 Not at all

Importance of your facial appearance	1	2	3	4	5	Satisfaction with your facial appearance	1	2	3	4	5
Importance of the appearance of your teeth	1	2	3	4	5	Satisfaction with the appearance of your teeth	1	2	3	4	5
Importance of your hearing	1	2	3	4	5	Satisfaction with your hearing	1	2	3	4	5
Importance of your clarity of speech	1	2	3	4	5	Satisfaction with your clarity of speech	1	2	3	4	5
Support from your parents	1	2	3	4	5	Satisfaction with support from parents	1	2	3	4	5
Support from your sisters and brothers	1	2	3	4	5	Satisfaction with support from sisters and brothers	1	2	3	4	5
Support from teacher	1	2	3	4	5	Satisfaction with support from teacher	1	2	3	4	5
Support from treatment givers	1	2	3	4	5	Satisfaction with support from treatment givers	1	2	3	4	5

Who has given you the most support?

Who has given you the least support?

Have you ever been teased or bullied because of your cleft condition? Yes No

If yes please answer : Where? At what age?

How did you respond to being teased?

Have you ever stayed home to avoid being teased?

What advice would you give to a child who is being teased?

.....

Would you like more help or information on coping with teasing or other issues? ((please select as required)

- | | | |
|---|-----------------------------------|--|
| <input type="checkbox"/> Teasing and bullying | <input type="checkbox"/> Pamphlet | <input type="checkbox"/> Talk to: councillor / nurse / support staff/ friend |
| <input type="checkbox"/> Self esteem | <input type="checkbox"/> Pamphlet | <input type="checkbox"/> Talk to: councillor / nurse / support staff/ friend |
| <input type="checkbox"/> Social skills | <input type="checkbox"/> Pamphlet | <input type="checkbox"/> Talk to: councillor / nurse / support staff/ friend |
| <input type="checkbox"/> Appearance issues | <input type="checkbox"/> Pamphlet | <input type="checkbox"/> Talk to: councillor / nurse / support staff/ friend |

As a result of your treatment –

Do you feel scared /anxious to go to the dentist? Yes No Are you happy with your smile? Yes No

Do you feel scared/ anxious to have a general anaesthetic? Yes No Are you able to chew properly? Yes No

please comment

3. Appearance Questions Ages 13 years to 21 years

Indicate how often you agree with the following statements ranging from
 “never” (0) to “always” (4).
 Please circle the most appropriate number beside each statement

	Statement	Never	Seldom	Sometimes	Often	Always
1.	I like what I look like in pictures.	0	1	2	3	4
2.	Other people consider me good looking.	0	1	2	3	4
3.	I'm proud of my body.	0	1	2	3	4
4.	I am preoccupied with trying to change my body weight.	0	1	2	3	4
5.	I think my appearance would help me get a job.	0	1	2	3	4
6.	I like what I see when I look in the mirror.	0	1	2	3	4
7.	There are lots of things I'd change about my looks if I could.	0	1	2	3	4
8.	I am satisfied with my weight.	0	1	2	3	4
9.	I wish I looked better.	0	1	2	3	4
10.	I really like what I weigh.	0	1	2	3	4
11.	I wish I looked like someone else.	0	1	2	3	4
12.	People my own age like my looks.	0	1	2	3	4
13.	My looks upset me.	0	1	2	3	4
14.	I'm as nice looking as most people.	0	1	2	3	4
15.	I'm pretty happy about the way I look.	0	1	2	3	4
16.	I feel I weigh the right amount for my height.	0	1	2	3	4
17.	I feel ashamed of how I look.	0	1	2	3	4
18.	Weighing myself depresses me.	0	1	2	3	4
19.	My weight makes me unhappy	0	1	2	3	4
20.	My looks help me to get dates.	0	1	2	3	4
21.	I worry about the way I look.	0	1	2	3	4
22.	I think I have a good body.	0	1	2	3	4
23.	I'm looking as nice as I'd like to.	0	1	2	3	4

What is your body weight?: Underweight Normal weight A little overweight Quite overweight
(please select):

Would you like to weigh more than you currently do ? Yes No

Would you like to have more muscle ? Yes No

On a scale of 0 to 10, please circle your rating of how happy you are:

0 1 2 3 4 5 6 7 8 9 10

Not usually happy Not happy but not unhappy Usually always happy

4. Our service to you

How would you rate the service provided by PMH and your experience of it?:

Excellent Good Average Poor

please comment

What is the best part of the treatment? (select one or more or just comment) Overall outcome Knowing there are treatment options Interactions with staff It has finished

please comment

What is the worst part of the treatment? (select one or more or just comment) Pain and recovery The sheer number of appointments and treatments Interactions with staff Treatment is a reminder that you have a cleft condition

please comment

Do you feel adequately prepared for the treatment? Yes No

please comment

Are any parts of treatment more important to you than others? Yes No

please comment

Do you feel that you have the opportunity to make decisions concerning your own treatment? Yes No

please comment

How can we improve the service at PMH and hence the experience here?

please comment

Suggestions

Thank you for completing this questionnaire.

4 PMH CLEFT LIP & PALATE PATIENT QUESTIONNAIRE 13 to 21 years

Cleft Research Questionnaire (CRQ) - Adult version

**PMH CLEFT LIP & PALATE
ADULT PATIENT QUESTIONNAIRE**

Your completion of this confidential questionnaire will contribute to a better understanding of what it is like to have a Cleft Lip and/or Palate and how we may improve the experience.

Please return by post in the envelope provided to: Wendy Nicholls
PMH Dental Department
PO Box D184, PERTH WA 6001

1. Life details What is your gender?: Male Female What is your year of birth?:

What is your racial heritage?: Caucasian Asian Aboriginal /TSI Other:
please specify

What is your home postcode?: Do you own your own home?: Yes No:
please specify below:

Rent Live with parents /family Work-related housing Government Assisted housing

What is your occupation?: Do you work: Fulltime Parttime N/A
please specify:

What is your annual income?: Under \$30 000 Under \$60 000 Under \$100 000 Over \$100 000
(please select as appropriate):

What is your highest level of education?: High School TAFE Cert/Diploma University Degree
(please select as appropriate): University postgraduate Other:
please specify:

Are you?: Single Widowed Separated/ Divorced Re-married

Married/de facto At what age were you first married?: How many times have you married?:

At what age was your first serious relationship?: How many serious relationships have you had?:

Do you have children of your own?: No Yes: Do any have a cleft?: No Yes:
How many
(please comment)

Do any of your children have a serious or long-term medical condition or illness? No Yes: N/A:
(please comment)

Do you think Genetic Counselling is important before having children?: No Yes: N/A:

What is your type of cleft?: Lip Palate Lip & Palate Other:
please specify

Has all of your treatment taken place at PMH?: Yes No:
please specify

Has all of your treatment been completed?: Yes No:
please specify

How is your general health?: Rarely get sick Sometimes get sick Frequently get sick
(please select as appropriate): Up to twice/year Up to five times/year More than five times/year

Do you suffer from any serious or long-term medical conditions or illness? No Yes:
please comment

Would you like to weigh:

More than you currently do? Yes No Would you like to have more muscle? Yes No

Less than you currently do? Yes No Which is your dominant hand?: Left Right:

What is your body weight?: Underweight Normal weight A little overweight Quite overweight
(please select):

Were you overweight growing up?: No Yes:

PMH CLEFT LIP & PALATE ADULT PATIENT QUESTIONNAIRE

2. Has having a cleft made an impact on your life ?

Please indicate whether having a cleft condition made an impact in your life in the following areas:

Participation in school Yes No Participation in sport Yes No

please comment

Physical health Yes No Physical restriction of any kind Yes No

please comment

Participation at work Yes No Getting work Yes No

please comment

Public speaking Yes No Being photographed Yes No

please comment

Going for job interviews Yes No Going to pubs and clubs Yes No

please comment

Please indicate whether having a cleft made an impact in your life in the following areas:

Your self-esteem Yes No Academic achievements Yes No

please comment

Friendships with the same age group Yes No Friendships with the opposite sex Yes No

please comment

Relationships with special people eg partner, boyfriend/girlfriend Yes No Your attitude to life Yes No

please comment

Your independence Yes No

please comment

Do you feel that you were over-protected as a child? No Yes

by whom?.....

please comment

Do you have a close relationship with: Your Mother? No Yes Your Father? No Yes

please comment

Have you ever suffered from?:

Depression Yes No Thoughts of suicide Yes No

Anxiety Yes No Feeling unworthy Yes No

Panic attacks Yes No Lack of motivation Yes No

Fear of going to the dentist Yes No Fear of having an anaesthetic Yes No

please comment

Are you happy with your smile? Yes No Can you chew food properly? Yes No

Using the scale of 1 = Extremely to 5 = Not at all, please circle your rating to the following issues

1 Extremely 2 Very 3 Somewhat 4 Not very 5 Not at all

Importance of your facial appearance	1	2	3	4	5	Satisfaction with your facial appearance	1	2	3	4	5
Importance of the appearance of your teeth	1	2	3	4	5	Satisfaction with the appearance of your teeth	1	2	3	4	5
Importance of your hearing	1	2	3	4	5	Satisfaction with your hearing	1	2	3	4	5
Importance your clarity of speech	1	2	3	4	5	Satisfaction with your clarity of speech	1	2	3	4	5
Support from your parents	1	2	3	4	5	Satisfaction with support from parents	1	2	3	4	5
Support from your sisters and brothers	1	2	3	4	5	Satisfaction with support from sisters and brothers	1	2	3	4	5
Support from employer	1	2	3	4	5	Satisfaction with support from employer	1	2	3	4	5
Support from treatment givers	1	2	3	4	5	Satisfaction with support from treatment givers	1	2	3	4	5

Who has given you the most support? Who has given you the least support?

please comment

Have you ever been teased or bullied because of your cleft condition? Yes No

If yes please answer : Where? At what age?

How did you respond to being teased?

Did you ever stay home to try to avoid being teased?

Have you ever bullied others? No Yes
please explain

What advice would you give to a child who is being teased?

Have you ever self-harmed? No Yes
please explain

What advice would you give to a child who is self-harming?

On a scale of 0 to 10, please circle your rating of how happy you are:

0 1 2 3 4 5 6 7 8 9 10

Not usually
happy

Not happy but
not unhappy

Usually
always happy

3. Appearance Questions

Indicate how often you agree with the following statements ranging from
 “never” (0) to “always” (4).
 Please circle the appropriate number beside each statement

	Statement	Never	Seldom	Sometimes	Often	Always
1.	I like what I look like in pictures.	0	1	2	3	4
2.	Other people consider me good looking.	0	1	2	3	4
3.	I'm proud of my body.	0	1	2	3	4
4.	I am preoccupied with trying to change my body weight.	0	1	2	3	4
5.	I think my appearance would help me get a job.	0	1	2	3	4
6.	I like what I see when I look in the mirror.	0	1	2	3	4
7.	There are lots of things I'd change about my looks if I could.	0	1	2	3	4
8.	I am satisfied with my weight.	0	1	2	3	4
9.	I wish I looked better.	0	1	2	3	4
10.	I really like what I weigh.	0	1	2	3	4
11.	I wish I looked like someone else.	0	1	2	3	4
12.	People my own age like my looks.	0	1	2	3	4
13.	My looks upset me.	0	1	2	3	4
14.	I'm as nice looking as most people.	0	1	2	3	4
15.	I'm pretty happy about the way I look.	0	1	2	3	4
16.	I feel I weigh the right amount for my height.	0	1	2	3	4
17.	I feel ashamed of how I look.	0	1	2	3	4
18.	Weighing myself depresses me.	0	1	2	3	4
19.	My weight makes me unhappy	0	1	2	3	4
20.	My looks help me to get dates.	0	1	2	3	4
21.	I worry about the way I look.	0	1	2	3	4
22.	I think I have a good body.	0	1	2	3	4
23.	I'm looking as nice as I'd like to.	0	1	2	3	4

How often do you?

- | | | | | | |
|--------------------------|--------------------------------|---------------------------------|----------------------------------|---------------------------------|--------------------------------|
| Smoke cigarettes | <input type="checkbox"/> Never | <input type="checkbox"/> Seldom | <input type="checkbox"/> Monthly | <input type="checkbox"/> Weekly | <input type="checkbox"/> Daily |
| Drink alcohol | <input type="checkbox"/> Never | <input type="checkbox"/> Seldom | <input type="checkbox"/> Monthly | <input type="checkbox"/> Weekly | <input type="checkbox"/> Daily |
| Exercise | <input type="checkbox"/> Never | <input type="checkbox"/> Seldom | <input type="checkbox"/> Monthly | <input type="checkbox"/> Weekly | <input type="checkbox"/> Daily |
| Use social drugs | <input type="checkbox"/> Never | <input type="checkbox"/> Seldom | <input type="checkbox"/> Monthly | <input type="checkbox"/> Weekly | <input type="checkbox"/> Daily |
| Use prescription drugs | <input type="checkbox"/> Never | <input type="checkbox"/> Seldom | <input type="checkbox"/> Monthly | <input type="checkbox"/> Weekly | <input type="checkbox"/> Daily |
| Use poisons or chemicals | <input type="checkbox"/> Never | <input type="checkbox"/> Seldom | <input type="checkbox"/> Monthly | <input type="checkbox"/> Weekly | <input type="checkbox"/> Daily |
| Self-harm | <input type="checkbox"/> Never | <input type="checkbox"/> Seldom | <input type="checkbox"/> Monthly | <input type="checkbox"/> Weekly | <input type="checkbox"/> Daily |

4. Our service to you

How would you rate the service provided by PMH and your experience of it?:

- Excellent Good Average Poor

please comment

- What has been the best part of the treatment? *(select one or more or just comment)*
- | | |
|--|--|
| <input type="checkbox"/> Overall outcome | <input type="checkbox"/> Knowing there are treatment options |
| <input type="checkbox"/> Interactions with staff | <input type="checkbox"/> It has finished |

please comment

- What has been the worst part of the treatment? *(select one or more or just comment)*
- | | |
|--|--|
| <input type="checkbox"/> Pain and recovery | <input type="checkbox"/> The sheer number of appointments and treatments |
| <input type="checkbox"/> Interactions with staff | <input type="checkbox"/> Treatment is a reminder that you have a cleft condition |

please comment

- Have you felt adequately prepared for the treatment? Yes No

please comment

- Do you feel that you have had the opportunity to make decisions concerning your own treatment? Yes No

please comment

- Is this important to you? Yes No

please comment

Is there anything that we could have done better? Yes No

please comment

What did you personally need when you were growing up and going through the treatment?

please comment

Do you feel that you would have benefited from talking to:

A counsellor Yes No

A support group Yes No

Other people with clefts Yes No

A clinic co-ordinator Yes No

A nurse or support staff Yes No

A friend Yes No

please comment

Would you have found pamphlets on the following issues helpful? No Yes
please select as required

Teasing and bullying Social/ coping skills Overview of cleft Depression/ anxiety

Self esteem Appearance issues Cleft treatment Other
please specify

5. How have you found the health services outside of PMH (going from child to adult services)?

please comment

6. How can we improve the service at PMH and hence the experience here?

please comment

7. Further comments, reflections or suggestions

Please use this area to add your own comments and reflections concerning your experience both at PMH and in your life of having a cleft and any suggestions that may improve or explain your experience

Suggestions

.....

.....

Thank you for completing this questionnaire.

Qualitative Interview Schedule

1. What impact did having a cleft have on your life?

Aim: Establish the person's background and upbringing

Probe: Would you describe your life as an easy one?

1a. What were the negative things?

Aim: Reinforce information from question 1 – look at resilience.

Probe: how did you cope with this?

1b. What were the positive things?

Aim: Reinforce information from question 1 – look at resilience and understanding

Probe: do you think that your outlook helped this?

2. Who were the people that made an impact in your life?

Aim: Determine if support from others played a major role

Probe: people from: Treatment, School, Family, Friends, Socially

3. Are there things that could have been done differently?

Aim: What other factors can be identified as having a significant role. What were the needs at the time.

Probes: with regard to: Treatment, School, Family, Friends, Socially

4. What advice would you give to a teenager with a cleft?

Aim: Determine whether adolescence was a significant time with regard to having a cleft condition

Probe: Do you feel that most teenagers would feel that way including those without a cleft condition?

Health Care Professionals Questionnaire (HCPQ)

Background Information

- Gender (Male or Female)
- What is your age (in years)?
- What is your professional background (nurse, doctor, orthodontist etc.)?
- What is your current role in providing care for people with disfigurement?
- How long have you worked in this role?
- In what year did you qualify in your current profession?
- Your patient population:
 - What is the age range of your patients?
 - How many patients are receiving care/treatment at your institution?
 - Children
 - Teenagers
 - Adults
 - What is the range of conditions being treated?

Interview Questions

1. How much value is attached to 'looks' in your society (e.g. are people preoccupied with their appearance)?
2. Are the rates of people undergoing:
 - cosmetic surgery increasing?
 - cosmetic procedures (for example, Botox) increasing?
3. Do people spend time taking 'selfies' (pictures of themselves) to post on social media?
4. How does the society in which you live treat people who have a 'visible difference' (disfigurement)?
5. Are there positive impacts to having a visible difference in your society?

6. Are there negative impacts to having a visible difference in your society?
7. Do you think people with visible differences (for example, a cleft lip) face any particular psychological or social challenges? What are these? (eg negative feelings about the self, lowered self-esteem, self-confidence, negative body image, impacts on the behaviour of the affected person)?
8. If so, do these issues affect the person's daily life? In what ways? (e.g. in social situations; meeting new people, teasing, bullying or negative stereotyping by others, relationships; school achievement or occupational functioning – such as limitations to choice of job)?
9. Are there positive or negative impacts on the family as a whole, or on individual family members (other than the affected person)?
 - a. families becoming stronger/more supportive of each other
 - b. a sibling receiving less attention
 - c. a drop in family income
 - d. family stress or tension
10. Is any support available for those experiencing difficulties?
11. Are any of the challenges for people with visible differences more prevalent/made worse for those belonging to socially disadvantaged groups (eg migrants; members of low income families)?
12. To what extent do you feel confident in addressing the needs of patients and their families? Are there other people in your team or hospital to whom you can refer patients/family members in need of support?
13. Have you received any training about the psychological impacts of disfigurement and how to meet the needs of patients?

14. What would help you address the needs of patients and their families more effectively? (e.g. training – what sort; how should it be delivered; who needs training – You? Other members of the team?)

Appendix 4. Thesis Instruments Internal Reliability Analysis

Background

To determine the internal reliability of the children, adolescent and adult versions of the CRQ, and also for the HCPQ, the data from all of the completed questionnaires were used rather than relying on the pilot results as the pilot sample sizes were not large enough. See section 3.6.1.6 in Chapter 3 for a description of the methodology used to conduct the internal reliability analysis. The internal reliability of the BES instruments were not analyzed as these questionnaires have previously been verified by Mendelson et al (1996, 2001).

Children CRQ Internal Reliability Analysis

Children Impact of Cleft

```
##
## Principal Components Analysis for Children Impact of Cleft
## Variables: Academic Attitude FriendsAge Health Independence Photographed PublicSp
eaking Restriction School Sport
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
## Warning in cor.smooth(mat): Matrix was not positive definite, smoothing was done
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.3906 Test Rating: Failed
## WARNING! Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test Failed. Review data.
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 0 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 5.814 58.14 58.14 * *
## PC2 1.249 12.49 70.63 * *
## PC3 1.197 11.97 82.60 *
## PC4 0.773 7.73 90.33
## PC5 0.403 4.03 94.36
## PC6 0.362 3.62 97.98
## PC7 0.137 1.37 99.34
## PC8 0.066 0.66 100.00
## PC9 0.000 0.00 100.00
## PC10 0.000 0.00 100.00
```

The Children Impact of Cleft PCA shows there are between 1 and 3 PCs for the impact variables. However, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test failed, i.e. need to look at smaller groupings of variables for this sample size. This was as expected.

Children Impact Health

Look at 3 variables related to health: Health, Physical Restriction, Sport (i.e. the same as for Adults and Adolescents).

```
##
## Principal Components Analysis for Children Impact Health
## Variables: Health Restriction Sport
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
##
##
```

```

## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.5814 Test Rating: Failed
## WARNING! Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test Failed. Review data.
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 2.684e-23 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.117 70.58 70.58 * *
## PC2 0.640 21.35 91.93
## PC3 0.242 8.07 100.00

```

These 3 variables group into one PC although the Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test failed ($0.581 < 0.6$). Run the CA in any case to see what happens.

```

##
## Cronbach's Alpha for Children Impact Health
## Variables: Health Restriction Sport
## Std Alpha:0.57 95%CI=(0.43,0.71) Rating: Poor

```

The internal reliability is poor for the grouping of the 3 variables for the Health PC. This implies these questions were not well understood by the study participants.

Children Impact School and Relationships

Look at 3 variables related to School and Relationships: Academic, School, Friends same age.

```

##
## Principal Components Analysis for Children Impact School & Relationships
## Variables: Academic FriendsAge School
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.5581 Test Rating: Failed
## WARNING! Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test Failed. Review data.
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 1.168e-63 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.557 85.23 85.23 * *
## PC2 0.396 13.18 98.42
## PC3 0.047 1.58 100.00

```

These 3 variables group into one PC although the Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test failed ($0.558 < 0.6$). Run the CA in any case to see what happens.

```

##
## Cronbach's Alpha for Children Impact School & Relationships
## Variables: Academic FriendsAge School
## Std Alpha:0.75 95%CI=(0.67,0.83) Rating: Acceptable

```

Children Impact Self

Look at 4 variables related to self: Public Speaking (i.e. being self conscious in public), being photographed, attitude to life (as per Adults) with the addition of Independence.

```
##
## Principal Components Analysis for Children Impact Self
## Variables: Attitude Photographed PublicSpeaking Independence
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.7314 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 3.671e-54 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 3.065 76.62 76.62 * *
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Children Impact Self
## Variables: Attitude Photographed PublicSpeaking Independence
## Std Alpha:0.72 95%CI=(0.64,0.81) Rating: Acceptable
```

Children Impact Summary

The 10 impact of cleft variables for Children were split into three sub-categories which each grouped to a single PC. Two of the three Cronbach's Alpha were acceptable, with Health being poor. Two of three Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test failed. Overall, the internal reliability for these 10 variables was marginal to ok.

Children Importance Physical Attributes

```
##
## Principal Components Analysis for Children Importance Physical
## Variables: Face Hearing Speech Teeth
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.5635 Test Rating: Failed
## WARNING! Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test Failed. Review data.
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 5.711e-34 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.439 60.99 60.99 * *
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule.

```
##
## Cronbach's Alpha for Children Importance Physical
## Variables: Face Hearing Speech Teeth
## Std Alpha:0.78 95%CI=(0.70,0.85) Rating: Acceptable
```

Children Importance Support

```
##
## Principal Components Analysis for Children Importance Support
## Variables: Teacher Parents Siblings TreatGivers
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.6644 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 3.31e-34 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.589 64.72 64.72 * *
## PC2 0.824 20.59 85.31
## PC3 0.370 9.25 94.56
## PC4 0.218 5.44 100.00
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Children Importance Support
## Variables: Teacher Parents Siblings TreatGivers
## Std Alpha:0.73 95%CI=(0.64,0.82) Rating: Acceptable
```

Children Satisfaction Physical Attributes

```
##
## Principal Components Analysis for Children Satisfaction Physical
## Variables: Face Hearing Speech Teeth
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.691 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 3.259e-24 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.400 60.01 60.01 * *
## PC2 0.861 21.53 81.54
## PC3 0.400 9.99 91.53
## PC4 0.339 8.47 100.00
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Children Satisfaction Physical
## Variables: Face Hearing Speech Teeth
## Std Alpha:0.73 95%CI=(0.65,0.82) Rating: Acceptable
```

Children Satisfaction Support

```
##
## Principal Components Analysis for Children Satisfaction Support
```

```

## Variables: Teacher Parents Siblings TreatGivers
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.7925 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 1.402e-26 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.604 65.09 65.09 * *
## PC2 0.561 14.02 79.12
## PC3 0.480 12.00 91.11
## PC4 0.355 8.89 100.00

```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```

##
## Cronbach's Alpha for Children Satisfaction Support
## Variables: Teacher Parents Siblings TreatGivers
## Std Alpha:0.73 95%CI=(0.64,0.82) Rating: Acceptable

```

Adolescents CRQ Internal Reliability Analysis

Adolescents Impact of Cleft

Look at all 12 variables associated with the impact of cleft on Adolescents. The following variables from the Adults dataset were dropped: Impact_Doing_Work, Impact_Friends_Opp_Sex, Impact_Job_Interviews, Impact_Pubs_Clubs, Impact_Self_Esteem.

```

##
## Principal Components Analysis for Adolescents Impact of Cleft
## Variables: Academic Attitude FriendsAge GettingWork Health Independence Photographed PublicSpeaking Restriction School SpecialRels Sport
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
## Warning in cor.smooth(mat): Matrix was not positive definite, smoothing was done
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.3413 Test Rating: Failed
## WARNING! Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test Failed. Review data.
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 0 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 6.085 50.71 50.71 * *
## PC2 1.676 13.97 64.68 * *
## PC3 1.304 10.87 75.55 *
## PC4 1.211 10.09 85.64 *
## PC5 0.610 5.09 90.73
## PC6 0.415 3.45 94.18
## PC7 0.306 2.55 96.73
## PC8 0.198 1.65 98.38
## PC9 0.128 1.07 99.45
## PC10 0.066 0.55 100.00

```

```
## PC11      0.000  0.00  100.00
## PC12      0.000  0.00  100.00
```

Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test failed. Need to look at smaller groupings of variables for this sample size. This was as expected.

Adolescents Impact Health

Look at 3 variables related to health: Health, Physical Restriction, Sport (i.e. the same as for Adults).

```
##
## Principal Components Analysis for Adolescents Impact Health
## Variables: Health Restriction Sport
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.646 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 1.244e-15 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1      1.989 66.31    66.31          *          *
## PC2      0.628 20.95    87.26
## PC3      0.382 12.74   100.00
```

These 3 variables group into one PC for the Kaiser Rule and Cumulative variance % rule.

```
##
## Cronbach's Alpha for Adolescents Impact Health
## Variables: Health Restriction Sport
## Std Alpha:0.52 95%CI=(0.36,0.69) Rating: Poor
```

The internal reliability is poor for the grouping of the 3 variables for the Health PC. This implies these questions were not well understood by the study participants.

Adolescents Impact School and Relationships

Look at 4 variables related to School and Relationships: Academic, School, Friends same age, and Special Relationships.

```
##
## Principal Components Analysis for Adolescents Impact School & Relationships
## Variables: Academic FriendsAge School SpecialRels
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.6829 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 9.176e-50 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
```

```
## PC1      2.791 69.78    69.78          *          *
## PC2      0.825 20.64    90.41
## PC3      0.220  5.50    95.91
## PC4      0.163  4.09    100.00
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Adolescents Impact School & Relationships
## Variables: Academic FriendsAge School SpecialRels
## Std Alpha:0.70 95%CI=(0.61,0.79) Rating: Questionable
```

The Alpha score is questionable ... but only just. It is very close to the > 0.7 cutoff for acceptable.

Adolescents Impact Self

Look at 4 variables related to self: Public Speaking (i.e. being self conscious in public), being photographed, attitude to life (as per Adults) with the addition of Independence. Note that Getting Work did not fit anywhere.

```
##
## Principal Components Analysis for Adolescents Impact Self
## Variables: Attitude Photographed PublicSpeaking Independence
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.5805 Test Rating: Failed
## WARNING! Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test Failed. Review data.
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 9.115e-49 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1      2.656 66.39    66.39          *          *
## PC2      0.908 22.69    89.08
## PC3      0.326  8.15    97.24
## PC4      0.111  2.76    100.00
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Adolescents Impact Self
## Variables: Attitude Photographed PublicSpeaking Independence
## Std Alpha:0.65 95%CI=(0.54,0.76) Rating: Questionable
```

The Alpha score is questionable.

Adolescents Impact Summary

The 12 impact of cleft variables for Adolescents were split into three sub-categories which each grouped to a single PC. The Cronbach's Alpha for each of these sub-groups were all low (Health: 0.523, School & Relationships: 0.699, Self: 0.651). Overall, the internal reliability for these 12 variables was marginal.

Adolescents Importance Physical Attributes

```

##
## Principal Components Analysis for Adolescents Importance Physical
## Variables: Face Hearing Speech Teeth
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.6147 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 3.68e-54 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.762 69.06 69.06 * *
## PC2 0.900 22.51 91.57
## PC3 0.206 5.16 96.73
## PC4 0.131 3.27 100.00

```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule.

```

##
## Cronbach's Alpha for Adolescents Importance Physical
## Variables: Face Hearing Speech Teeth
## Std Alpha:0.84 95%CI=(0.79,0.90) Rating: Good

```

Adolescents Importance Support

```

##
## Principal Components Analysis for Adolescents Importance Support
## Variables: Teacher Parents Siblings TreatGivers
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.836 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 7.011e-55 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 3.122 78.04 78.04 * *
## PC2 0.429 10.73 88.77
## PC3 0.269 6.73 95.51
## PC4 0.180 4.49 100.00

```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```

##
## Cronbach's Alpha for Adolescents Importance Support
## Variables: Teacher Parents Siblings TreatGivers
## Std Alpha:0.86 95%CI=(0.82,0.91) Rating: Good

```

Adolescents Satisfaction Physical Attributes

```

##
## Principal Components Analysis for Adolescents Satisfaction Physical
## Variables: Face Hearing Speech Teeth
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.6957 Test Rating: Passed
##

```

```
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 8.036e-32 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.575 64.37 64.37 * *
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Adolescents Satisfaction Physical
## Variables: Face Hearing Speech Teeth
## Std Alpha:0.78 95%CI=(0.71,0.85) Rating: Acceptable
```

Adolescents Satisfaction Support

```
##
## Principal Components Analysis for Adolescents Satisfaction Support
## Variables: Teacher Parents Siblings TreatGivers
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.797 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 1.147e-45 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.972 74.30 74.30 * *
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Adolescents Satisfaction Support
## Variables: Teacher Parents Siblings TreatGivers
## Std Alpha:0.84 95%CI=(0.78,0.89) Rating: Good
```

Adult CRQ Reliability Analysis

Adults Impact of Cleft

Look at all 17 variables associated with the impact of cleft on Adults.

```
##
## Principal Components Analysis for Adults Impact of Cleft
## Variables: Academic Attitude DoingWork FriendsAge FriendsOpSex GettingWork Health
Independence JobInterviews Photographed PublicSpeaking PubsClubs Restriction School
SelfEsteem SpecialRels Sport
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
## Warning in optimize(tetraF, interval = c(-1, 1), rc = rc, cc = cc, tab = tab): NA/Inf re
placed by maximum positive value
## Warning in log(P): NaNs produced
## Warning in optimize(tetraF, interval = c(-1, 1), rc = rc, cc = cc, tab = tab): NA/Inf re
placed by maximum positive value
```

```

## Warning in cor.smooth(mat): Matrix was not positive definite, smoothing was done
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.5986 Test Rating: Failed
## WARNING! Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test Failed. Review data.
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 0 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 9.578 56.34 56.34 * *
## PC2 2.221 13.06 69.41 * *
## PC3 1.297 7.63 77.03 *
## PC4 0.949 5.58 82.61
## PC5 0.614 3.61 86.22
## PC6 0.594 3.50 89.72
## PC7 0.562 3.31 93.02
## PC8 0.369 2.17 95.19
## PC9 0.272 1.60 96.79
## PC10 0.224 1.32 98.11
## PC11 0.166 0.97 99.08
## PC12 0.098 0.58 99.66
## PC13 0.058 0.34 100.00
## PC14 0.000 0.00 100.00
## PC15 0.000 0.00 100.00
## PC16 0.000 0.00 100.00
## PC17 0.000 0.00 100.00

```

The Adults Impact of Cleft PCA shows there were at least 2 PC's and possibly 4 PC's for the 17 impact variables. This indicates these variables cannot be treated as one group, i.e. need to consider smaller groups. This was as expected.

Adults Impact Work Life

Look at 4 variables related to work life: Job Interviews, Getting Work, Doing Work and Independence.

```

##
## Principal Components Analysis for Adults Impact Work Life
## Variables: DoingWork GettingWork Independence JobInterviews
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.7545 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 4.628e-102 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 3.129 78.22 78.22 * *
## PC2 0.530 13.24 91.46
## PC3 0.228 5.69 97.15
## PC4 0.114 2.85 100.00

```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule


```
##
## Cronbach's Alpha for Adults Impact Work Life
## Variables: DoingWork GettingWork Independence JobInterviews
## Std Alpha:0.77 95%CI=(0.71,0.83) Rating: Acceptable
```

Adults Impact Health

Look at 3 variables related to health: Health, Physical Restriction and Sport.

```
##
## Principal Components Analysis for Adults Impact Health
## Variables: Health Restriction Sport
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.6385 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 1.132e-59 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.312 77.06 77.06 * *
## PC2 0.558 18.59 95.65
## PC3 0.130 4.35 100.00
```

These 3 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Adults Impact Health
## Variables: Health Restriction Sport
## Std Alpha:0.68 95%CI=(0.59,0.77) Rating: Questionable
```

Adults Impact School and Relationships

Look at 6 variables related to School and Relationships: Academic, School, Friends same age, Friends opposite sex, going to Pubs and Clubs, and Special Relationships.

```
##
## Principal Components Analysis for Adults Impact School & Relationships
## Variables: Academic FriendsAge FriendsOpSex PubsClubs School SpecialRel
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
## Warning in cor.smooth(mat): Matrix was not positive definite, smoothing was done
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.266 Test Rating: Failed
## WARNING! Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test Failed. Review data.
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 0 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 3.945 65.76 65.76 * *
## PC2 0.824 13.74 79.50
## PC3 0.670 11.17 90.67
## PC4 0.376 6.27 96.94
```

```
## PC5      0.184  3.06  100.00
## PC6      0.000  0.00  100.00
```

These 6 variables failed the Kaiser-Meyer-Olkin Measure of Sample Adequacy therefore grouping to single PC is not reliable. Run CA test in any case to see what happens.

```
##
## Cronbach's Alpha for Adults Impact School & Relationships
## Variables: Academic FriendsAge FriendsOpSex PubsClubs School SpecialReIs
## Std Alpha:0.77 95%CI=(0.71,0.82) Rating: Acceptable
```

Adults Impact Self

Look at remaining 4 variables related to self: Public Speaking (i.e. being self conscious in public), self esteem, being photographed, attitude to life.

```
##
## Principal Components Analysis for Adults Impact Self
## Variables: Attitude Photographed PublicSpeaking SelfEsteem
## Correlation Type:tetrachoric Rotation:none Cumulative Var% Threshold:60%
## Warning in optimize(tetraF, interval = c(-1, 1), rc = rc, cc = cc, tab = tab): NA/Inf replaced by maximum positive value
## Warning in cor.smooth(mat): Matrix was not positive definite, smoothing was done
##
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.3588 Test Rating: Failed
## WARNING! Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test Failed. Review data.
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 0 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1      3.224 80.61    80.61          *          *
## PC2      0.482 12.05    92.66
## PC3      0.294  7.34   100.00
## PC4      0.000  0.00   100.00
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Adults Impact Self
## Variables: Attitude Photographed PublicSpeaking SelfEsteem
## Std Alpha:0.78 95%CI=(0.72,0.84) Rating: Acceptable
```

Adults Impact Summary

The 17 impact of cleft variables for adults were split into four sub-categories which each grouped to a single PC. The Cronbach's Alpha for each of these sub-groups was > 0.7 (i.e. Acceptable) with the exception of Health (made up of General Health, Physical Restriction and Participate in Sport) which had an Alpha of 0.679 (i.e. questionable). Overall, the internal reliability for these 17 variables was acceptable.

Adults Importance Physical Attributes

```
##
## Principal Components Analysis for Adults Importance Physical
## Variables: Face Hearing Speech Teeth
```

```
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.6466 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 1.896e-49 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.496 62.41 62.41 * *
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Adults Importance Physical
## Variables: Face Hearing Speech Teeth
## Std Alpha:0.75 95%CI=(0.68,0.81) Rating: Acceptable
```

Adults Importance Support

```
##
## Principal Components Analysis for Adults Importance Support
## Variables: Employer Parents Siblings TreatGivers
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.783 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 2.773e-57 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.753 68.82 68.82 * *
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Adults Importance Support
## Variables: Employer Parents Siblings TreatGivers
## Std Alpha:0.80 95%CI=(0.75,0.85) Rating: Acceptable
```

Adults Satisfaction Physical Attributes

```
##
## Principal Components Analysis for Adults Satisfaction Physical
## Variables: Face Hearing Speech Teeth
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.7044 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 1.426e-35 Test Rating: Passed
```

```
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.372 59.31 59.31 * *
## PC2 0.814 20.36 79.66 *
## PC3 0.428 10.71 90.37
## PC4 0.385 9.63 100.00
```

These 4 variables group into one PC for the Kaiser Rule, although the Cumulative variance % rule may indicate 2 Pcs.

```
##
## Cronbach's Alpha for Adults Satisfaction Physical
## Variables: Face Hearing Speech Teeth
## Std Alpha:0.73 95%CI=(0.66,0.80) Rating: Acceptable
```

Adults Satisfaction Support

```
##
## Principal Components Analysis for Adults Satisfaction Support
## Variables: Employer Parents Siblings TreatGivers
## Correlation Type:polychoric Rotation:none Cumulative Var% Threshold:60%
##
## Kaiser-Meyer-Olkin Measure of Sampling Adequacy Test
## Values near 1 are better with 0.6 a suggested minimum.
## MSA Score: 0.7602 Test Rating: Passed
##
## Bartlett's Test of Sphericity
## Null hypothesis: correlation matrix is an identity matrix
## P value: 8.467e-61 Test Rating: Passed
##
## EigenValues Table
## EigenValues Var% Cum Var% Cum Var% Rule Kaiser Rule
## PC1 2.783 69.58 69.58 * *
## PC2 0.549 13.71 83.29
## PC3 0.454 11.35 94.64
## PC4 0.214 5.36 100.00
```

These 4 variables group into one PC for the Kaiser Rule and Cumulative variance % rule

```
##
## Cronbach's Alpha for Adults Satisfaction Support
## Variables: Employer Parents Siblings TreatGivers
## Std Alpha:0.79 95%CI=(0.74,0.85) Rating: Acceptable
```

Appendix 5. Data Analyses

Data Analysis for Chapter 4 Paper 1: Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups

Background

The Body Esteem Scale for Children (BESC) was developed and validated by Mendelson et al in 1996. The BESC has three factors: BESC-Appearance, BESC-Weight and BESC-Attribution, however the latter (BESC-Attribution) was unreliable and was dropped from further analysis. The Body Esteem Scale for Adolescents and Adults (BES) was developed and validated by Mendelson et al in 2001. It also has the same three factors, all of which were reliable.

The purpose of this analysis was two fold:

Firstly, to compare the normative results from the Mendelson papers with the results from this study for each of the factors in the Children, Adolescent and Adult age-groups.

Secondly, to conduct linear regression analysis for each age-group to determine which of the following variables were associated with each of the factors: Gender, Cleft Type, Body Weight rating, and Importance of Facial Appearance rating.

Notes:

The approach used in the regression analysis was based on suggestions/guidelines in *The R Book* by Michael J Crawley, 2nd Ed, Wiley, 2013, ISBN: 978-0-470-97392-9.

Alpha level of 0.05 (i.e. 95% Confidence Level) was used for all hypothesis tests. This analysis used R version: 3.4.1 and RStudio version: 1.0.143 using RMarkdown version:1.6.

Children BESC Analysis Study v Mendelson By Gender

Children BESC_Appearance

```
## t-Test for Children BESC_Appearance for Males
## Study      mean=11.19  sd=2.69  n=48
## Mendelson  mean=11.20  sd=2.20  n=159
## p-value: 0.9739  Result: Not Significant
## ##
```

```
## t-Test for Children BESC_Appearance for Females
## Study      mean=9.54  sd=4.07  n=52
## Mendelson  mean=9.70  sd=3.60  n=220
## p-value: 0.7768  Result: Not Significant
## ##
```

Children BESC_Weight

```
## t-Test for Children BESC_Weight for Males
## Study      mean=2.46  sd=0.87  n=48
## Mendelson  mean=2.40  sd=0.90  n=159
## p-value: 0.6924  Result: Not Significant
## ##
```

```
## t-Test for Children BESC_Weight for Females
## Study mean=2.23 sd=1.00 n=52
## Mendelson mean=1.90 sd=1.20 n=220
## p-value: 0.0667 Result: Not Significant
## ##
```

Adolescents BES Analysis Study v Mendelson By Gender

Adolescents BES_Appearance

```
## t-Test for Adolescents BES_Appearance for Males
## Study mean=2.46 sd=0.80 n=63
## Mendelson mean=2.90 sd=0.70 n=488
## p-value: 0.0000 Result: Significant
## ##
```

```
## t-Test for Adolescents BES_Appearance for Females
## Study mean=2.14 sd=0.80 n=38
## Mendelson mean=2.10 sd=0.90 n=630
## p-value: 0.7918 Result: Not Significant
## ##
```

Adolescents BES_Weight

```
## t-Test for Adolescents BES_Weight for Males
## Study mean=2.76 sd=0.89 n=63
## Mendelson mean=2.90 sd=0.90 n=488
## p-value: 0.2319 Result: Not Significant
## ##
```

```
## t-Test for Adolescents BES_Weight for Females
## Study mean=2.54 sd=0.90 n=38
## Mendelson mean=2.00 sd=1.10 n=630
## p-value: 0.0030 Result: Significant
## ##
```

Adolescents BES_Attribution

```
## t-Test for Adolescents BES_Attribution for Males
## Study mean=1.57 sd=0.78 n=63
## Mendelson mean=2.30 sd=0.80 n=488
## p-value: 0.0000 Result: Significant
## ##
```

```
## t-Test for Adolescents BES_Attribution for Females
## Study mean=1.76 sd=0.76 n=38
## Mendelson mean=2.10 sd=0.80 n=630
## p-value: 0.0105 Result: Significant
## ##
```

Adults BES Analysis Study v Mendelson By Gender

Adults BES_Appearance

```
## t-Test for Adults BES_Appearance for Males
## Study mean=2.39 sd=0.85 n=71
## Mendelson mean=2.70 sd=0.70 n=83
## p-value: 0.0135 Result: Significant
## ##
```

```
## t-Test for Adults BES_Appearance for Females
## Study mean=2.26 sd=0.80 n=87
## Mendelson mean=2.50 sd=0.70 n=133
## p-value: 0.0193 Result: Significant
## ##
```

Adults BES_Weight

```
## t-Test for Adults BES_Weight for Males
## Study mean=2.45 sd=0.93 n=71
## Mendelson mean=2.70 sd=0.80 n=83
```

```
## p-value: 0.0800 Result: Not Significant
## ##

## t-Test for Adults BES_Weight for Females
## Study mean=2.21 sd=0.96 n=87
## Mendelson mean=2.30 sd=1.00 n=133
## p-value: 0.5280 Result: Not Significant
## ##
```

Adults BES_Attribution

```
## t-Test for Adults BES_Attribution for Males
## Study mean=1.77 sd=0.75 n=71
## Mendelson mean=2.40 sd=0.80 n=83
## p-value: 0.0000 Result: Significant
## ##

## t-Test for Adults BES_Attribution for Females
## Study mean=1.90 sd=0.72 n=87
## Mendelson mean=2.50 sd=0.70 n=133
## p-value: 0.0000 Result: Significant
## ##
```

Summary of Study v Mendelson

Apply Holm adjustment to the p values for all of the tests and then print the results.

Test_Name	PValue	Significant	PAdjust	SignifAdjust
Children BESC_Appearance for Males	0.9739	Not Significant	1.0000	Not Significant
Children BESC_Appearance for Females	0.7768	Not Significant	1.0000	Not Significant
Children BESC_Weight for Males	0.6924	Not Significant	1.0000	Not Significant
Children BESC_Weight for Females	0.0667	Not Significant	0.5338	Not Significant
Adolescents BES_Appearance for Males	0.0000	Significant	0.0001	Significant
Adolescents BES_Appearance for Females	0.7918	Not Significant	1.0000	Not Significant
Adolescents BES_Weight for Males	0.2319	Not Significant	1.0000	Not Significant
Adolescents BES_Weight for Females	0.0030	Significant	0.0357	Significant
Adolescents BES_Attribution for Males	0.0000	Significant	0.0000	Significant
Adolescents BES_Attribution for Females	0.0105	Significant	0.1152	Not Significant
Adults BES_Appearance for Males	0.0135	Significant	0.1346	Not Significant
Adults BES_Appearance for Females	0.0193	Significant	0.1737	Not Significant
Adults BES_Weight for Males	0.0800	Not Significant	0.5598	Not Significant
Adults BES_Weight for Females	0.5280	Not Significant	1.0000	Not Significant
Adults BES_Attribution for Males	0.0000	Significant	0.0000	Significant
Adults BES_Attribution for Females	0.0000	Significant	0.0000	Significant

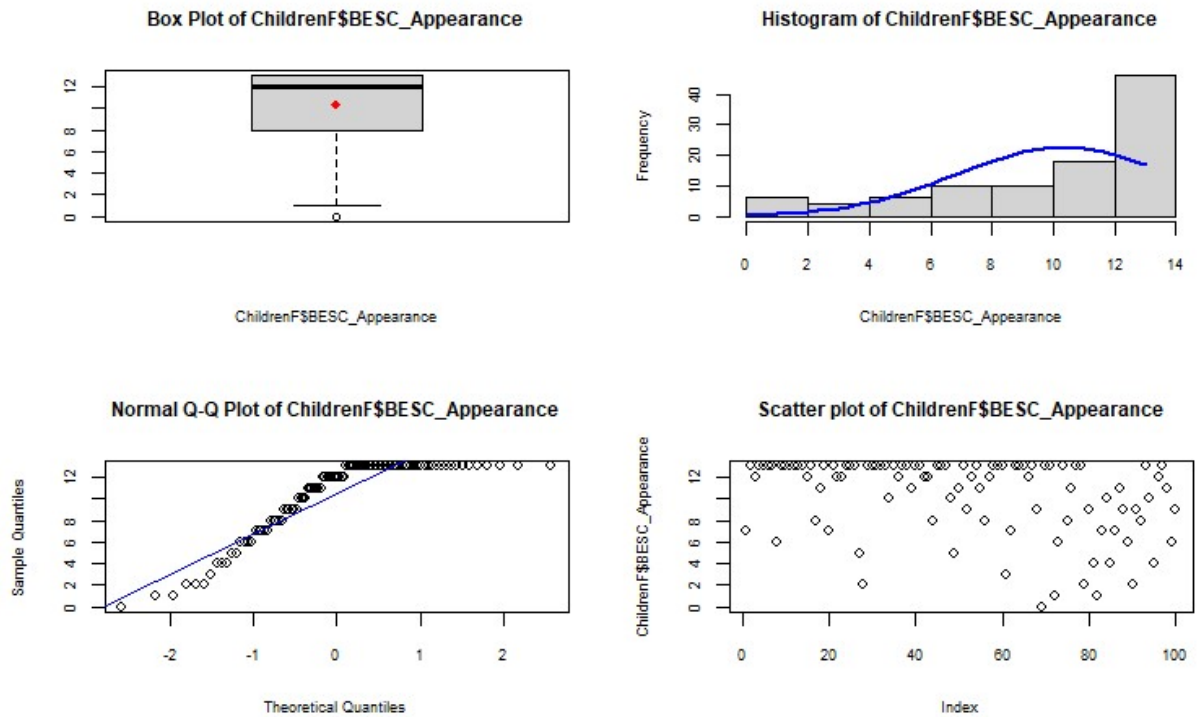
Children Regression Analysis

Children BESC_Appearance

Summary Stats and Visualisation

BESC_Appearance was treated as a continuous variable ranging from 0 to 13. The higher the number the more a person is happy with their appearance.

```
## Descriptive Stats for: ChildrenF$BESC_Appearance
##   n mean  sd median min max range skew kurtosis  se
## 100 10.33 3.55   12   0 13   13 -1.24   0.44 0.36
```



```
## Normality Tests p-values. Shapiro-Wilk:0.0000 Anderson-Darling:0.0000
## Data are not normally distributed.
```

The data are not normally distributed (highly negatively skewed) with one outlier identified.

ChildrenApp1a Baseline Model

Combine all the variables used for the analysis into one baseline model.

```
## Factor: Gender           Levels: Female, Male
## Factor: Body_Weight1     Levels: Normal, Overweight, Under
## Factor: Cleft_Type       Levels: Palate-only, Lip & Palate, Lip-only
## Factor: Imp_Face_Appearance Levels: Somewhat, Extremely, Very, Not Very, Not At All

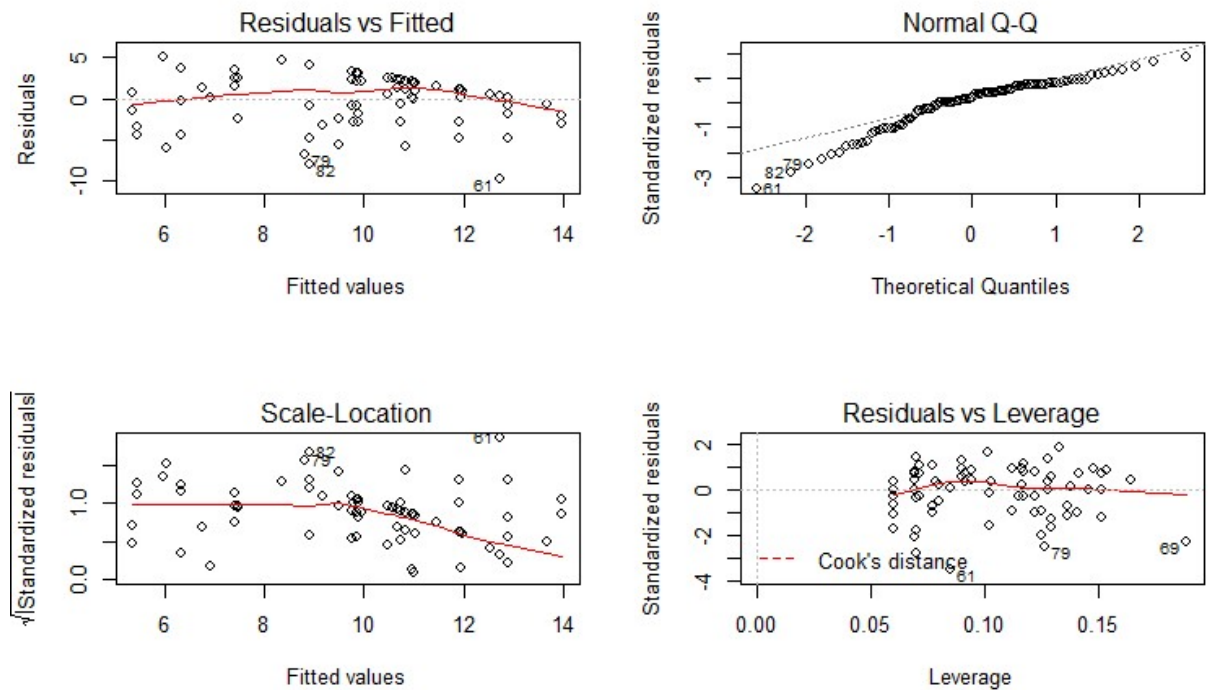
##
## Call:
## lm(formula = BESC_Appearance ~ Gender + Body_Weight1 + Cleft_Type +
##     Imp_Face_Appearance, data = ChildrenF)
##
## Residuals:
##   Min     1Q  Median     3Q    Max
## -9.723 -1.023  0.582  2.049  5.035
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)      11.920      0.824   14.47 < 2e-16 ***
## GenderMale         0.960      0.654    1.47  0.1454
## Body_Weight1Overweight -3.545      0.838   -4.23  5.6e-05 ***
## Body_Weight1Under    -2.145      1.007   -2.13  0.0359 *
## Cleft_TypeLip & Palate -2.040      0.686   -2.98  0.0038 **
## Cleft_TypeLip-only  -1.439      0.988   -1.46  0.1488
```



```

## Imp_Face_AppearanceExtremely    -0.888    1.053   -0.84    0.4013
## Imp_Face_AppearanceVery         -0.970    0.800   -1.21    0.2286
## Imp_Face_AppearanceNot Very      1.104    1.156    0.95    0.3425
## Imp_Face_AppearanceNot At All    0.803    1.036    0.77    0.4408
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 2.94 on 90 degrees of freedom
## Multiple R-squared:  0.378, Adjusted R-squared:  0.316
## F-statistic: 6.07 on 9 and 90 DF, p-value: 1.25e-06

```



```

## Normality Tests p-values. Shapiro-Wilk:0.0000 Anderson-Darling:0.0000
## Data are not normally distributed.

```

The adjusted R-squared 0.316 is moderate, however the residuals are not normally distributed and are heteroscedastic.

ChildrenApp1a Multi-collinearity.

Check the Variance Inflation Factor (VIF) for the model. Any value > 10 indicates multi-collinearity.

```

##          df VIF Value
## Gender          1  1.235
## Body_Weight1    2  1.170
## Cleft_Type       2  1.127
## Imp_Face_Appearance 4  1.131

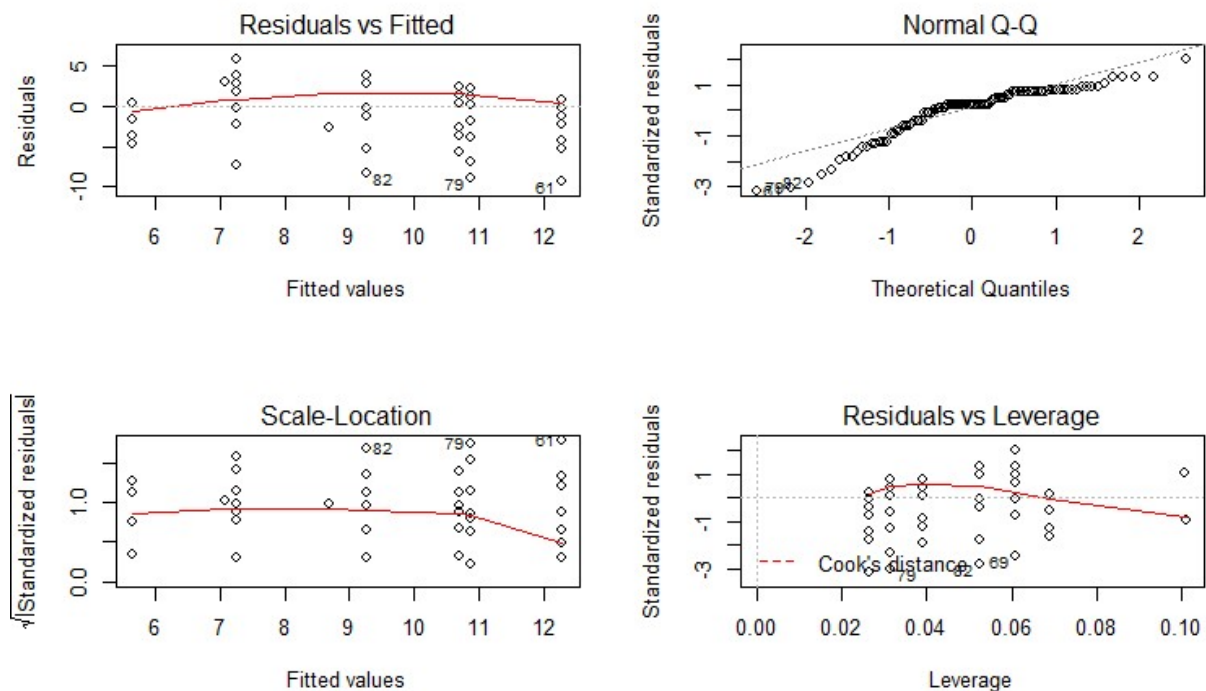
```

Multi-collinearity does not appear to be an issue (no values > 10).

ChildrenApp2a Reduced Model

The baseline model was reduced by successively removing non-significant variables and/or compressing factor levels to reach a minimal adequate model (i.e. all coefficients are significant) for the variables used.

```
## Factor: Body_Weight2      Levels: Not Overweight, Overweight
## Factor: Cleft_Type2      Levels: Not L&P, Lip & Palate
## Factor: Imp_Face_Appearance3 Levels: Some-Not Important, Important
##
## Call:
## lm(formula = BESC_Appearance ~ Body_Weight2 + Cleft_Type2 + Imp_Face_Appearance3,
##     data = ChildrenF)
##
## Residuals:
##   Min     1Q  Median     3Q    Max
## -9.281 -1.281  0.719  2.146  5.746
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)      12.281      0.486   25.28 < 2e-16 ***
## Body_Weight2Overweight -3.600      0.826   -4.36 3.3e-05 ***
## Cleft_Type2Lip & Palate -1.586      0.636   -2.49  0.014 *
## Imp_Face_Appearance3Important -1.426      0.647   -2.20  0.030 *
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 2.99 on 96 degrees of freedom
## Multiple R-squared:  0.315, Adjusted R-squared:  0.293
## F-statistic: 14.7 on 3 and 96 DF,  p-value: 6.02e-08
```



```
## Normality Tests p-values. Shapiro-Wilk:0.0000 Anderson-Darling:0.0000
## Data are not normally distributed.
```

Compare ChildrenApp1a and ChildrenApp2a Models

Use anova to determine if the reduced model is significantly worse as a description of the data than the baseline model. A non-significant test result indicates the reduction was justified.

```
## Analysis of Variance F-Test
## Model 1: BESC_Appearance ~ Gender + Body_Weight1 + Cleft_Type + Imp_Face_Appearance
## Model 2: BESC_Appearance ~ Body_Weight2 + Cleft_Type2 + Imp_Face_Appearance3
## p-value: 0.1795 Rating: Not Significant
```

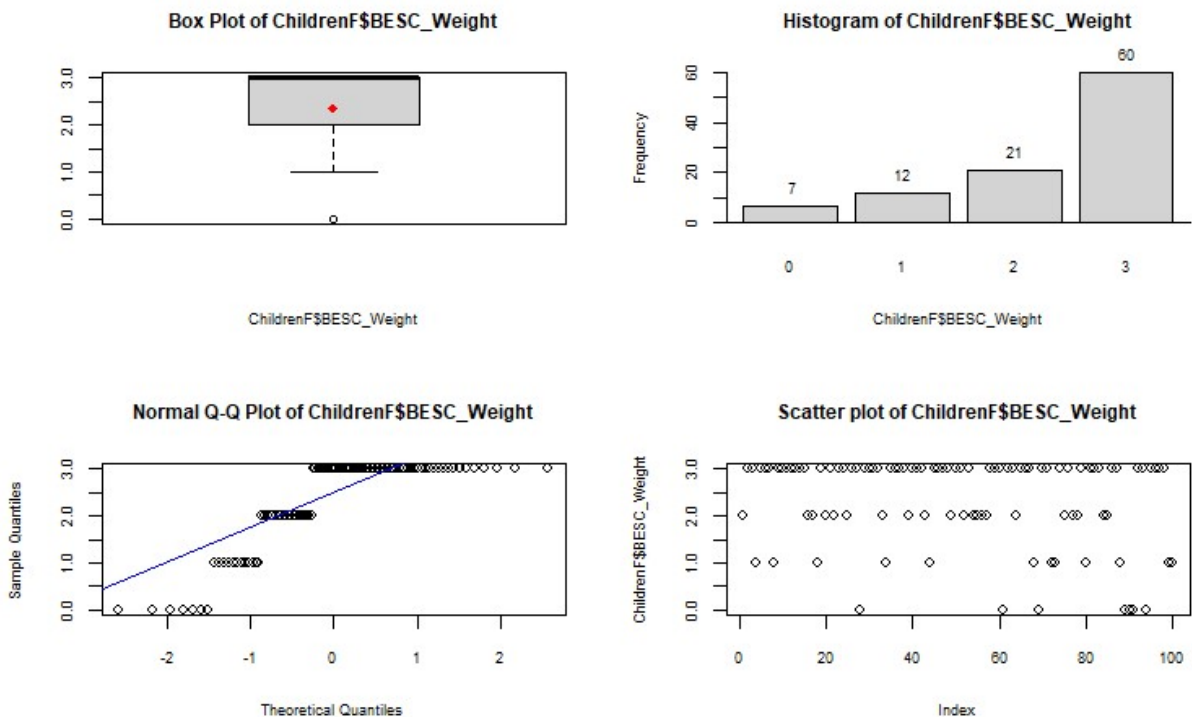
The non-significant test result confirms model reduction was justified, therefore ChildrenApp2a is the minimal adequate model for the variables used with an adjusted R-Squared of 0.293 compared to the baseline model 0.316.

Children BESC_Weight POLR Analysis

Summary Stats and Visualisation

BESC_Weight is an ordinal variable with integer values ranging from 0 to 3. The higher the number the more a person is happy with their weight. BESC_Weight1 is a factor version with levels very low, low, high, very high.

```
## Descriptive Stats for: ChildrenF$BESC_Weight
## n mean sd median min max range skew kurtosis se
## 100 2.34 0.95 3 0 3 3 -1.21 0.26 0.09
```



```
## Normality Tests p-values. Shapiro-Wilk:0.0000 Anderson-Darling:0.0000
## Data are not normally distributed.
```

The data are not normally distributed with one outlier identified.

ChildrenWgt1a Baseline model

Combine all the variables used for the analysis into one baseline model. The polr command from the MASS package was used to estimate an ordered logistic regression model. The command name comes from proportional odds logistic regression, highlighting the proportional odds assumption in the model. polr uses the standard formula interface in R for specifying a regression model. Specify Hess=TRUE to have the model return the observed information matrix from optimization (called the Hessian) which is used to get standard errors. Coefficient estimates are in units of ordered logits (ordered log odds).

```
## Factor: BESC_Weight1      Levels: very low, low, high, very high
## Factor: Gender           Levels: Female, Male
## Factor: Body_Weight      Levels: Normal, Little Over, Quite Over, Under
## Factor: Cleft_Type       Levels: Palate-only, Lip & Palate, Lip-only
## Factor: Imp_Face_Appearance Levels: Somewhat, Extremely, Very, Not Very, Not At All

## Call:
## polr(formula = BESC_Weight1 ~ Gender + Body_Weight1 + Cleft_Type +
##       Imp_Face_Appearance, data = ChildrenF, Hess = TRUE)
##
## Coefficients:
##                Value Std. Error t value
## GenderMale      -0.3990    0.496  -0.804
## Body_Weight1Overweight -3.9729    0.709  -5.602
## Body_Weight1Under    -1.8035    0.681  -2.650
## Cleft_TypeLip & Palate -0.5817    0.497  -1.170
## Cleft_TypeLip-only    0.3573    0.863   0.414
## Imp_Face_AppearanceExtremely -0.5773    0.792  -0.729
## Imp_Face_AppearanceVery -0.3618    0.605  -0.598
## Imp_Face_AppearanceNot Very -0.0802    0.966  -0.083
## Imp_Face_AppearanceNot At All -0.7924    0.758  -1.045
##
## Intercepts:
##                Value Std. Error t value
## very low|low    -5.544    0.924   -6.003
## low|high        -3.736    0.771   -4.847
## high|very high -1.947    0.671   -2.899
##
## Residual Deviance: 164.11
## AIC: 188.11
```

Calculate 95% CI for each coefficient using profiling of the likelihood function. If the 95% CI does not cross 0, the parameter estimate is statistically significant.

```
##                Low95%CI High95%CI Signif
## GenderMale      -1.394    0.565
## Body_Weight1Overweight -5.452  -2.652  *
## Body_Weight1Under    -3.167  -0.473  *
## Cleft_TypeLip & Palate -1.571    0.391
## Cleft_TypeLip-only    -1.253    2.185
## Imp_Face_AppearanceExtremely -2.136    1.010
## Imp_Face_AppearanceVery -1.581    0.815
## Imp_Face_AppearanceNot Very -1.895    2.045
## Imp_Face_AppearanceNot At All -2.301    0.704
```

The Body_Weight variable is the only one that has significant coefficients.

ChildrenWgt2a Reduced Model

The baseline model was reduced by successively removing non-significant variables and/or compressing factor levels to reach a minimal adequate model (i.e. all coefficients are significant) for the variables used.

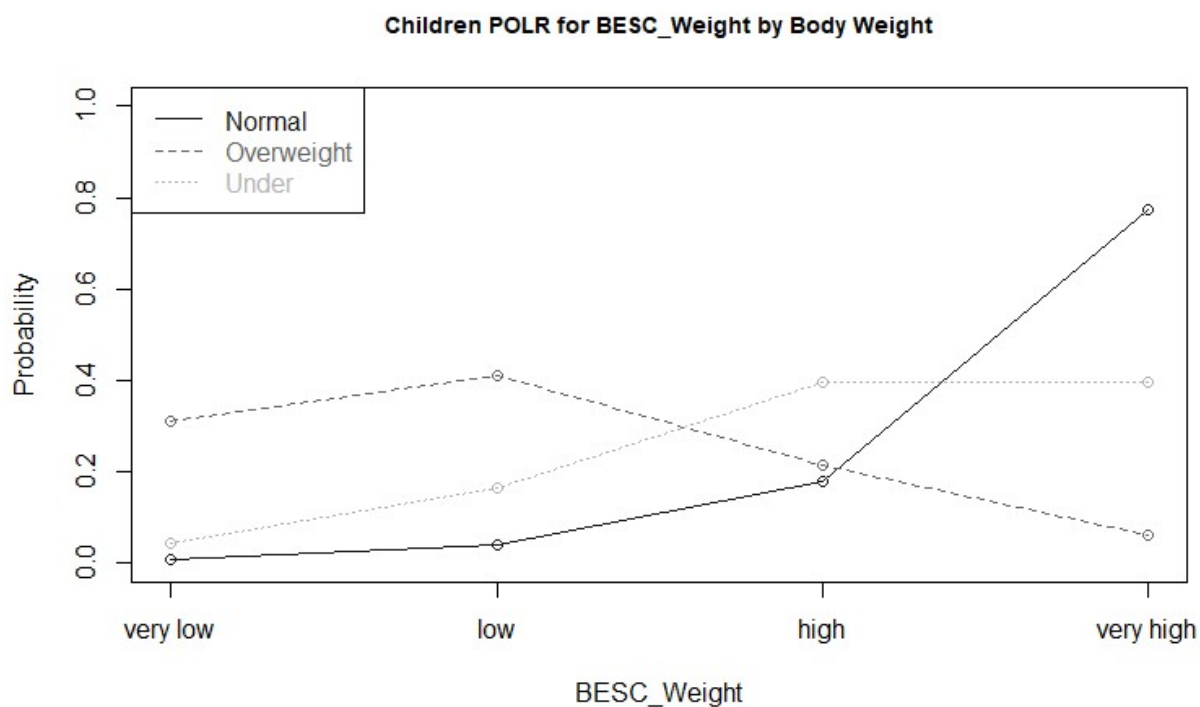
```
## Factor: BESC_Weight1      Levels: very low, low, high, very high
## Factor: Body_Weight1     Levels: Normal, Overweight, Under
##
##           Normal Overweight Under
## very low      1         6      0
## low           2         8      2
## high          13        3      5
## very high     54        2      4
## Call:
## polr(formula = BESC_Weight1 ~ Body_Weight1, data = ChildrenF,
##       Hess = TRUE)
##
## Coefficients:
##                Value Std. Error t value
## Body_Weight1Overweight -3.94      0.658  -5.98
## Body_Weight1Under      -1.65      0.623  -2.65
##
## Intercepts:
##                Value Std. Error t value
## very low|low      -4.728    0.643  -7.358
## low|high          -2.978    0.454  -6.554
## high|very high   -1.222    0.284  -4.307
##
## Residual Deviance: 167.43
## AIC: 177.43
##
##   Body_Weight1 very low      low      high very high
## 1      Normal 0.008763 0.03965 0.1792  0.77243
## 4      Overweight 0.311591 0.41101 0.2152  0.06217
## 7           Under 0.043977 0.16534 0.3959  0.39479
```

Calculate 95% CI for each coefficient using profiling of the likelihood function. If the 95% CI does not cross 0, the parameter estimate is statistically significant.

```
##                Low95%CI High95%CI Signif
## Body_Weight1Overweight -5.312   -2.714   *
## Body_Weight1Under      -2.891   -0.419   *
```

ChildrenWgt2a Plot

Plot the BESC_Weight by Body_Weight to show how these vary.



Compare ChildrenWgt1a and ChildrenWgt2a Models.

Use anova to determine if the reduced model is significantly worse as a description of the data than the baseline model. A non-significant test result indicates the reduction was justified.

```
## Likelihood ratio tests of ordinal regression models
##
## Response: BESC_Weight1
##
Df LR stat. Pr(Chi)          Model Resid. df Resid. Dev   Test
## 1                               Body_Weight1          95      167.4
## 2 Gender + Body_Weight1 + Cleft_Type + Imp_Face_Appearance          88      164.1 1 vs 2
7   3.314  0.8545
```

The non-significant test result confirms model reduction was justified, therefore ChildrenWgt2a is the minimal adequate model for the variables used with an AIC of 177.4 compared to the baseline model 188.1.

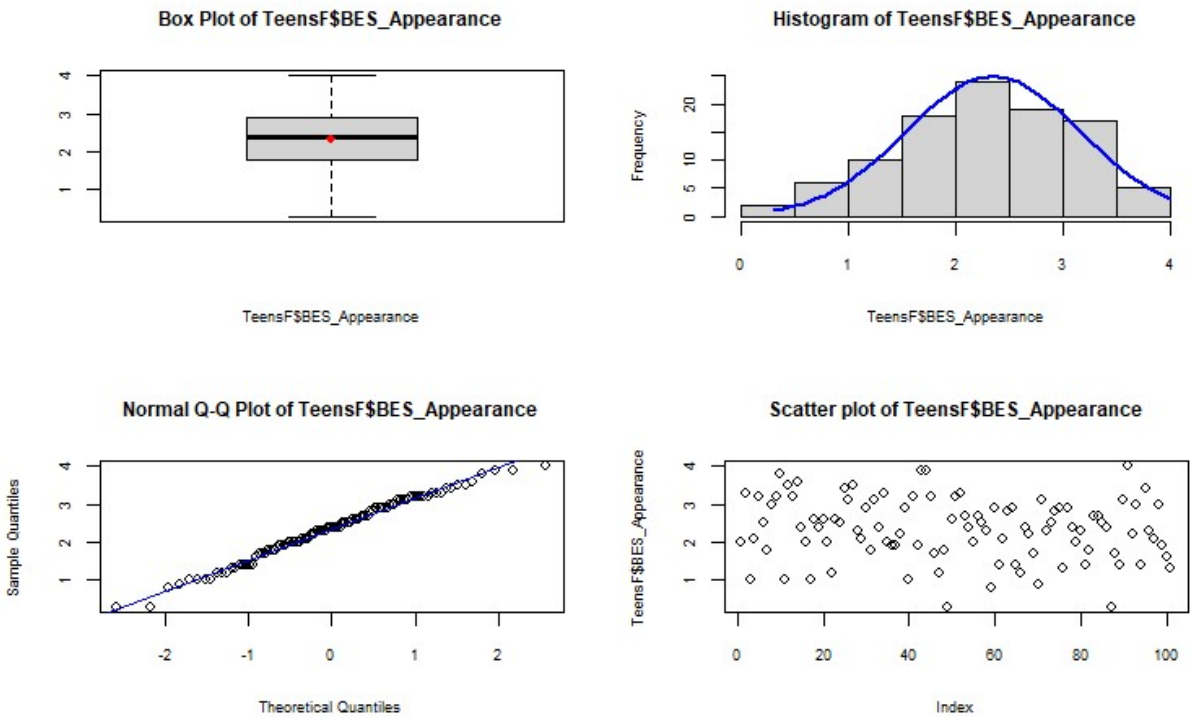
Adolescents Regression Analysis

Adolescents BES_Appearance

Summary Stats and Visualisation

BES_Appearance was treated as a continuous variable ranging from 0 to 4. The higher the number the more a person is happy with their appearance.

```
## Descriptive Stats for: TeensF$BES_Appearance
##   n mean  sd median min max range skew kurtosis  se
## 101 2.34 0.81   2.4 0.3  4   3.7 -0.25  -0.43 0.08
```



```
## Normality Tests p-values. Shapiro-Wilk:0.3859 Anderson-Darling:0.4570
## Data are normally distributed.
```

The data are normally distributed with no outliers identified.

TeensApp1a Baseline Model

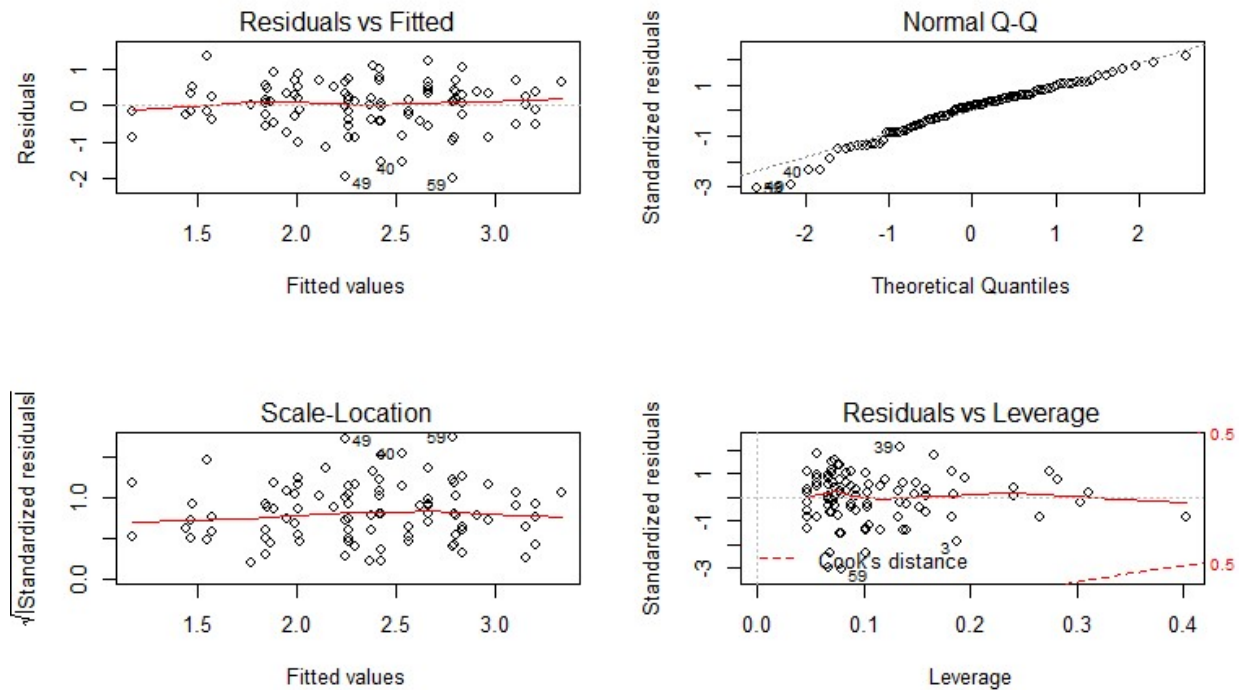
Combine all the variables used for the analysis into one baseline model.

```
## Factor: Gender           Levels: Female, Male
## Factor: Body_Weight      Levels: Normal, Little Over, Quite Over, Under
## Factor: Cleft_Type       Levels: Palate-only, Lip & Palate, Lip-only
## Factor: Imp_Face_Appearance Levels: Somewhat, Extremely, Very, Not Very, Not At All
##
## Call:
## lm(formula = BES_Appearance ~ Gender + Body_Weight + Cleft_Type +
##     Imp_Face_Appearance, data = TeensF)
##
## Residuals:
##   Min     1Q   Median     3Q    Max
## -1.991 -0.381  0.109  0.399  1.351
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)      2.835      0.184   15.39  <2e-16 ***
## GenderMale        0.375      0.161    2.33  0.0221 *
## Body_WeightLittle Over -0.420      0.158   -2.66  0.0093 **
## Body_WeightQuite Over -0.822      0.251   -3.28  0.0015 **
```

```

## Body_WeightUnder          -0.411    0.366   -1.12    0.2640
## Cleft_TypeLip & Palate   -0.543    0.173   -3.14    0.0023 **
## Cleft_TypeLip-only       -0.238    0.242   -0.98    0.3286
## Imp_Face_AppearanceExtremely -0.297    0.215   -1.38    0.1712
## Imp_Face_AppearanceVery  -0.404    0.171   -2.36    0.0205 *
## Imp_Face_AppearanceNot Very  0.133    0.283    0.47    0.6392
## Imp_Face_AppearanceNot At All  0.371    0.339    1.09    0.2766
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.685 on 90 degrees of freedom
## Multiple R-squared:  0.356, Adjusted R-squared:  0.284
## F-statistic: 4.97 on 10 and 90 DF, p-value: 1.02e-05

```



```

## Normality Tests p-values. Shapiro-Wilk:0.0146 Anderson-Darling:0.0215
## Data are not normally distributed.

```

The adjusted R-squared 0.284 is low, however the residuals are normally distributed and are homoscedastic.

TeensApp1a Multi-collinearity.

Check the Variance Inflation Factor (VIF) for the model. Any value > 10 indicates multi-collinearity.

```

##          df VIF Value
## Gender          1  1.314
## Body_Weight      3  1.092
## Cleft_Type        2  1.188
## Imp_Face_Appearance  4  1.110

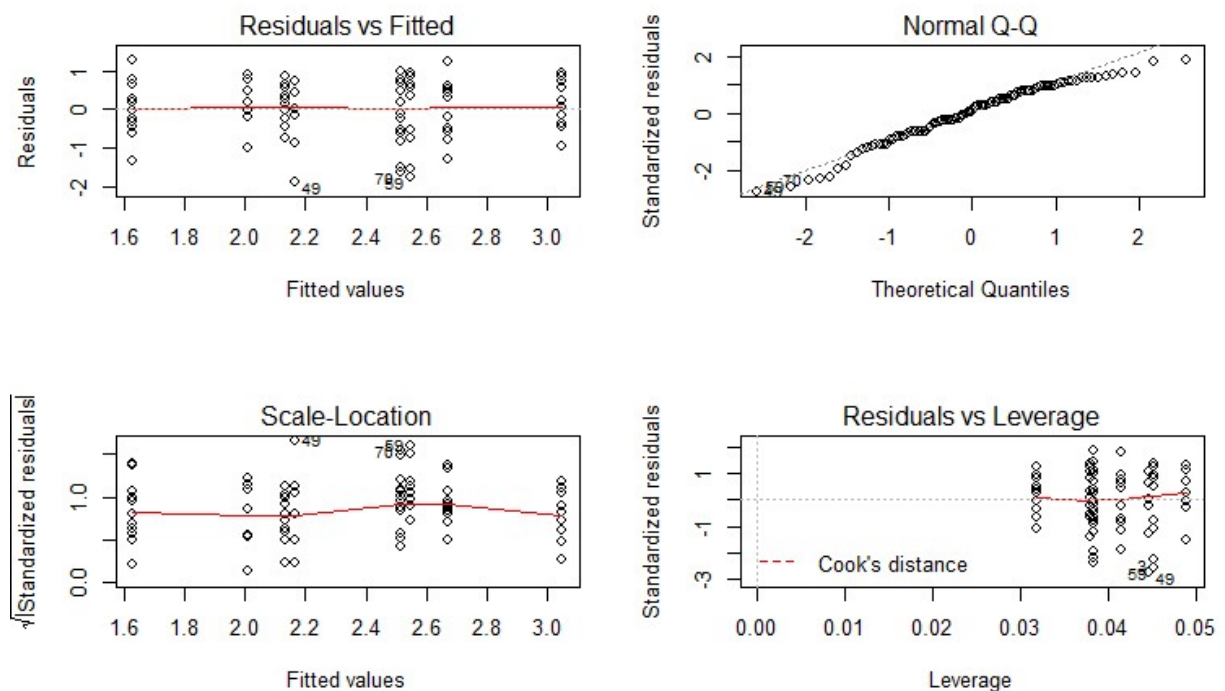
```


Multi-collinearity does not appear to be an issue (no values > 10).

TeensApp2a Reduced Model

The baseline model was reduced by successively removing non-significant variables and/or compressing factor levels to reach a minimal adequate model (i.e. all coefficients are significant) for the variables used.

```
## Factor: Body_Weight2      Levels: Not Overweight, Little Over, Quite Over
## Factor: Cleft_Type2      Levels: Not L&P, Lip & Palate
## Factor: Imp_Face_Appearance3 Levels: Some-Not Important, Important
##
## Call:
## lm(formula = BES_Appearance ~ Body_Weight3 + Cleft_Type2 + Imp_Face_Appearance3,
##     data = TeensF)
##
## Residuals:
##      Min       1Q   Median       3Q      Max
## -1.8652 -0.4326  0.0477  0.5301  1.2722
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)         3.052      0.136  22.49 < 2e-16 ***
## Body_Weight3Overweight -0.505      0.141  -3.58  0.00054 ***
## Cleft_Type2Lip & Palate -0.382      0.140  -2.72  0.00769 **
## Imp_Face_Appearance3Important -0.537      0.140  -3.83  0.00023 ***
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.697 on 97 degrees of freedom
## Multiple R-squared:  0.28, Adjusted R-squared:  0.258
## F-statistic: 12.6 on 3 and 97 DF, p-value: 5.04e-07
```



```
## Normality Tests p-values. Shapiro-Wilk:0.0104 Anderson-Darling:0.0283
## Data are not normally distributed.
```

Compare TeensApp1a and TeensApp2a Models

Use anova to determine if the reduced model is significantly worse as a description of the data than the baseline model. A non-significant test result indicates the reduction was justified.

```
## Analysis of Variance F-Test
## Model 1: BES_Appearance ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
## Model 2: BES_Appearance ~ Body_Weight3 + Cleft_Type2 + Imp_Face_Appearance3
## p-value: 0.1755 Rating: Not Significant
```

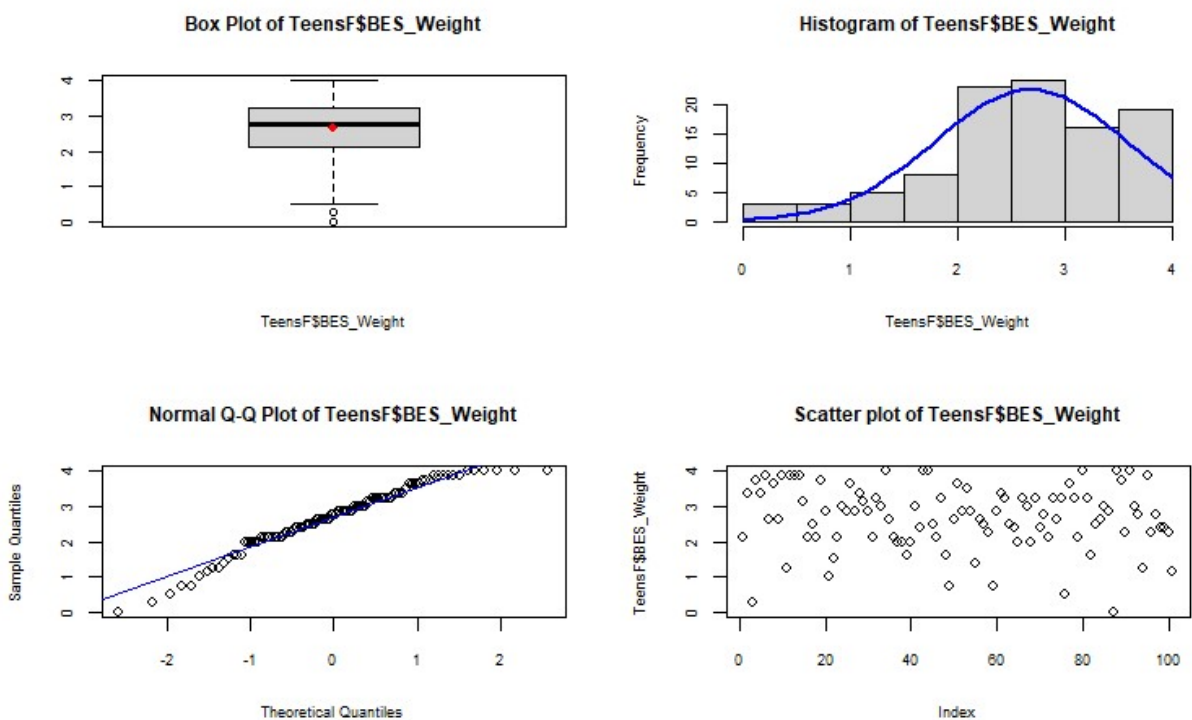
The non-significant test result confirms model reduction was justified, therefore TeensApp2a is the minimal adequate model for the variables used with an adjusted R-Squared of 0.258 compared to the baseline model 0.284.

Adolescents BES_Weight Regression Analysis

Summary Stats and Visualisation

BES_Weight was treated as a continuous variable ranging from 0 to 4. The higher the number the more a person is happy with their weight.

```
## Descriptive Stats for: TeensF$BES_Weight
## n mean sd median min max range skew kurtosis se
## 101 2.68 0.9 2.75 0 4 4 -0.65 0.2 0.09
```



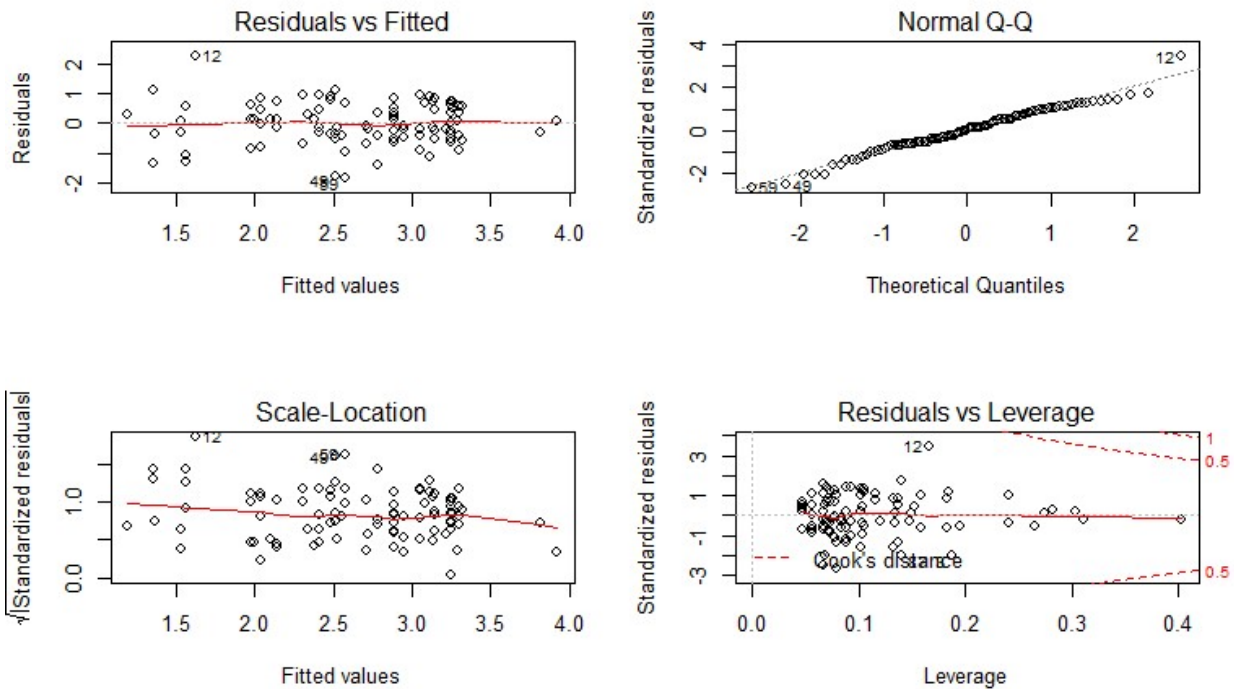
```
## Normality Tests p-values. Shapiro-Wilk:0.0017 Anderson-Darling:0.0176
## Data are not normally distributed.
```

The data are not normally distributed and have outliers at the low end (contributing to the negatively skewed distribution).

TeensWgt1a Baseline model

Combine all the variables used for the analysis into one baseline model.

```
## Factor: Gender           Levels: Female, Male
## Factor: Body_Weight      Levels: Normal, Little Over, Quite Over, Under
## Factor: Cleft_Type       Levels: Palate-only, Lip & Palate, Lip-only
## Factor: Imp_Face_Appearance Levels: Somewhat, Extremely, Very, Not Very, Not At All
##
## Call:
## lm(formula = BES_Weight ~ Gender + Body_Weight + Cleft_Type +
##     Imp_Face_Appearance, data = TeensF)
##
## Residuals:
##     Min       1Q   Median       3Q      Max
## -1.8247 -0.4280 -0.0016  0.4906  2.2511
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)      3.1469    0.1933   16.28 < 2e-16 ***
## GenderMale        0.1701    0.1691    1.01  0.317
## Body_WeightLittle Over -0.7422    0.1655  -4.49 2.1e-05 ***
## Body_WeightQuite Over -1.6931    0.2630  -6.44 5.8e-09 ***
## Body_WeightUnder   -0.7887    0.3836  -2.06  0.043 *
## Cleft_TypeLip & Palate -0.0653    0.1811  -0.36  0.719
## Cleft_TypeLip-only  -0.0621    0.2543  -0.24  0.808
## Imp_Face_AppearanceExtremely -0.0310    0.2255  -0.14  0.891
## Imp_Face_AppearanceVery  -0.3672    0.1795  -2.05  0.044 *
## Imp_Face_AppearanceNot Very  0.0481    0.2966   0.16  0.871
## Imp_Face_AppearanceNot At All 0.6722    0.3555   1.89  0.062 .
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.718 on 90 degrees of freedom
## Multiple R-squared:  0.423, Adjusted R-squared:  0.359
## F-statistic: 6.59 on 10 and 90 DF, p-value: 1.39e-07
```



```
## Normality Tests p-values. Shapiro-Wilk:0.2443 Anderson-Darling:0.4058
## Data are normally distributed.
```

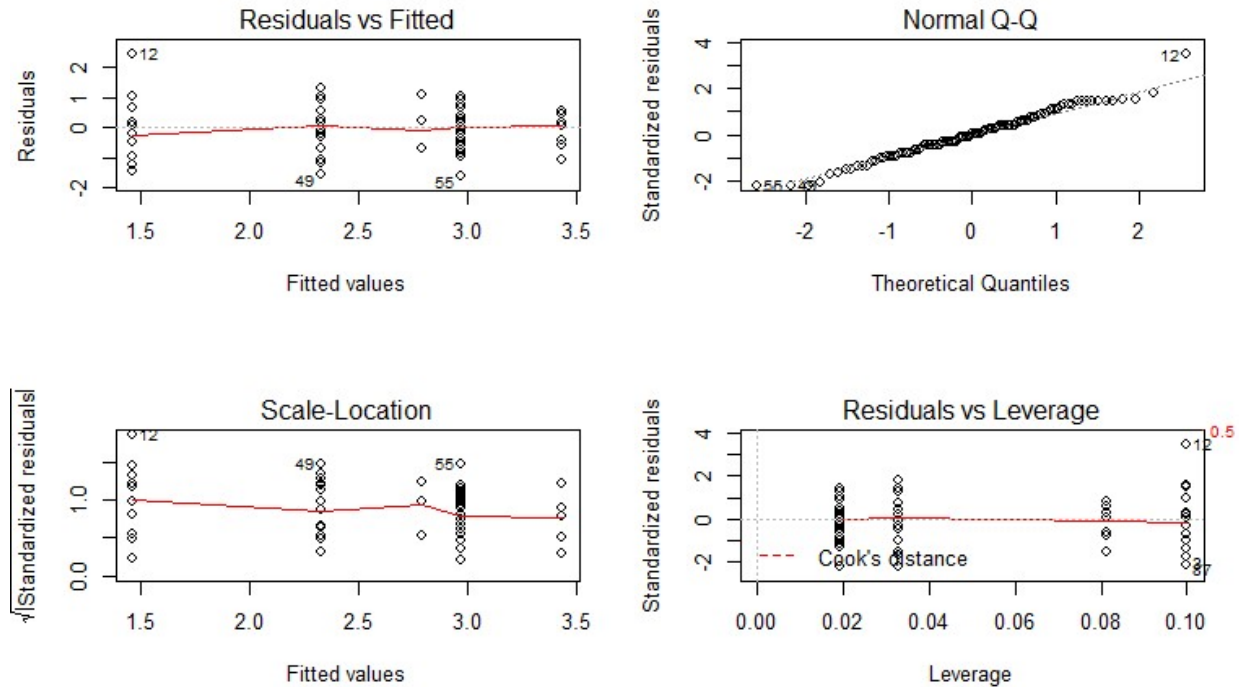
The adjusted R-squared 0.359 is moderate, and the residuals are normally distributed and are homoscedastic.

TeensWgt2a Reduced Model

The baseline model was reduced by successively removing non-significant variables and/or compressing factor levels to reach a minimal adequate model (i.e. all coefficients are significant) for the variables used.

```
## Factor: Body_Weight2      Levels: Not Overweight, Little Over, Quite Over
## Factor: Imp_Face_Appearance4 Levels: Some-Important, Not Important
##
## Call:
## lm(formula = BES_Weight ~ Body_Weight2 + Imp_Face_Appearance4,
##     data = TeensF)
##
## Residuals:
##      Min       1Q   Median       3Q      Max
## -1.5935 -0.4685  0.0315  0.4363  2.4125
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)      2.969      0.102   29.20 < 2e-16 ***
## Body_Weight2Little Over    -0.644      0.162   -3.98  0.00013 ***
## Body_Weight2Quite Over    -1.506      0.254   -5.92  4.8e-08 ***
## Imp_Face_Appearance4Not Important  0.470      0.221    2.13  0.03581 *
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
```

```
##
## Residual standard error: 0.737 on 97 degrees of freedom
## Multiple R-squared: 0.345, Adjusted R-squared: 0.325
## F-statistic: 17.1 on 3 and 97 DF, p-value: 5.68e-09
```



```
## Normality Tests p-values. Shapiro-Wilk:0.2513 Anderson-Darling:0.5629
## Data are normally distributed.
```

Compare TeensWgt1a and TeensWgt2a Models

Use anova to determine if the reduced model is significantly worse as a description of the data than the baseline model. A non-significant test result indicates the reduction was justified.

```
## Analysis of Variance F-Test
## Model 1: BES_Weight ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
## Model 2: BES_Weight ~ Body_Weight2 + Imp_Face_Appearance4
## p-value: 0.1128 Rating: Not Significant
```

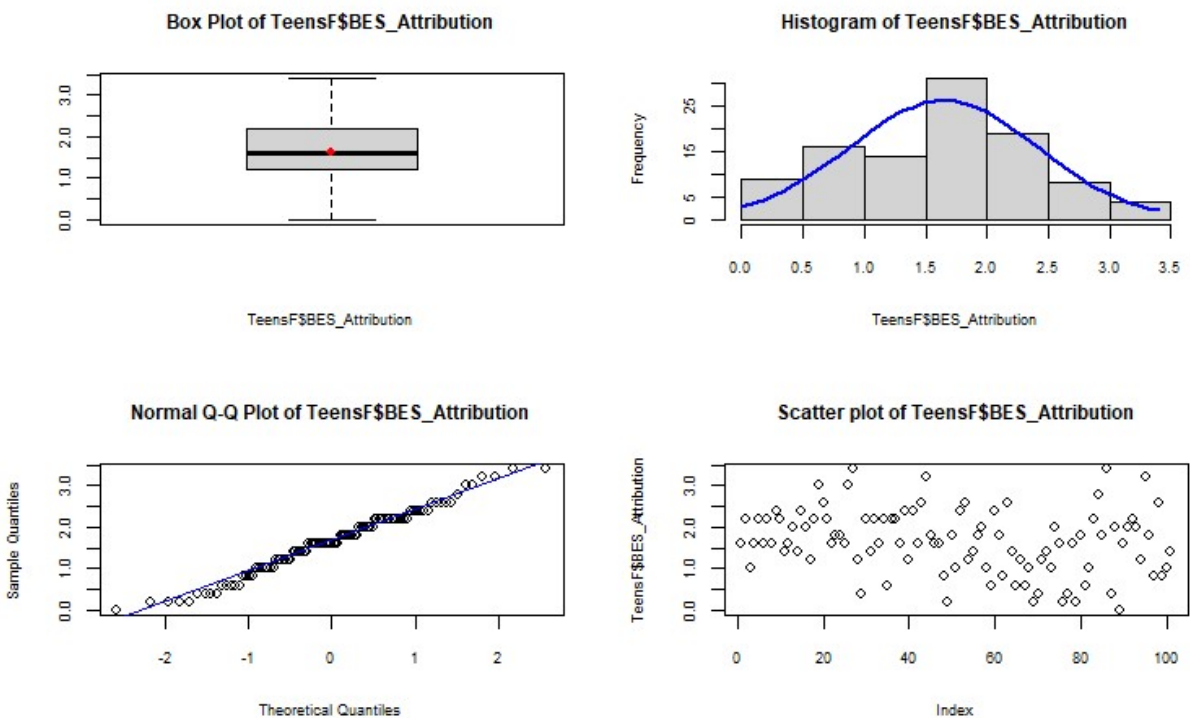
The non-significant test result confirms model reduction was justified, therefore TeensWgt2a is the minimal adequate model for the variables used with an adjusted R-Squared of 0.325 compared to the baseline model 0.359.

Adolescents BES_Attribution Regression Analysis

Summary Stats and Visualisation

BES_Attribution was treated as a continuous variable ranging from 0 to 4. The higher the number the more a person is happy with how they believe others perceive their appearance.

```
## Descriptive Stats for: TeensF$BES_Attribution
##   n mean  sd median min max range  skew kurtosis  se
## 101 1.64 0.77   1.6   0 3.4   3.4 -0.01   -0.46 0.08
```



```
## Normality Tests p-values. Shapiro-Wilk:0.1994 Anderson-Darling:0.1608
## Data are normally distributed.
```

The data are normally distributed with no outliers identified.

TeensAtt1a Baseline model

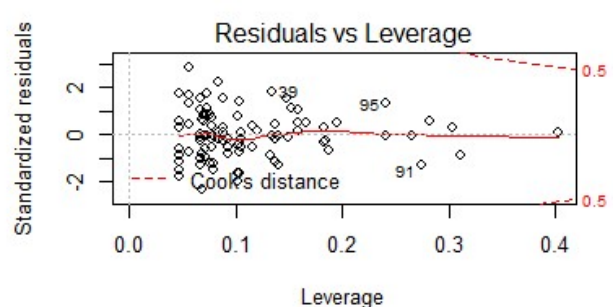
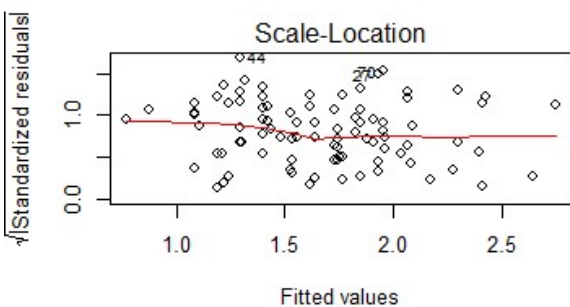
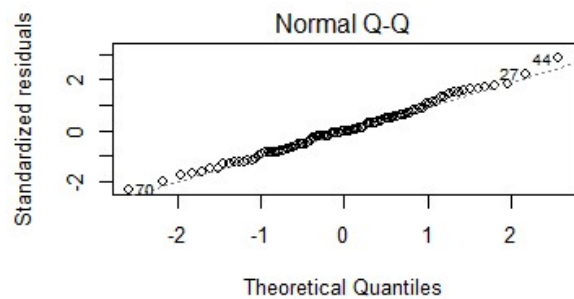
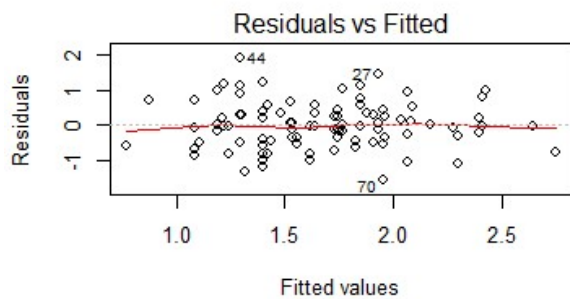
Combine all the original predictors: Gender, Body_Weight, Cleft_Type and Imp_Face_Appearance into one model. Initial reference Levels: Female, Cleft Lip, Normal, Somewhat.

```
## Factor: Gender           Levels: Female, Male
## Factor: Body_Weight      Levels: Normal, Little Over, Quite Over, Under
## Factor: Cleft_Type       Levels: Palate-only, Lip & Palate, Lip-only
## Factor: Imp_Face_Appearance Levels: Somewhat, Extremely, Very, Not Very, Not At All
##
## Call:
## lm(formula = BES_Attribution ~ Gender + Body_Weight + Cleft_Type +
##     Imp_Face_Appearance, data = TeensF)
##
## Residuals:
##   Min       1Q   Median       3Q      Max
## -1.5536 -0.4938 -0.0401  0.4014  1.9062
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)      1.8488     0.1860   9.94 3.8e-16 ***
```

```

## GenderMale                -0.0211    0.1628   -0.13    0.8973
## Body_WeightLittle Over    -0.2088    0.1593   -1.31    0.1933
## Body_WeightQuite Over    -0.5224    0.2531   -2.06    0.0419 *
## Body_WeightUnder         0.0827    0.3692    0.22    0.8233
## Cleft_TypeLip & Palate   -0.5340    0.1743   -3.06    0.0029 **
## Cleft_TypeLip-only       0.1314    0.2447    0.54    0.5925
## Imp_Face_AppearanceExtremely 0.4507    0.2171    2.08    0.0407 *
## Imp_Face_AppearanceVery  0.1048    0.1727    0.61    0.5457
## Imp_Face_AppearanceNot Very 0.4394    0.2854    1.54    0.1272
## Imp_Face_AppearanceNot At All 0.7955    0.3421    2.33    0.0223 *
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.691 on 90 degrees of freedom
## Multiple R-squared:  0.276, Adjusted R-squared:  0.196
## F-statistic: 3.44 on 10 and 90 DF,  p-value: 0.000752

```



```

## Normality Tests p-values. Shapiro-Wilk:0.8839 Anderson-Darling:0.7733
## Data are normally distributed.

```

The adjusted R-squared 0.196 is very low, however the residuals are normally distributed and are homoscedastic.

TeensAtt2a Reduced Model

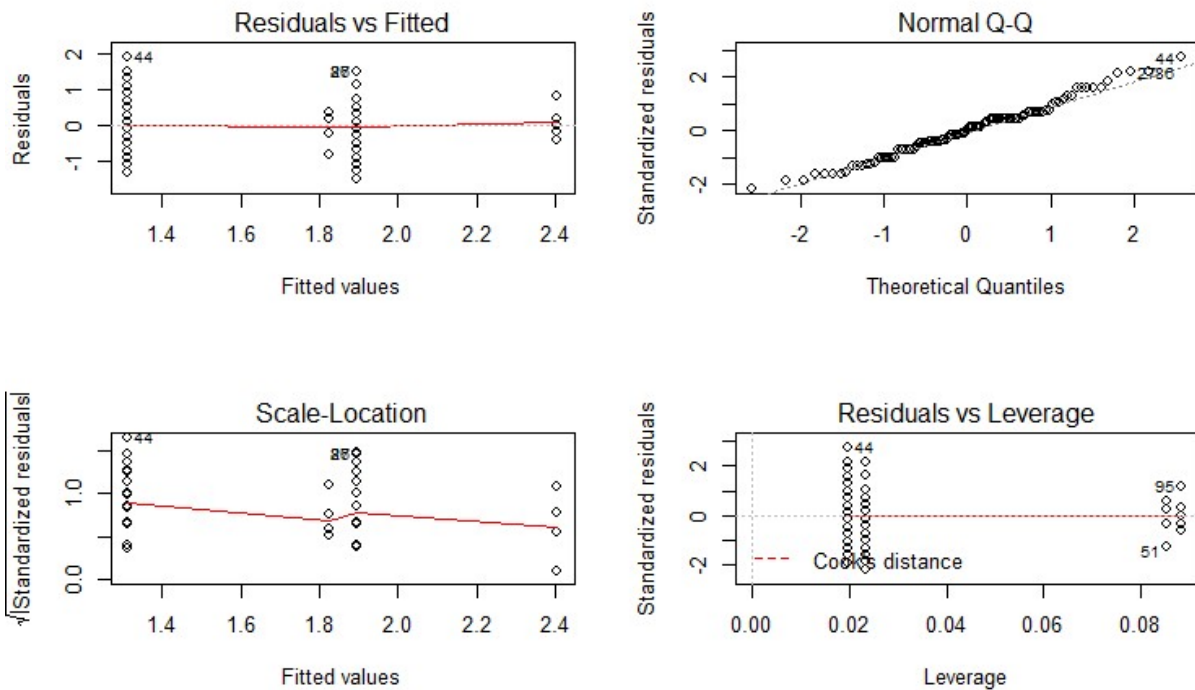
The baseline model was reduced by successively removing non-significant variables and/or compressing factor levels to reach a minimal adequate model (i.e. all coefficients are significant) for the variables used.

```

## Factor: Cleft_Type2          Levels: Not L&P, Lip & Palate
## Factor: Imp_Face_Appearance4 Levels: Some-Important, Not Important

```

```
##
## Call:
## lm(formula = BES_Attribution ~ Cleft_Type2 + Imp_Face_Appearance4,
##     data = TeensF)
##
## Residuals:
##      Min       1Q   Median       3Q      Max
## -1.4942 -0.4942 -0.0052  0.3759  1.8869
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)         1.894      0.107   17.76 < 2e-16 ***
## Cleft_Type2Lip & Palate -0.581      0.140   -4.16 6.9e-05 ***
## Imp_Face_Appearance4Not Important  0.511      0.208    2.46  0.016 *
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.699 on 98 degrees of freedom
## Multiple R-squared:  0.193, Adjusted R-squared:  0.176
## F-statistic: 11.7 on 2 and 98 DF, p-value: 2.74e-05
```



```
## Normality Tests p-values. Shapiro-Wilk:0.3527 Anderson-Darling:0.2824
## Data are normally distributed.
```

Compare TeensAtt1a and TeensAtt2a models

Use anova to determine if the reduced model is significantly worse as a description of the data than the baseline model. A non-significant test result indicates the reduction was justified.

```
## Analysis of Variance F-Test
## Model 1: BES_Attribution ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
## Model 2: BES_Attribution ~ Cleft_Type2 + Imp_Face_Appearance4
## p-value: 0.2560 Rating: Not Significant
```


The non-significant test result confirms model reduction was justified, therefore TeensAtt2a is the minimal adequate model for the variables used with an adjusted R-Squared of 0.176 compared to the baseline model 0.196.

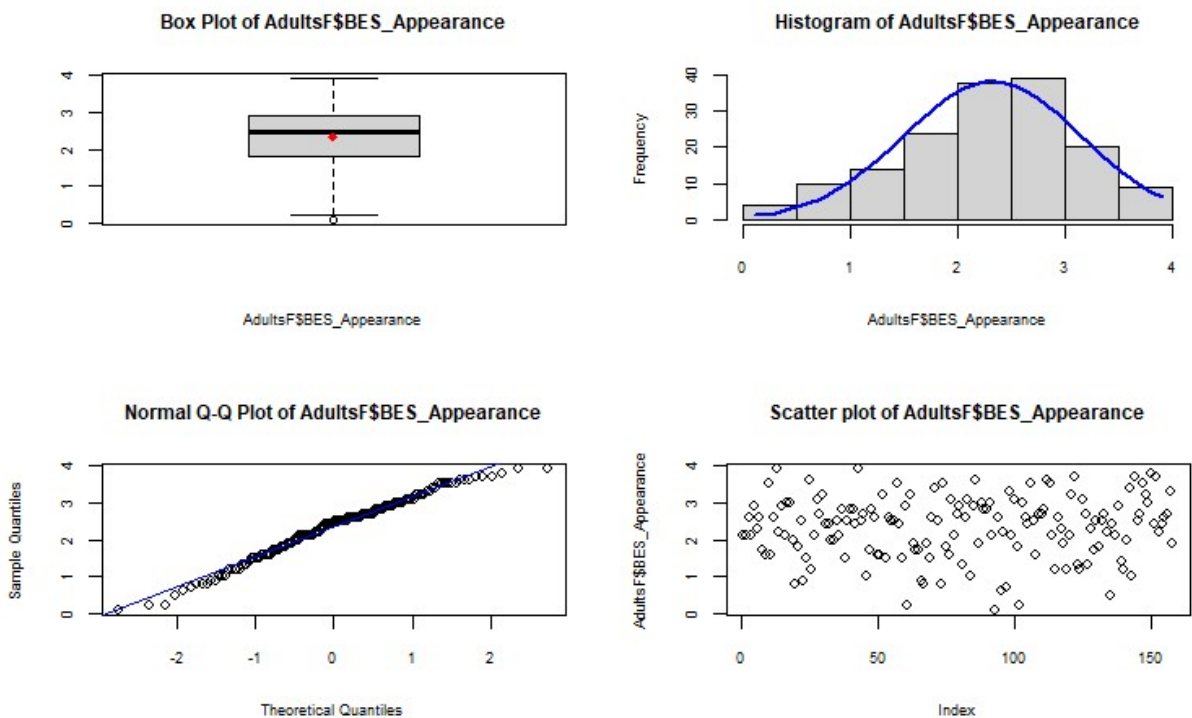
Adults Regression Analysis

Adults BES_Appearance

Summary Stats and Visualisation

BES_Appearance was treated as a continuous variable ranging from 0 to 4. The higher the number the more a person is happy with their appearance.

```
## Descriptive Stats for: AdultsF$BES_Appearance
##   n mean  sd median min max range skew kurtosis  se
## 158 2.32 0.83  2.45 0.1 3.9  3.8 -0.4  -0.26 0.07
```



```
## Normality Tests p-values. Shapiro-Wilk:0.0237 Anderson-Darling:0.0369
## Data are not normally distributed.
```

The data are normally distributed with one outlier identified.

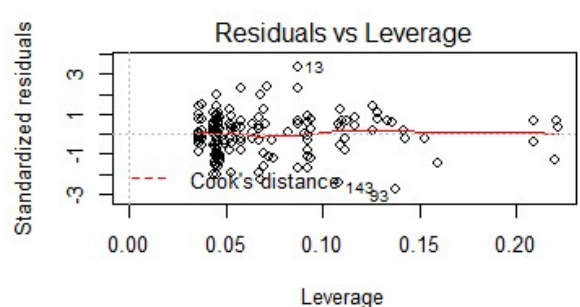
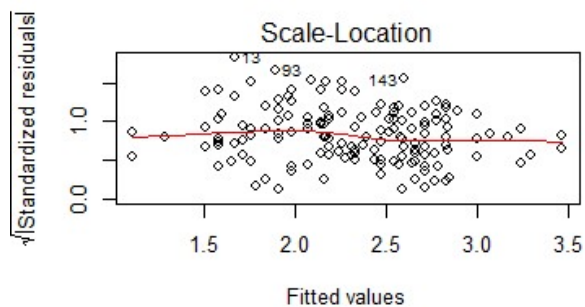
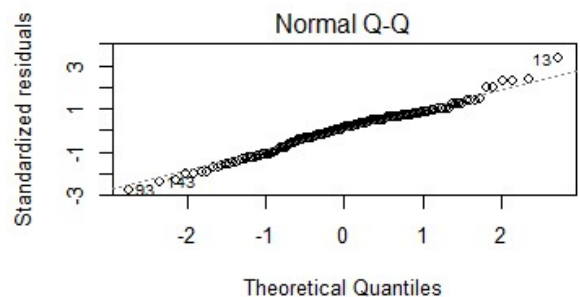
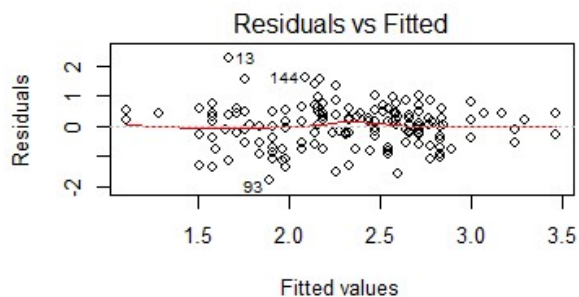
AdultsApp1a Baseline Model

Combine all the variables used for the analysis into one baseline model.

```

## Factor: Gender           Levels: Female, Male
## Factor: Body_Weight      Levels: Normal, Little Over, Quite Over, Under
## Factor: Cleft_Type      Levels: Palate-only, Lip & Palate, Lip-only
## Factor: Imp_Face_Appearance Levels: Somewhat, Extremely, Very, Not Very, Not At All
##
## Call:
## lm(formula = BES_Appearance ~ Gender + Body_Weight + Cleft_Type +
##     Imp_Face_Appearance, data = AdultsF)
##
## Residuals:
##   Min     1Q   Median     3Q      Max
## -1.793 -0.408  0.101  0.429  2.236
##
## Coefficients:
##
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)    2.8353    0.1474   19.24 < 2e-16 ***
## GenderMale     -0.0713    0.1264   -0.56  0.5736
## Body_WeightLittle Over -0.4025    0.1268   -3.17  0.0018 **
## Body_WeightQuite Over -0.8763    0.2046   -4.28  3.3e-05 ***
## Body_WeightUnder  -0.2645    0.2456   -1.08  0.2833
## Cleft_TypeLip & Palate -0.1748    0.1365   -1.28  0.2024
## Cleft_TypeLip-only    0.0138    0.1826    0.08  0.9400
## Imp_Face_AppearanceExtremely -0.6778    0.1577   -4.30  3.1e-05 ***
## Imp_Face_AppearanceVery -0.1197    0.1420   -0.84  0.4007
## Imp_Face_AppearanceNot Very  0.4076    0.2404    1.70  0.0921 .
## Imp_Face_AppearanceNot At All 0.7070    0.3427    2.06  0.0409 *
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.702 on 147 degrees of freedom
## Multiple R-squared:  0.322, Adjusted R-squared:  0.276
## F-statistic: 6.99 on 10 and 147 DF, p-value: 6.45e-09

```



```

## Normality Tests p-values. Shapiro-Wilk:0.0809 Anderson-Darling:0.0158
## Data are normally distributed.

```

The adjusted R-squared 0.276 is low, however the residuals are normally distributed and are homoscedastic.

AdultsApp1a Multi-collinearity.

Check the Variance Inflation Factor (VIF) for the model. Any value > 10 indicates multi-collinearity.

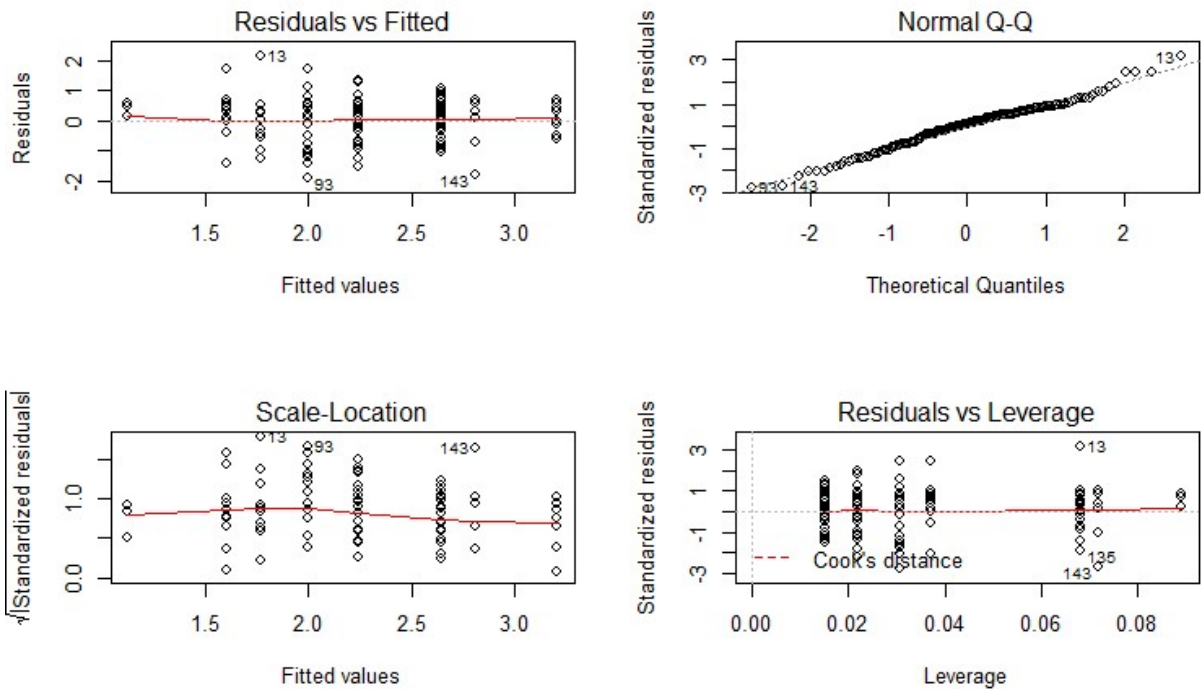
```
##           df VIF Value
## Gender           1  1.268
## Body_Weight      3  1.065
## Cleft_Type       2  1.158
## Imp_Face_Appearance 4  1.060
```

Multi-collinearity does not appear to be an issue (no values > 10).

AdultsApp2a Reduced Model

The baseline model was reduced by successively removing non-significant variables and/or compressing factor levels to reach a minimal adequate model (i.e. all coefficients are significant) for the variables used.

```
## Factor: Body_Weight2      Levels: Not Overweight, Little Over, Quite Over
## Factor: Imp_Face_Appearance4 Levels: VSomehat, Extremely, Not Important
##
## Call:
## lm(formula = BES_Appearance ~ Body_Weight2 + Imp_Face_Appearance4,
##     data = AdultsF)
##
## Residuals:
##      Min       1Q   Median       3Q      Max
## -1.9013 -0.4929  0.0601  0.4413  2.1323
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)      2.640      0.086   30.70 < 2e-16 ***
## Body_Weight2Little Over    -0.395      0.120   -3.29  0.0012 **
## Body_Weight2Quite Over    -0.872      0.197   -4.43  1.8e-05 ***
## Imp_Face_Appearance4Extremely  -0.638      0.132   -4.84  3.1e-06 ***
## Imp_Face_Appearance4Not Important  0.564      0.190    2.98  0.0034 **
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.7 on 153 degrees of freedom
## Multiple R-squared:  0.298, Adjusted R-squared:  0.28
## F-statistic: 16.3 on 4 and 153 DF, p-value: 3.98e-11
```



```
## Normality Tests p-values. Shapiro-Wilk:0.0825 Anderson-Darling:0.0198
## Data are normally distributed.
```

Compare AdultsApp1a and AdultsApp2a Models

Use anova to determine if the reduced model is significantly worse as a description of the data than the baseline model. A non-significant test result indicates the reduction was justified.

```
## Analysis of Variance F-Test
## Model 1: BES_Appearance ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
## Model 2: BES_Appearance ~ Body_Weight2 + Imp_Face_Appearance4
## p-value: 0.5264 Rating: Not Significant
```

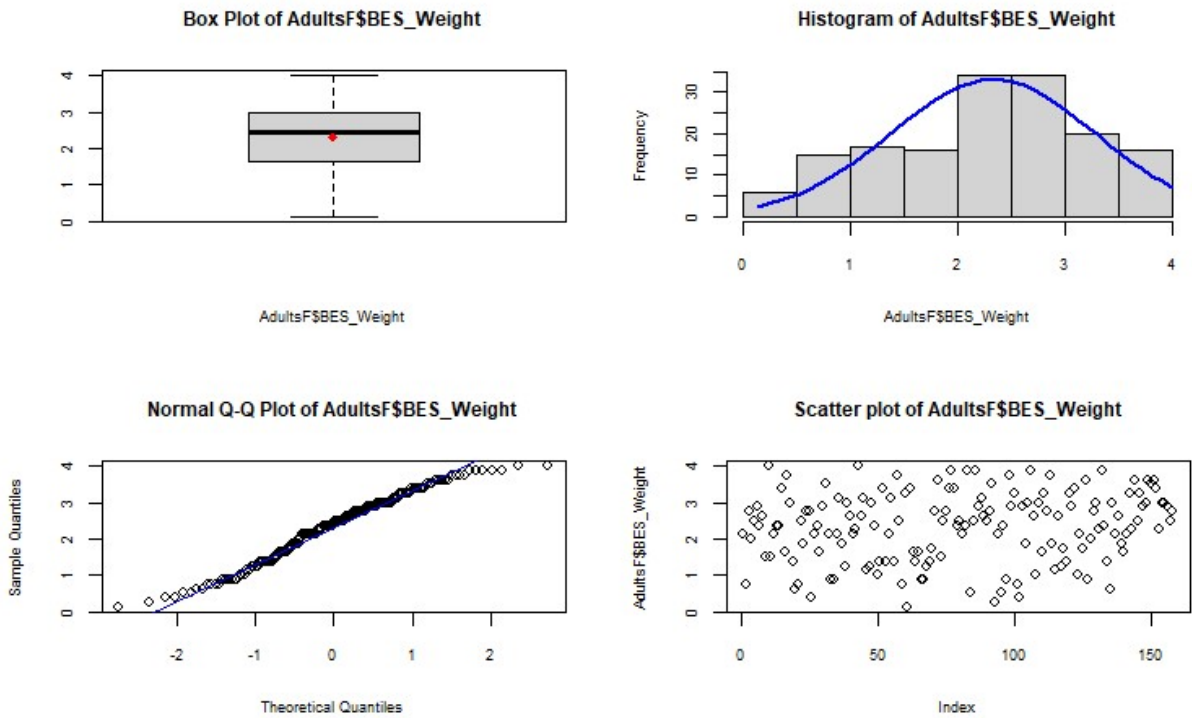
The non-significant test result confirms model reduction was justified, therefore AdultsApp2a is the minimal adequate model for the variables used with an adjusted R-Squared of 0.280 compared to the baseline model 0.276.

Adults BES_Weight Regression Analysis

Summary Stats and Visualisation

BES_Weight was treated as a continuous variable ranging from 0 to 4. The higher the number the more a person is happy with their weight.

```
## Descriptive Stats for: AdultsF$BES_Weight
##   n mean  sd median min max range skew kurtosis  se
## 158 2.32 0.95  2.44 0.12  4  3.88 -0.3  -0.79 0.08
```



```
## Normality Tests p-values. Shapiro-Wilk:0.0024 Anderson-Darling:0.0044
## Data are not normally distributed.
```

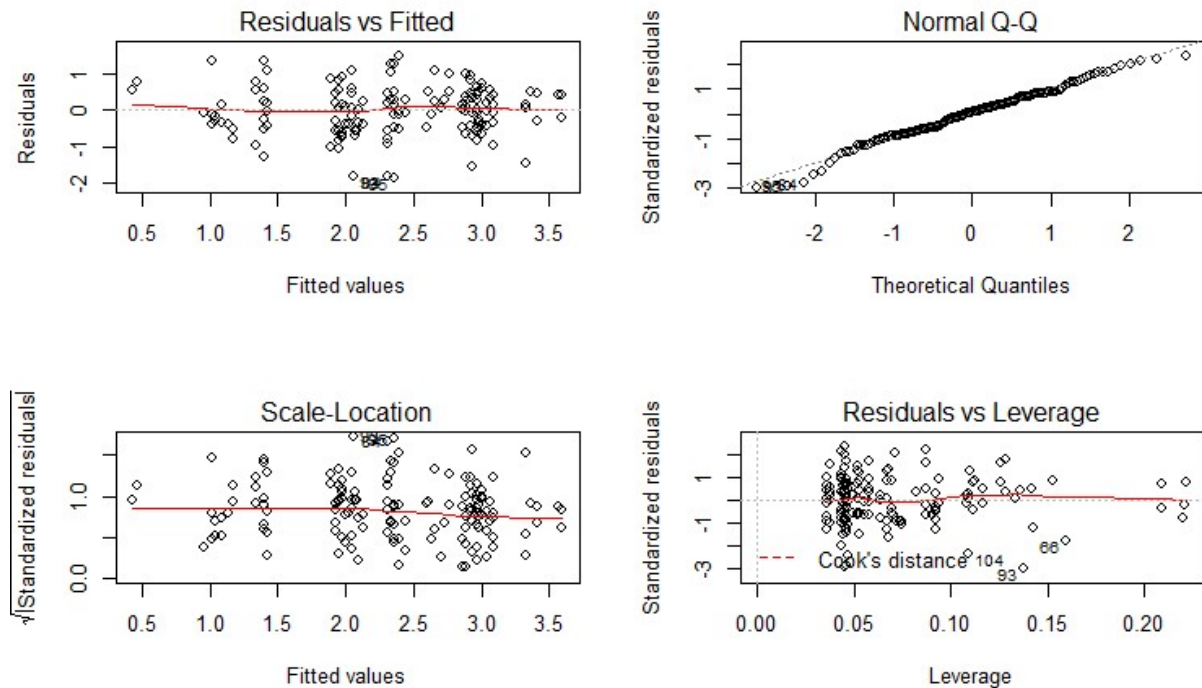
The data are not normally distributed however there are no outliers.

AdultsWgt1a Baseline model

Combine all the variables used for the analysis into one baseline model.

```
## Factor: Gender           Levels: Female, Male
## Factor: Body_Weight     Levels: Normal, Little Over, Quite Over, Under
## Factor: Cleft_Type      Levels: Palate-only, Lip & Palate, Lip-only
## Factor: Imp_Face_Appearance Levels: Somewhat, Extremely, Very, Not Very, Not At All
##
## Call:
## lm(formula = BES_Weight ~ Gender + Body_Weight + Cleft_Type +
##     Imp_Face_Appearance, data = AdultsF)
##
## Residuals:
##   Min     1Q   Median     3Q    Max
## -1.8592 -0.4119  0.0366  0.4409  1.4841
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)      3.0936     0.1379   22.44 < 2e-16 ***
## GenderMale       -0.0513     0.1183    -0.43  0.665
## Body_WeightLittle Over -0.9659     0.1187   -8.14 1.5e-13 ***
## Body_WeightQuite Over -1.9269     0.1914  -10.07 < 2e-16 ***
## Body_WeightUnder   -0.3306     0.2298   -1.44  0.152
## Cleft_TypeLip & Palate -0.0316     0.1277   -0.25  0.805
## Cleft_TypeLip-only  -0.0557     0.1708   -0.33  0.745
## Imp_Face_AppearanceExtremely -0.7028     0.1476   -4.76 4.5e-06 ***
```

```
## Imp_Face_AppearanceVery      -0.1242    0.1328   -0.94    0.351
## Imp_Face_AppearanceNot Very    0.3179    0.2249    1.41    0.160
## Imp_Face_AppearanceNot At All  0.5567    0.3206    1.74    0.085 .
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.657 on 147 degrees of freedom
## Multiple R-squared:  0.555, Adjusted R-squared:  0.525
## F-statistic: 18.4 on 10 and 147 DF, p-value: <2e-16
```



```
## Normality Tests p-values. Shapiro-Wilk:0.1263 Anderson-Darling:0.3314
## Data are normally distributed.
```

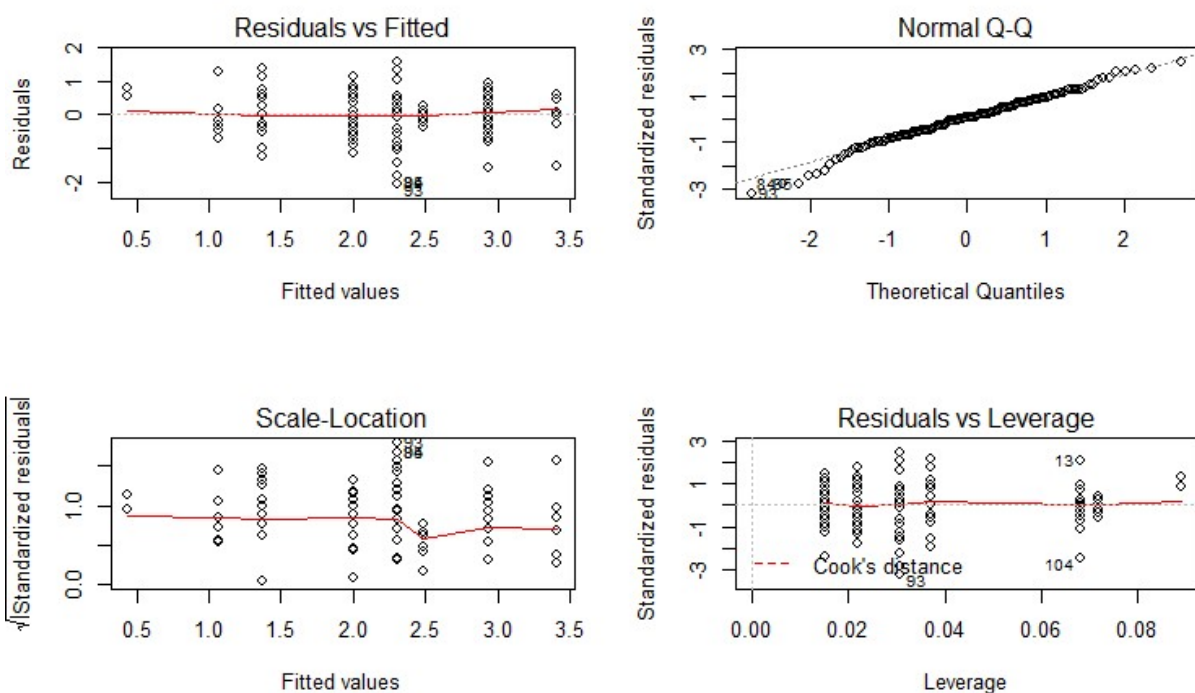
The adjusted R-squared 0.525 is moderate, and the residuals are normally distributed and are homoscedastic.

AdultsWgt2a Reduced Model

The baseline model was reduced by successively removing non-significant variables and/or compressing factor levels to reach a minimal adequate model (i.e. all coefficients are significant) for the variables used.

```
## Factor: Body_Weight2          Levels: Not Overweight, Little Over, Quite Over
## Factor: Imp_Face_Appearance4 Levels: VSomewhat, Extremely, Not Important
##
## Call:
## lm(formula = BES_Weight ~ Body_Weight2 + Imp_Face_Appearance4,
##     data = AdultsF)
##
## Residuals:
##      Min       1Q   Median       3Q      Max
```

```
## -2.0590 -0.3782 0.0633 0.4383 1.5660
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)      2.937      0.080   36.71 < 2e-16 ***
## Body_Weight2Little Over    -0.933      0.112   -8.36 3.6e-14 ***
## Body_Weight2Quite Over    -1.869      0.183  -10.20 < 2e-16 ***
## Imp_Face_Appearance4Extremely  -0.628      0.123   -5.12 9.3e-07 ***
## Imp_Face_Appearance4Not Important  0.479      0.176    2.72 0.0073 **
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.652 on 153 degrees of freedom
## Multiple R-squared:  0.545, Adjusted R-squared:  0.533
## F-statistic: 45.8 on 4 and 153 DF,  p-value: <2e-16
```



```
## Normality Tests p-values. Shapiro-Wilk:0.0585 Anderson-Darling:0.1426
## Data are normally distributed.
```

Compare AdultsWgt1a and AdultsWgt2a Models

Use anova to determine if the reduced model is significantly worse as a description of the data than the baseline model. A non-significant test result indicates the reduction was justified.

```
## Analysis of Variance F-Test
## Model 1: BES_Weight ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
## Model 2: BES_Weight ~ Body_Weight2 + Imp_Face_Appearance4
## p-value: 0.7425 Rating: Not Significant
```

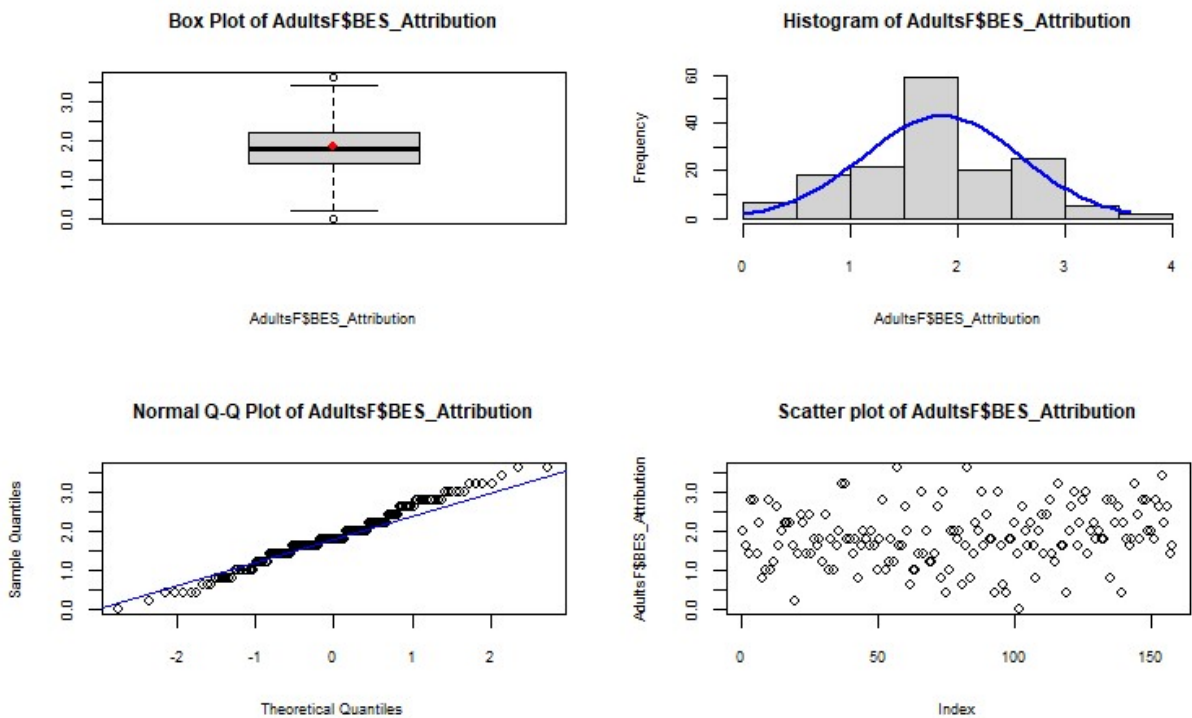
The non-significant test result confirms model reduction was justified, therefore AdultsWgt2a is the minimal adequate model for the variables used with an adjusted R-Squared of 0.533 compared to the baseline model 0.525.

Adults BES_Attribution Regression Analysis

Summary Stats and Visualisation

BES_Attribution was treated as a continuous variable ranging from 0 to 4. The higher the number the more a person is happy with how they believe others perceive their appearance.

```
## Descriptive Stats for: AdultsF$BES_Attribution
##   n mean  sd median min max range skew kurtosis  se
## 158 1.84 0.73   1.8   0 3.6  3.6 0.02  -0.28 0.06
```



```
## Normality Tests p-values. Shapiro-Wilk:0.1331 Anderson-Darling:0.0281
## Data are normally distributed.
```

The data are normally distributed with no outliers identified.

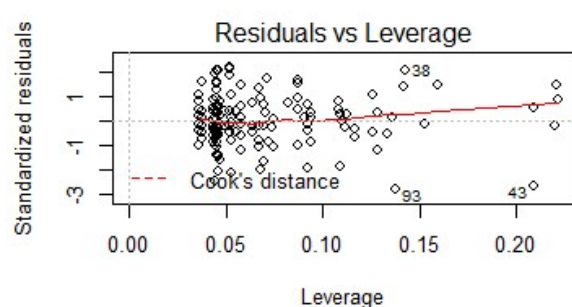
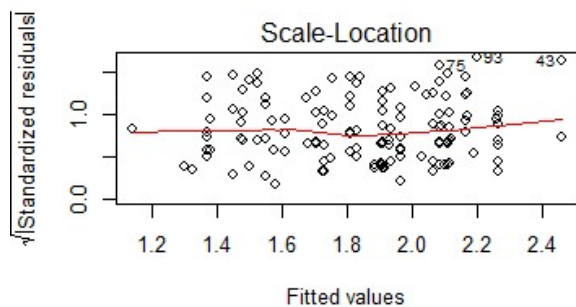
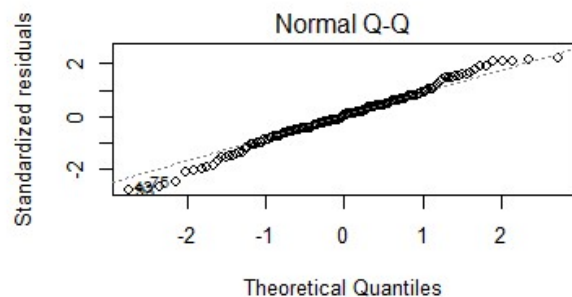
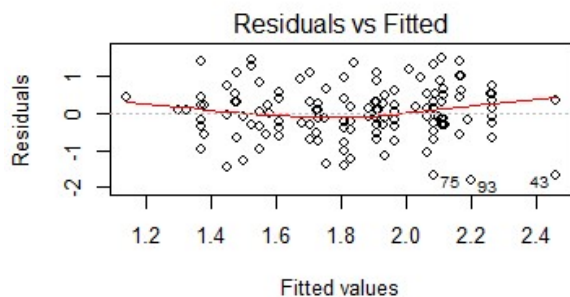
AdultsAtt1a Baseline model

Combine all the original predictors: Gender, Body_Weight, Cleft_Type and Imp_Face_Appearance into one model. Initial reference Levels: Female, Cleft Lip, Normal, Somewhat.


```

## Factor: Gender           Levels: Female, Male
## Factor: Body_Weight     Levels: Normal, Little Over, Quite Over, Under
## Factor: Cleft_Type     Levels: Palate-only, Lip & Palate, Lip-only
## Factor: Imp_Face_Appearance Levels: Somewhat, Extremely, Very, Not Very, Not At All
##
## Call:
## lm(formula = BES_Attribution ~ Gender + Body_Weight + Cleft_Type +
##     Imp_Face_Appearance, data = AdultsF)
##
## Residuals:
##   Min     1Q  Median     3Q    Max
## -1.800 -0.369  0.025  0.421  1.488
##
## Coefficients:
##
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)    2.08641    0.14611   14.28 <2e-16 ***
## GenderMale     -0.15672    0.12534   -1.25  0.2132
## Body_WeightLittle Over -0.36020    0.12574   -2.86  0.0048 **
## Body_WeightQuite Over -0.58724    0.20285   -2.89  0.0044 **
## Body_WeightUnder    0.03160    0.24348    0.13  0.8969
## Cleft_TypeLip & Palate -0.20022    0.13532   -1.48  0.1411
## Cleft_TypeLip-only    0.00448    0.18101    0.02  0.9803
## Imp_Face_AppearanceExtremely 0.08237    0.15636    0.53  0.5991
## Imp_Face_AppearanceVery    0.18240    0.14074    1.30  0.1970
## Imp_Face_AppearanceNot Very 0.10401    0.23829    0.44  0.6631
## Imp_Face_AppearanceNot At All 0.53448    0.33973    1.57  0.1178
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.696 on 147 degrees of freedom
## Multiple R-squared:  0.153, Adjusted R-squared:  0.0949
## F-statistic: 2.65 on 10 and 147 DF, p-value: 0.00538

```



```

## Normality Tests p-values. Shapiro-Wilk:0.3206 Anderson-Darling:0.3806
## Data are normally distributed.

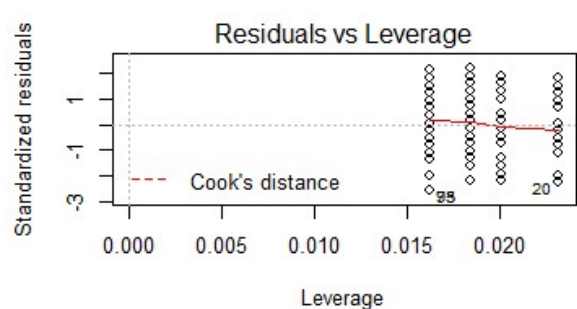
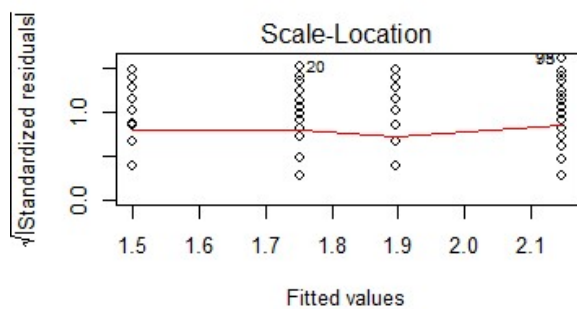
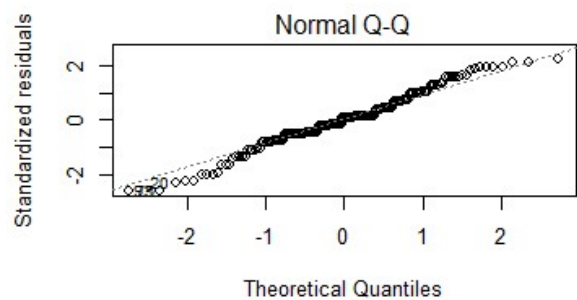
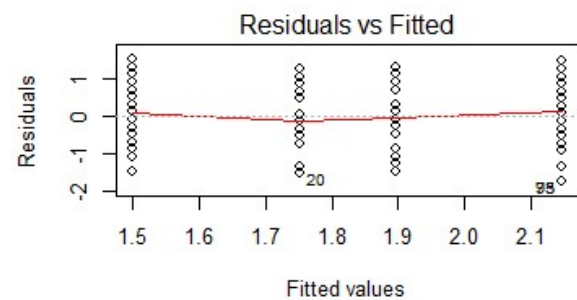
```

The adjusted R-squared 0.095 is very low, however the residuals are normally distributed and are homoscedastic.

AdultsAtt2a Reduced Model

The baseline model was reduced by successively removing non-significant variables and/or compressing factor levels to reach a minimal adequate model (i.e. all coefficients are significant) for the variables used.

```
## Factor: Body_Weight3          Levels: Not Overweight, Overweight
## Factor: Cleft_Type2          Levels: Not L&P, Lip & Palate
##
## Call:
## lm(formula = BES_Attribution ~ Body_Weight3 + Cleft_Type2, data = AdultsF)
##
## Residuals:
##      Min       1Q   Median       3Q      Max
## -1.7482 -0.3514  0.0486  0.4510  1.4998
##
## Coefficients:
##              Estimate Std. Error t value Pr(>|t|)
## (Intercept)         2.148     0.088   24.41 < 2e-16 ***
## Body_Weight3Overweight -0.397     0.112   -3.54  0.00053 ***
## Cleft_Type2Lip & Palate -0.251     0.112   -2.25  0.02576 *
## ---
## Signif. codes:  0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1
##
## Residual standard error: 0.691 on 155 degrees of freedom
## Multiple R-squared:  0.118, Adjusted R-squared:  0.107
## F-statistic: 10.4 on 2 and 155 DF,  p-value: 5.79e-05
```



```
## Normality Tests p-values. Shapiro-Wilk:0.0573 Anderson-Darling:0.0320
## Data are normally distributed.
```

Compare AdultsAtt1a and AdultsAtt2a models

Use anova to determine if the reduced model is significantly worse as a description of the data than the baseline model. A non-significant test result indicates the reduction was justified.

```
## Analysis of Variance F-Test
## Model 1: BES_Attribution ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
## Model 2: BES_Attribution ~ Body_Weight3 + Cleft_Type2
## p-value: 0.6537 Rating: Not Significant
```

The non-significant test result confirms model reduction was justified, therefore AdultsAtt2a is the minimal adequate model for the variables used with an adjusted R-Squared of 0.107 compared to the baseline model 0.095.

Summary of Regression Analysis

The following table summarises the results for each of the regression models. A model names ending in 1a indicates the baseline model and 2a indicates the reduced (minimal adequate) model. Note that the Childrens BESC_Weight analysis used proportional ordinal logistic regression rather than OLSR, hence the AIC is reported for ChildrenWgt1a and ChildrenWgt2a, not the adjusted R-Squared.

Model	AdjRSqr	Formula
ChildrenApp1a	0.316	BESC_Appearance ~ Gender + Body_Weight1 + Cleft_Type + Imp_Face_Appearance
ChildrenApp2a	0.293	BESC_Appearance ~ Body_Weight2 + Cleft_Type2 + Imp_Face_Appearance3
ChildrenWgt1a	188.1	BESC_Weight1 ~ Gender + Body_Weight1 + Cleft_Type + Imp_Face_Appearance
ChildrenWgt2a	177.4	BESC_Weight1 ~ Body_Weight1
TeensApp1a	0.284	BES_Appearance ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
TeensApp2a	0.258	BES_Appearance ~ Body_Weight3 + Cleft_Type2 + Imp_Face_Appearance3
TeensWgt1a	0.359	BES_Weight ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
TeensWgt2a	0.325	BES_Weight ~ Body_Weight2 + Imp_Face_Appearance4
TeensAtt1a	0.196	BES_Attribution ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
TeensAtt2a	0.176	BES_Attribution ~ Cleft_Type2 + Imp_Face_Appearance4

AdultsApp1a	0.276	BES_Appearance ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
AdultsApp2a	0.280	BES_Appearance ~ Body_Weight2 + Imp_Face_Appearance4
AdultsWgt1a	0.525	BES_Weight ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
AdultsWgt2a	0.533	BES_Weight ~ Body_Weight2 + Imp_Face_Appearance4
AdultsAtt1a	0.095	BES_Attribution ~ Gender + Body_Weight + Cleft_Type + Imp_Face_Appearance
AdultsAtt2a	0.107	BES_Attribution ~ Body_Weight3 + Cleft_Type2

Data Analysis for Chapter 5 Paper 2. The psychosocial impact of cleft in a Western Australian cohort across three age-groups.

Background

Three age-appropriate versions of the Cleft Research Questionnaire (CRQ) were developed to capture psychosocial impacts of cleft amongst current and former patients across three age-groups: Children, Adolescents and Adults. Many of the questions were the same for all three versions of the CRQ. The purpose of this document was to conduct an analysis of these consistent questions to identify similarities and differences. This was primarily done using hypothesis tests.

For count data, the Chi-squared hypothesis test was used to test for independence of variables. In the case where the Chi-squared test returned a warning (e.g. cells had expected values < 5) then the Fisher's Exact test was used. For paired samples, the Wilcoxon signed rank test was used to check for a significant difference in location. In some cases where a significant difference was found, the Relative Risk was calculated. The Kolmogorov-Smirnov test was used to determine if there were differences between the Gender and Cleft_Type distributions for proportion of participants reporting teasing or bullying at age of occurrence.

Notes:

Alpha level of 0.05 (i.e. 95% Confidence Level) was used for all hypothesis tests.

This analysis was developed with R version: 3.4.1 and RStudio version: 1.0.143 using RMarkdown version:1.6.

Sample Bias Study v PMH

As per Linda Selvey (Supervisor) do not need to Holm adjust p-values as have independent variables (Nov 2016).

Children

Compare children (aged 6 to 12) study vs PMH to check for study sample bias using cleft_Type, Gender, Residence_Area and Age.

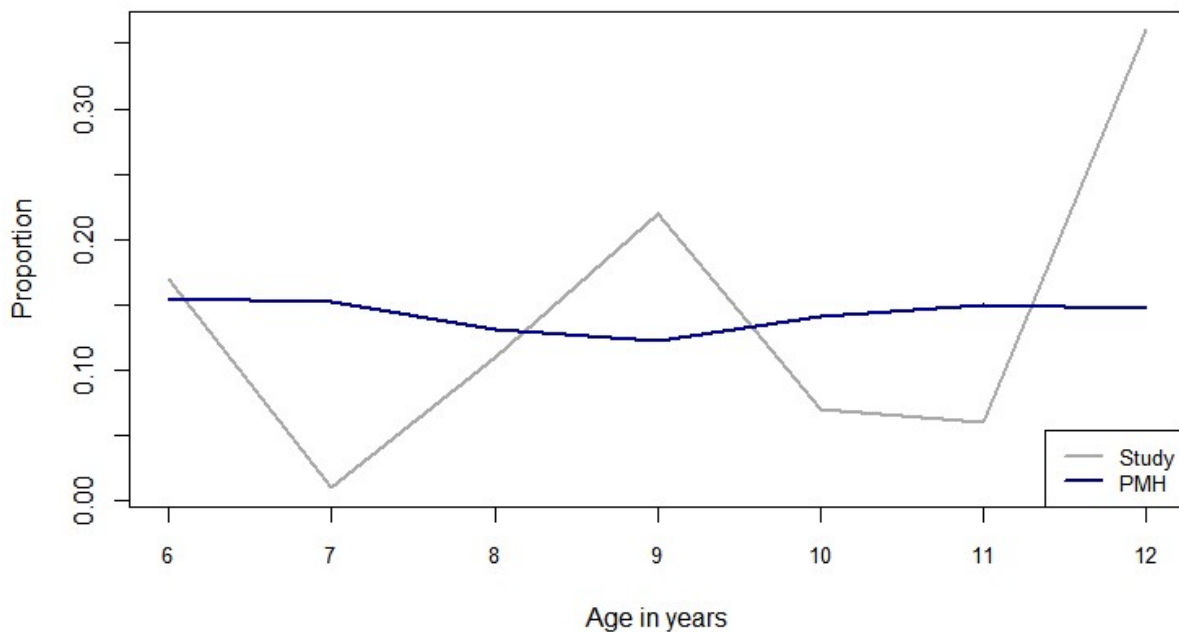
```
##           Children
## Gender   Study PMH   Prop % by col Study   PMH
##   Female    52  198             52.0%  45.0%
##   Male     48  242             48.0%  55.0%
##
## Study v PMH By Gender                Chi-squared   p-value=0.2051
## #
##           Children
## Cleft_Type Study PMH   Prop % by col Study   PMH
##   Lip-only    13  101             13.0%  23.0%
##   Lip & Palate 34  115             34.0%  26.1%
##   Palate-only 53  224             53.0%  50.9%
##
## Study v PMH By Cleft_Type            Chi-squared   p-value=0.0573
## #
##           Children
## Residence_Area Study PMH   Prop % by col Study   PMH
##   Perth Metro   68  334             68.0%  75.9%
##   WA Country    32  106             32.0%  24.1%
##
## Study v PMH By Residence_Area        Chi-squared   p-value=0.1017
## #
##           Children
## Age   Study PMH   Prop % by col Study   PMH
##   6    17   68             17.0%  15.5%
##   7     1   67             1.0%   15.2%
```

##	8	11	58	11.0%	13.2%
##	9	22	54	22.0%	12.3%
##	10	7	62	7.0%	14.1%
##	11	6	66	6.0%	15.0%
##	12	36	65	36.0%	14.8%
##					
##	Study v PMH By Age			Chi-squared	p-value=0.0000
##	#				

There was a dependence found between Children' age and data source (study and PMH database).
 There were less 7, 10 and 11 year olds in the study than in the PMH database.
 There were more 9 and 12 year olds in the study than in the PMH database.

Plot the age counts as proportions.

Children Study vs PMH proportions at each age in years



Teens

Compare teens (aged 13 to 21) study vs PMH to check for study sample bias using cleft_Type, Gender, Residence_Area and Age.

##	Teens				
##	Gender	Study	PMH	Prop % by col	Study PMH
##	Female	38	227		37.6% 46.0%
##	Male	63	266		62.4% 54.0%
##					
##	Study v PMH By Gender			Chi-squared	p-value=0.1209
##	#				
##					
##	Teens				
##	Cleft_Type	Study	PMH	Prop % by col	Study PMH
##	Lip-only	13	111		12.9% 22.5%
##	Lip & Palate	55	149		54.5% 30.2%
##	Palate-only	33	233		32.7% 47.3%
##					
##	Study v PMH By Cleft_Type			Chi-squared	p-value=0.0000
##	#				

```

##           Teens
## Residence_Area Study PMH   Prop % by col Study  PMH
##   Perth Metro    66   330             65.3%  66.9%
##   WA Country    35   163             34.7%  33.1%
##
## Study v PMH By Residence_Area           Chi-squared   p-value=0.7574
## #
##           Teens
## Age   Study PMH   Prop % by col Study  PMH
##   13     9   62             8.9%  12.6%
##   14     4   59             4.0%  12.0%
##   15    24   54            23.8%  11.0%
##   16     7   57             6.9%  11.6%
##   17     8   50             7.9%  10.1%
##   18    24   58            23.8%  11.8%
##   19     9   54             8.9%  11.0%
##   20     4   53             4.0%  10.8%
##   21    12   46            11.9%   9.3%
##
## Study v PMH By Age           Chi-squared   p-value=0.0001
## #

```

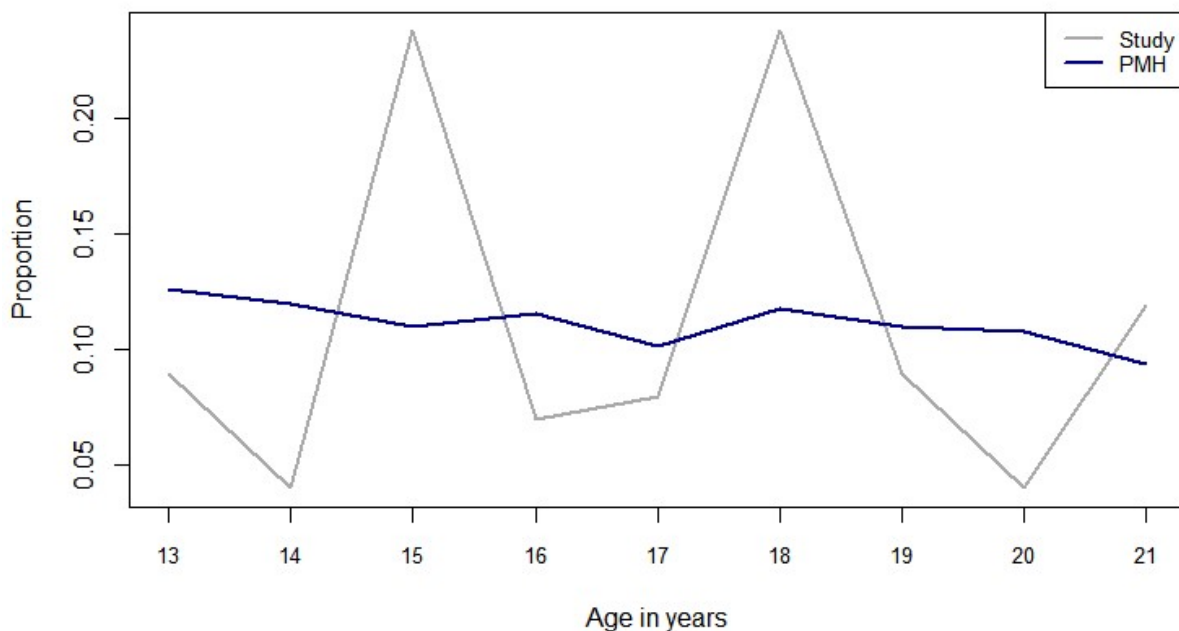
There were dependencies found for Teens Cleft_Type and Age compared data source (study and PMH database).

There were more Lip & Palate cleft types in the study than in the PMH database and less Lip-only and Palate-only.

There were more 15 and 18 year olds in the study than in the PMH database.

Plot the age counts as proportions.

Teens Study vs PMH proportions at each age in years



Adults

Compare adults (aged 22 to 42) study vs PMH to check for study sample bias using cleft_Type, Gender, Residence_Area and Age.

```

##           Adults
## Gender      Study PMH   Prop % by col Study  PMH
##   Female      87   363             55.1% 45.0%
##   Male        71   443             44.9% 55.0%
##
## Study v PMH By Gender                               Chi-squared   p-value=0.0209
## #
##           Adults
## Cleft_Type      Study PMH   Prop % by col Study  PMH
##   Lip-only       25   162             15.8% 20.1%
##   Lip & Palate   79   347             50.0% 43.1%
##   Palate-only    54   297             34.2% 36.8%
##
## Study v PMH By Cleft_Type                           Chi-squared   p-value=0.2291
## #
##           Adults
## Residence_Area Study PMH   Prop % by col Study  PMH
##   Perth Metro  125   569             79.1% 70.6%
##   WA Country   33    237             20.9% 29.4%
##
## Study v PMH By Residence_Area                       Chi-squared   p-value=0.0292
## #
##           Adults
## Age      Study PMH   Prop % by col Study  PMH
##   22      16   54             10.1% 6.7%
##   23       8   41              5.1% 5.1%
##   24       5   41              3.2% 5.1%
##   25       8   57              5.1% 7.1%
##   26      14   60              8.9% 7.4%
##   27       5   39              3.2% 4.8%
##   28      10   49              6.3% 6.1%
##   29      11   67              7.0% 8.3%
##   30      10   48              6.3% 6.0%
##   31       7   59              4.4% 7.3%
##   32       6   45              3.8% 5.6%
##   33       5   34              3.2% 4.2%
##   34       5   25              3.2% 3.1%
##   35       7   33              4.4% 4.1%
##   36       7   30              4.4% 3.7%
##   37       6   31              3.8% 3.8%
##   38       4   16              2.5% 2.0%
##   39       5   22              3.2% 2.7%
##   40       5   16              3.2% 2.0%
##   41       6   18              3.8% 2.2%
##   42       8   21              5.1% 2.6%
##
## Study v PMH By ABS Age Group                       Chi-squared   p-value=0.8601
## #

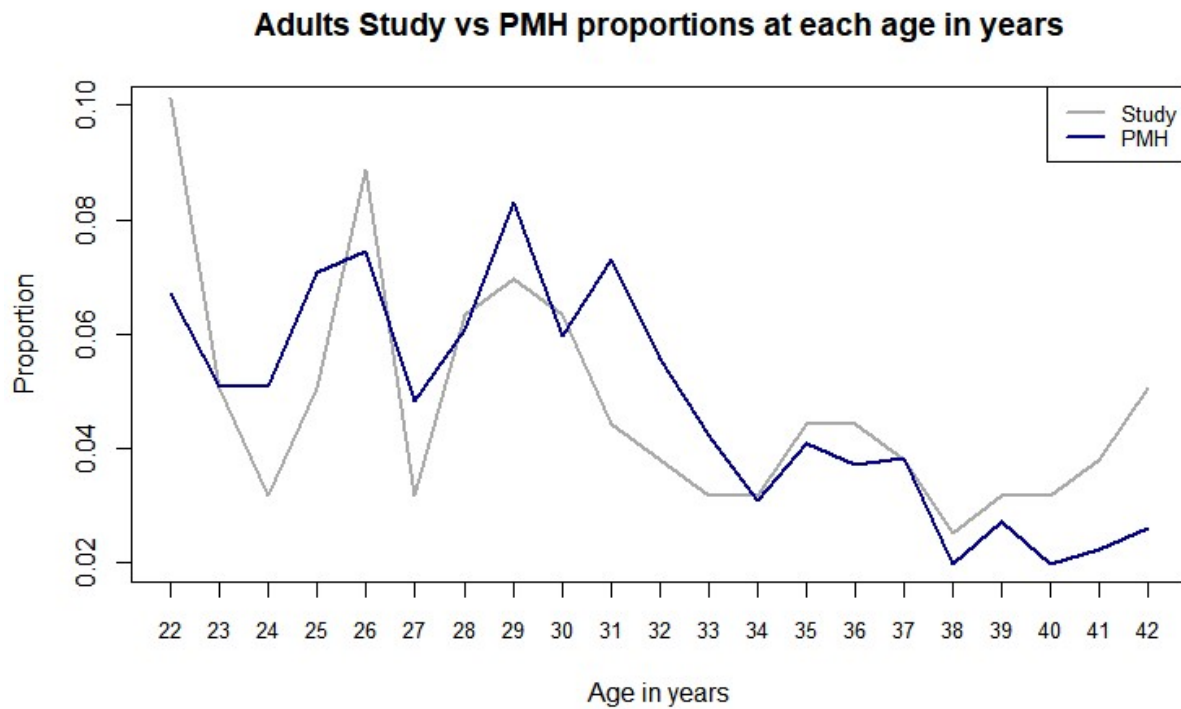
```

There were dependencies found for Adults gender and residence area compared data source (study and PMH database).

There were more females in the study than in the PMH database and less males.

There were more Perth Metro residents in the study than in the PMH database and less country residents.

Plot the age counts as proportions.



Impact of Cleft

Children Impact of Cleft By Gender

For Children compare impact of cleft for the following by Gender:

Impact_Academic, Impact_Attitude, Impact_Friends_Age, Impact_Health, Impact_Independence, Impact_Photographed, Impact_Public_Speaking, Impact_Restriction, Impact_School, Impact_Sport.

```
##
##          Gender
## Impact_Academic Female Male  Prop % by col Female Male
##   Not Impacted   40    39      76.9%  81.2%
##   Impacted       12     9       23.1%  18.8%
##
## Impact_Academic          Chi-squared  p-value=0.5956
## #
##          Gender
## Impact_Attitude Female Male  Prop % by col Female Male
##   Not Impacted   39    41      75.0%  85.4%
##   Impacted       13     7       25.0%  14.6%
##
## Impact_Attitude          Chi-squared  p-value=0.1932
## #
##          Gender
## Impact_Friends_Age Female Male  Prop % by col Female Male
##   Not Impacted   45    39      86.5%  81.2%
##   Impacted        7     9       13.5%  18.8%
##
## Impact_Friends_Age          Chi-squared  p-value=0.4711
## #
##          Gender
## Impact_Health Female Male  Prop % by col Female Male
##   Not Impacted   43    40      82.7%  83.3%
##   Impacted        9     8       17.3%  16.7%
##
## Impact_Health          Chi-squared  p-value=0.9321
## #
```

```

##          Gender
## Impact_Independence Female Male Prop % by col Female Male
##       Not Impacted   49   45           94.2%  93.8%
##       Impacted       3    3           5.8%   6.2%
##
## Impact_Independence           Fishers Exact p-value=1.0000
## #
##          Gender
## Impact_Photographed Female Male Prop % by col Female Male
##       Not Impacted   39   41           75.0%  85.4%
##       Impacted       13    7           25.0%  14.6%
##
## Impact_Photographed           Chi-squared  p-value=0.1932
## #
##          Gender
## Impact_Public_Speaking Female Male Prop % by col Female Male
##       Not Impacted   33   34           63.5%  70.8%
##       Impacted       19   14           36.5%  29.2%
##
## Impact_Public_Speaking           Chi-squared  p-value=0.4335
## #
##          Gender
## Impact_Restriction Female Male Prop % by col Female Male
##       Not Impacted   43   44           82.7%  91.7%
##       Impacted       9    4           17.3%   8.3%
##
## Impact_Restriction           Chi-squared  p-value=0.1825
## #
##          Gender
## Impact_School Female Male Prop % by col Female Male
##       Not Impacted   31   34           59.6%  70.8%
##       Impacted       21   14           40.4%  29.2%
##
## Impact_School           Chi-squared  p-value=0.2400
## #
##          Gender
## Impact_Sport Female Male Prop % by col Female Male
##       Not Impacted   47   43           90.4%  89.6%
##       Impacted       5    5           9.6%  10.4%
##
## Impact_Sport           Fishers Exact p-value=1.0000
## #

```

There were no significant differences for impact of cleft within Children by Gender.

Children Impact of Cleft By Cleft_Type

For Children compare impact of cleft for the following by Cleft_Type:

Impact_Academic, Impact_Attitude, Impact_Friends_Age, Impact_Health, Impact_Independence, Impact_Photographed, Impact_Public_Speaking, Impact_Restriction, Impact_School, Impact_Sport.

```

##          Cleft_Type
## Impact_Academic Lip-Only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##       Not Impacted   11   28   40           84.6%  82.4%  75.5%
##       Impacted       2    6   13           15.4%  17.6%  24.5%
##
## Impact_Academic           Fishers Exact p-value=0.7350
## #
##          Cleft_Type
## Impact_Attitude Lip-Only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##       Not Impacted   10   25   45           76.9%  73.5%  84.9%
##       Impacted       3    9    8           23.1%  26.5%  15.1%
##
## Impact_Attitude           Fishers Exact p-value=0.3846
## #
##          Cleft_Type
## Impact_Friends_Age Lip-Only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##       Not Impacted   12   29   43           92.3%  85.3%  81.1%
##       Impacted       1    5   10           7.7%  14.7%  18.9%
##

```

```

## Impact_Friends_Age                               Fishers Exact p-value=0.8019
## #
##           Cleft_Type
## Impact_Health Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted   11    30    42    84.6%   88.2%   79.2%
##   Impacted       2     4    11    15.4%   11.8%   20.8%
##
## Impact_Health                                     Fishers Exact p-value=0.6084
## #
##           Cleft_Type
## Impact Independence Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted   13    31    50   100.0%   91.2%   94.3%
##   Impacted       0     3     3    0.0%    8.8%    5.7%
##
## Impact_Independence                               Fishers Exact p-value=0.7189
## #
##           Cleft_Type
## Impact Photographed Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted    7    24    49    53.8%   70.6%   92.5%
##   Impacted        6    10     4    46.2%   29.4%    7.5%
##
## Impact_Photographed                               Fishers Exact p-value=0.0013
## #
##           Cleft_Type
## Impact Public Speaking Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted    9    24    34    69.2%   70.6%   64.2%
##   Impacted        4    10    19    30.8%   29.4%   35.8%
##
## Impact_Public_Speaking                           Fishers Exact p-value=0.8718
## #
##           Cleft_Type
## Impact Restriction Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted   11    32    44    84.6%   94.1%   83.0%
##   Impacted       2     2     9    15.4%    5.9%   17.0%
##
## Impact Restriction                               Fishers Exact p-value=0.2595
## #
##           Cleft_Type
## Impact_School Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted    9    21    35    69.2%   61.8%   66.0%
##   Impacted        4    13    18    30.8%   38.2%   34.0%
##
## Impact_School                                     Fishers Exact p-value=0.8757
## #
##           Cleft_Type
## Impact_Sport Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted   12    30    48    92.3%   88.2%   90.6%
##   Impacted       1     4     5     7.7%   11.8%    9.4%
##
## Impact Sport                                     Fishers Exact p-value=0.8968
## #

```

There was a significant difference for Impact of Cleft within Children by Cleft_Type for Impact_Photographed.

Children with a Cleft_Type of Palate-only reported less impact than both Lip-only and Lip & Palate. This is consistent with Palate-only being less likely to have a visible facial difference (i.e. no lip scar).

Teens Impact of Cleft By Gender

For Teens compare impact of cleft for the following by Gender:

Impact_Academic, Impact_Attitude, Impact_Friends_Age, Impact_Health, Impact_Independence, Impact_Photographed, Impact_Public_Speaking, Impact_Restriction, Impact_School, Impact_Sport, Impact_Getting_Work, Impact_Special_Relationships.

```

##           Gender
## Impact_Academic Female Male Prop % by col Female Male
##   Not Impacted   32    55    84.2%   87.3%
##   Impacted       6     8    15.8%   12.7%
##
## Impact_Academic                                     Chi-squared   p-value=0.6632
## #
##           Gender
## Impact_Attitude Female Male Prop % by col Female Male
##   Not Impacted   25    46    65.8%   73.0%
##   Impacted       13    17    34.2%   27.0%
##

```

```

## Impact_Attitude                               Chi-squared   p-value=0.4413
## #
##                               Gender
## Impact_Friends_Age Female Male Prop % by col Female Male
##   Not Impacted    30    48    78.9%  76.2%
##   Impacted         8    15    21.1%  23.8%
##
## Impact_Friends_Age                               Chi-squared   p-value=0.7489
## #
##                               Gender
## Impact_Health Female Male Prop % by col Female Male
##   Not Impacted    35    54    92.1%  85.7%
##   Impacted         3     9     7.9%  14.3%
##
## Impact_Health                                   Fishers Exact p-value=0.5272
## #
##                               Gender
## Impact_Independence Female Male Prop % by col Female Male
##   Not Impacted    34    57    89.5%  90.5%
##   Impacted         4     6    10.5%  9.5%
##
## Impact_Independence                             Fishers Exact p-value=1.0000
## #
##                               Gender
## Impact_Photographed Female Male Prop % by col Female Male
##   Not Impacted    20    36    52.6%  57.1%
##   Impacted        18    27    47.4%  42.9%
##
## Impact_Photographed                             Chi-squared   p-value=0.6586
## #
##                               Gender
## Impact_Public_Speaking Female Male Prop % by col Female Male
##   Not Impacted    14    32    36.8%  50.8%
##   Impacted        24    31    63.2%  49.2%
##
## Impact_Public_Speaking                           Chi-squared   p-value=0.1726
## #
##                               Gender
## Impact_Restriction Female Male Prop % by col Female Male
##   Not Impacted    33    55    86.8%  87.3%
##   Impacted         5     8    13.2%  12.7%
##
## Impact_Restriction                               Fishers Exact p-value=1.0000
## #
##                               Gender
## Impact_School Female Male Prop % by col Female Male
##   Not Impacted    27    38    71.1%  60.3%
##   Impacted        11    25    28.9%  39.7%
##
## Impact_School                                   Chi-squared   p-value=0.2752
## #
##                               Gender
## Impact_Sport Female Male Prop % by col Female Male
##   Not Impacted    31    51    81.6%  81.0%
##   Impacted         7    12    18.4%  19.0%
##
## Impact_Sport                                   Chi-squared   p-value=0.9378
## #
##                               Gender
## Impact_Getting_Work Female Male Prop % by col Female Male
##   Not Impacted    30    58    78.9%  92.1%
##   Impacted         8     5    21.1%  7.9%
##
## Impact_Getting_Work                             Fishers Exact p-value=0.0703
## #
##                               Gender
## Impact_Special_Relationships Female Male Prop % by col Female Male
##   Not Impacted    26    42    68.4%  66.7%

```

```
##           Impacted           12      21           31.6%  33.3%
##
## Impact_Special_Relationships           Chi-squared  p-value=0.8555
## #
```

There were no significant differences for impact of cleft within Teens by Gender.

Teens Impact of Cleft By Cleft_Type

For Teens compare impact of cleft for the following by Cleft_Type:

Impact_Academic, Impact_Attitude, Impact_Friends_Age, Impact_Health, Impact_Independence, Impact_Photographed, Impact_Public_Speaking, Impact_Restriction, Impact_School, Impact_Sport.

```
##           Cleft_Type
## Impact_Academic Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted   13      45           29           100.0%  81.8%  87.9%
##   Impacted       0      10            4            0.0%  18.2%  12.1%
##
## Impact_Academic           Fishers Exact p-value=0.2806
## #
##           Cleft_Type
## Impact Attitude Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted   7      35           29           53.8%  63.6%  87.9%
##   Impacted       6      20            4           46.2%  36.4%  12.1%
##
## Impact_Attitude           Fishers Exact p-value=0.0147
## #
##           Cleft_Type
## Impact_Friends_Age Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted  11      36           31           84.6%  65.5%  93.9%
##   Impacted      2      19            2           15.4%  34.5%   6.1%
##
## Impact_Friends_Age           Fishers Exact p-value=0.0046
## #
##           Cleft_Type
## Impact Health Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted  13      45           31           100.0%  81.8%  93.9%
##   Impacted      0      10            2            0.0%  18.2%   6.1%
##
## Impact_Health           Fishers Exact p-value=0.1274
## #
##           Cleft_Type
## Impact_Independence Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted  12      49           30           92.3%  89.1%  90.9%
##   Impacted      1      6            3            7.7%  10.9%   9.1%
##
## Impact Independence           Fishers Exact p-value=1.0000
## #
##           Cleft_Type
## Impact_Photographed Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted  8      21           27           61.5%  38.2%  81.8%
##   Impacted      5      34            6           38.5%  61.8%  18.2%
##
## Impact Photographed           Fishers Exact p-value=0.0002
## #
##           Cleft_Type
## Impact_Public_Speaking Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted  11      17           18           84.6%  30.9%  54.5%
##   Impacted      2      38           15           15.4%  69.1%  45.5%
##
## Impact Public Speaking           Fishers Exact p-value=0.0010
## #
##           Cleft_Type
## Impact_Restriction Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted  13      45           30           100.0%  81.8%  90.9%
##   Impacted      0      10            3            0.0%  18.2%   9.1%
##
## Impact_Restriction           Fishers Exact p-value=0.1850
## #
##           Cleft_Type
## Impact_School Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted  11      26           28           84.6%  47.3%  84.8%
##   Impacted      2      29            5           15.4%  52.7%  15.2%
##
## Impact School           Fishers Exact p-value=0.0004
## #
##           Cleft_Type
## Impact_Sport Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted  12      41           29           92.3%  74.5%  87.9%
##   Impacted      1      14            4            7.7%  25.5%  12.1%
##
```

```

## Impact_Sport Fishers Exact p-value=0.2538
## #
## Cleft_Type
## Impact_Getting_Work Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 13 45 30 100.0% 81.8% 90.9%
## Impacted 0 10 3 0.0% 18.2% 9.1%
##
## Impact_Getting_Work Fishers Exact p-value=0.1850
## #
## Cleft Type
## Impact Special Relationships Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 8 31 29 61.5% 56.4% 87.9%
## Impacted 5 24 4 38.5% 43.6% 12.1%
##
## Impact Special Relationships Fishers Exact p-value=0.0059
## #

```

There were significant differences for Impact of Cleft within Teens by Cleft_Type for the following: For the following, Teens with Lip & Palate Cleft_Type were more likely to be impacted than Palate-only or Lip-only for: Impact_Attitude, Impact_Friends_Age, Impact_Photographed, Impact_Public_Speaking, Impact_School, Impact_Special_Relationships.

Adults Impact of Cleft By Gender

For Adults compare impact of cleft for the following by Gender: Impact_Academic, Impact_Attitude, Impact_Friends_Age, Impact_Health, Impact_Independence, Impact_Photographed, Impact_Public_Speaking, Impact_Restriction, Impact_School, Impact_Sport, Impact_Getting_Work, Impact_Special_Relationships.

Note: These are not included here as they were not included in the journal paper. Impact_Doing_Work, Impact_Friends_Opp_Sex, Impact_Job_Interviews, Impact_Pubs_Clubs, Impact_Self_Esteem

```

## Gender
## Impact_Academic Female Male Prop % by col Female Male
## Not Impacted 75 67 86.2% 94.4%
## Impacted 12 4 13.8% 5.6%
##
## Impact_Academic Chi-squared p-value=0.0908
## #
## Gender
## Impact_Attitude Female Male Prop % by col Female Male
## Not Impacted 55 53 63.2% 74.6%
## Impacted 32 18 36.8% 25.4%
##
## Impact_Attitude Chi-squared p-value=0.1244
## #
## Gender
## Impact_Friends_Age Female Male Prop % by col Female Male
## Not Impacted 68 61 78.2% 85.9%
## Impacted 19 10 21.8% 14.1%
##
## Impact_Friends_Age Chi-squared p-value=0.2104
## #
## Gender
## Impact_Health Female Male Prop % by col Female Male
## Not Impacted 66 61 75.9% 85.9%
## Impacted 21 10 24.1% 14.1%
##
## Impact_Health Chi-squared p-value=0.1134
## #
## Gender
## Impact_Independence Female Male Prop % by col Female Male
## Not Impacted 75 63 86.2% 88.7%
## Impacted 12 8 13.8% 11.3%
##

```

```

## Impact_Independence                               Chi-squared    p-value=0.6349
## #
##                               Gender
## Impact_Photographed Female Male Prop % by col Female Male
##   Not Impacted      45    48          51.7%  67.6%
##   Impacted          42    23          48.3%  32.4%
##
## Impact_Photographed                               Chi-squared    p-value=0.0436
## #
##                               Gender
## Impact_Public_Speaking Female Male Prop % by col Female Male
##   Not Impacted      44    40          50.6%  56.3%
##   Impacted          43    31          49.4%  43.7%
##
## Impact_Public_Speaking                           Chi-squared    p-value=0.4702
## #
##                               Gender
## Impact_Restriction Female Male Prop % by col Female Male
##   Not Impacted      75    62          86.2%  87.3%
##   Impacted          12     9          13.8%  12.7%
##
## Impact_Restriction                               Chi-squared    p-value=0.8370
## #
##                               Gender
## Impact_School Female Male Prop % by col Female Male
##   Not Impacted      50    36          57.5%  50.7%
##   Impacted          37    35          42.5%  49.3%
##
## Impact_School                                   Chi-squared    p-value=0.3956
## #
##                               Gender
## Impact_Sport Female Male Prop % by col Female Male
##   Not Impacted      68    55          78.2%  77.5%
##   Impacted          19    16          21.8%  22.5%
##
## Impact_Sport                                   Chi-squared    p-value=0.9165
## #
##                               Gender
## Impact_Getting_Work Female Male Prop % by col Female Male
##   Not Impacted      72    59          82.8%  83.1%
##   Impacted          15    12          17.2%  16.9%
##
## Impact_Getting_Work                           Chi-squared    p-value=0.9550
## #
##                               Gender
## Impact_Special_Relationships Female Male Prop % by col Female Male
##   Not Impacted      53    53          60.9%  74.6%
##   Impacted          34    18          39.1%  25.4%
##
## Impact_Special_Relationships                   Chi-squared    p-value=0.0677
## #

```

There was one significant difference for impact of cleft within Adults .

Females were more likely to be impacted for being photographed than males, however this result was marginal (p=0.0436).

Adults Impact of Cleft By Cleft_Type

For Adults compare impact of cleft for the following:

Impact_Academic, Impact_Attitude, Impact_Friends_Age, Impact_Health, Impact_Independence, Impact_Photographed, Impact_Public_Speaking, Impact_Restriction, Impact_School, Impact_Sport.

```

##                               Cleft_Type
## Impact_Academic Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Not Impacted    25    70          100.0%  88.6%  87.0%
##   Impacted         0     9           0.0%   11.4%  13.0%
##

```

```

## Impact_Academic Fishers Exact p-value=0.1759
## #
## Cleft_Type
## Impact Attitude Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 19 50 39 76.0% 63.3% 72.2%
## Impacted 6 29 15 24.0% 36.7% 27.8%
##
## Impact Attitude Fishers Exact p-value=0.4205
## #
## Cleft_Type
## Impact Friends Age Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 23 62 44 92.0% 78.5% 81.5%
## Impacted 2 17 10 8.0% 21.5% 18.5%
##
## Impact_Friends_Age Fishers Exact p-value=0.3249
## #
## Cleft_Type
## Impact Health Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 22 65 40 88.0% 82.3% 74.1%
## Impacted 3 14 14 12.0% 17.7% 25.9%
##
## Impact_Health Fishers Exact p-value=0.3405
## #
## Cleft_Type
## Impact Independence Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 22 70 46 88.0% 88.6% 85.2%
## Impacted 3 9 8 12.0% 11.4% 14.8%
##
## Impact_Independence Fishers Exact p-value=0.8980
## #
## Cleft_Type
## Impact Photographed Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 12 38 43 48.0% 48.1% 79.6%
## Impacted 13 41 11 52.0% 51.9% 20.4%
##
## Impact Photographed Fishers Exact p-value=0.0005
## #
## Cleft_Type
## Impact Public Speaking Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 15 40 29 60.0% 50.6% 53.7%
## Impacted 10 39 25 40.0% 49.4% 46.3%
##
## Impact_Public_Speaking Fishers Exact p-value=0.7297
## #
## Cleft_Type
## Impact Restriction Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 24 67 46 96.0% 84.8% 85.2%
## Impacted 1 12 8 4.0% 15.2% 14.8%
##
## Impact Restriction Fishers Exact p-value=0.3509
## #
## Cleft_Type
## Impact School Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 17 34 35 68.0% 43.0% 64.8%
## Impacted 8 45 19 32.0% 57.0% 35.2%
##
## Impact_School Fishers Exact p-value=0.0181
## #
## Cleft_Type
## Impact Sport Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 21 58 44 84.0% 73.4% 81.5%
## Impacted 4 21 10 16.0% 26.6% 18.5%
##
## Impact Sport Fishers Exact p-value=0.4652
## #
## Cleft_Type
## Impact Getting Work Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 24 62 45 96.0% 78.5% 83.3%
## Impacted 1 17 9 4.0% 21.5% 16.7%
##
## Impact_Getting_Work Fishers Exact p-value=0.1163
## #
## Cleft_Type
## Impact Special Relationships Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Not Impacted 17 51 38 68.0% 64.6% 70.4%
## Impacted 8 28 16 32.0% 35.4% 29.6%
##
## Impact_Special_Relationships Fishers Exact p-value=0.8041
## #

```


There were significant differences for Impact of Cleft within Adults by Cleft_Type for the following:
 Impact_Photoshopped - Adults with Palate-only Cleft_Type were less likely to be impacted.
 Impact_School - Adults with Lip & Palate Cleft_Type were more likely to be impacted.

Importance of Physical Attributes and Support

Importance ratings used the following Likert scale: 1=Extremely, 2=Very, 3=Somewhat, 4=Not Very, 5=Not At All.

For pairwise comparisons use paired Wilcoxon-Mann-Whitney U Test for each combination of the following:

Imp_Facial_Appearance, Imp_Teeth_Appearance, Imp_Speech, Imp_Hearing and
 Imp_Support_Siblings, Imp_Support_Teacher, Imp_Support_Treat_Givers, Imp_Support_Parents

Note: Use Wilcoxon as Chi-square has cells with estimated counts < 5 and Fisher's exact test cannot handle the complexity. This is a paired test as we are comparing ratings by the same person. Adjust the p-values using the Holm correction as we are re-using the same variables in multiple tests.

Children Importance of Physical Attributes By Gender

Determine if Gender had a relationship with importance of physical attributes: facial appearance, teeth appearance, speech and hearing.

```
##                               Gender
## Imp_Facial_Appearance Female Male Prop % by col Female Male
##     Extremely          10     4          19.2%   8.3%
##     Very                19    18          36.5%  37.5%
##     Somewhat            9    16          17.3%  33.3%
##     Not Very            2     8           3.8%  16.7%
##     Not At All         12     2          23.1%   4.2%
##
## Imp_Facial_Appearance          Fishers Exact p-value=0.0039
## #
##                               Gender
## Imp_Teeth_Appearance Female Male Prop % by col Female Male
##     Extremely          13    10          25.0%  20.8%
##     Very                19    22          36.5%  45.8%
##     Somewhat            6     9          11.5%  18.8%
##     Not Very            7     3          13.5%   6.2%
##     Not At All         7     4          13.5%   8.3%
##
## Imp_Teeth_Appearance          Fishers Exact p-value=0.5013
## #
##                               Gender
## Imp_Speech      Female Male Prop % by col Female Male
##     Extremely    18     15          34.6%  31.2%
##     Very          18    20          34.6%  41.7%
##     Somewhat      6     5          11.5%  10.4%
##     Not Very      3     3           5.8%   6.2%
##     Not At All    7     5          13.5%  10.4%
##
## Imp_Speech          Fishers Exact p-value=0.9686
## #
##                               Gender
## Imp_Hearing  Female Male Prop % by col Female Male
##     Extremely  23     21          44.2%  43.8%
##     Very       16     17          30.8%  35.4%
##     Somewhat   4      5           7.7%  10.4%
##     Not Very   3      2           5.8%   4.2%
##     Not At All 6      3          11.5%   6.2%
##
## Imp_Hearing          Fishers Exact p-value=0.8793
## #
```

Children Importance of Physical Attributes By Cleft_Type

Determine if Cleft_Type had a relationship with importance of physical attributes: facial appearance, teeth appearance, speech and hearing.

```
##                               Cleft_Type
## Imp_Facial_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##     Extremely          1         3         10         7.7%      8.8%      18.9%
##     Very                6        13         18         46.2%     38.2%     34.0%
##     Somewhat           2         9         14         15.4%     26.5%     26.4%
##     Not_Very            4         4         2          30.8%     11.8%     3.8%
##     Not_At_All         0         5         9          0.0%     14.7%     17.0%
##
## Imp_Facial_Appearance                               Fishers Exact p-value=0.1643
## #
##                               Cleft_Type
## Imp_Teeth_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##     Extremely          2         9         12         15.4%     26.5%     22.6%
##     Very                9        11         21         69.2%     32.4%     39.6%
##     Somewhat           1         4         10         7.7%     11.8%     18.9%
##     Not_Very            0         5         5          0.0%     14.7%     9.4%
##     Not_At_All         1         5         5          7.7%     14.7%     9.4%
##
## Imp_Teeth_Appearance                               Fishers Exact p-value=0.5932
## #
##                               Cleft_Type
## Imp_Speech Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##     Extremely          4        11         18         30.8%     32.4%     34.0%
##     Very                2        13         23         15.4%     38.2%     43.4%
##     Somewhat           2         3         6         15.4%     8.8%     11.3%
##     Not_Very            1         3         2          7.7%     8.8%     3.8%
##     Not_At_All         4         4         4         30.8%     11.8%     7.5%
##
## Imp_Speech                                         Fishers Exact p-value=0.3668
## #
##                               Cleft_Type
## Imp_Hearing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##     Extremely          4        17         23         30.8%     50.0%     43.4%
##     Very                4         9         20         30.8%     26.5%     37.7%
##     Somewhat           3         1         5         23.1%     2.9%     9.4%
##     Not_Very            1         2         2          7.7%     5.9%     3.8%
##     Not_At_All         1         5         3          7.7%     14.7%     5.7%
##
## Imp_Hearing                                         Fishers Exact p-value=0.3565
## #
```

Children pairwise comparison of Importance of Physical Attributes

Determine if there was a relationship between each pair of importance of physical attributes variables.

```
##                               Imp_Teeth_Appearance
## Imp_Facial_Appearance Extremely Very Somewhat Not_Very Not_At_All Total
##     Extremely          10         1         3         0         0         14
##     Very                6         29         1         0         1         37
##     Somewhat           4         9         9         2         1         25
##     Not_Very            2         2         2         3         1         10
##     Not_At_All         1         0         0         5         8         14
##     Total              23         41         15         10         11         100
##
## Imp_Facial_Appearance v Imp_Teeth_Appearance       Wilcox Paired p-value=0.0100
## #
##                               Imp_Speech
## Imp_Facial_Appearance Extremely Very Somewhat Not_Very Not_At_All Total
##     Extremely          9         3         2         0         0         14
##     Very                8         24         2         2         1         37
##     Somewhat           8         8         5         1         3         25
##     Not_Very            4         1         2         0         3         10
##     Not_At_All         4         2         0         3         5         14
##     Total              33         38         11         6         12         100
##
## Imp_Facial_Appearance v Imp_Speech                 Wilcox Paired p-value=0.0029
## #
##                               Imp_Hearing
## Imp_Facial_Appearance Extremely Very Somewhat Not_Very Not_At_All Total
##     Extremely          10         2         1         0         1         14
##     Very                12         20         3         0         2         37
##     Somewhat           11         9         3         1         1         25
```

```

##           Not Very           5     1           1     3           0     10
##           Not At All         6     1           1     1           5     14
##           Total              44    33           9     5           9    100
##
## Imp_Facial_Appearance v Imp_Hearing           Wilcox Paired p-value=0.0000
## #
##           Imp_Speech
## Imp_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely          13     6           2     1           1     23
##           Very                8    25           3     1           4     41
##           Somewhat            7     4           4     0           0     15
##           Not Very            3     2           2     1           2     10
##           Not At All          2     1           0     3           5     11
##           Total               33    38           11     6           12    100
##
## Imp_Teeth_Appearance v Imp_Speech           Wilcox Paired p-value=0.1628
## #
##           Imp_Hearing
## Imp_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely          18     2           1     1           1     23
##           Very               11    24           4     1           1     41
##           Somewhat           7     5           3     0           0     15
##           Not Very           5     1           0     2           2     10
##           Not At All         3     1           1     1           5     11
##           Total              44    33           9     5           9    100
##
## Imp_Teeth_Appearance v Imp_Hearing           Wilcox Paired p-value=0.0021
## #
##           Imp_Hearing
## Imp_Speech   Extremely Very Somewhat Not Very Not At All Total
##           Extremely  27     5           1     0           0     33
##           Very       12    24           1     1           0     38
##           Somewhat   2     2           5     1           1     11
##           Not Very   2     1           0     0           3     6
##           Not At All 1     1           2     3           5     12
##           Total      44    33           9     5           9    100
##
## Imp_Speech v Imp_Hearing           Wilcox Paired p-value=0.0235
## #

```

**** There were Significant differences for importance of physical attributes within Children for all tests except for Teeth Appearance and Speech.****

Imp_Facial_Appearance was rated *lower* in importance than the other attributes.

Children Importance of Support By Gender

Determine if Gender had a relationship with importance of support provided by: Parents, Treatment Givers, Siblings and Teachers.

```

##           Gender
## Imp_Support_Parents Female Male Prop % by col Female Male
##           Extremely      40    28           76.9%  58.3%
##           Very            9    15           17.3%  31.2%
##           Somewhat        2     3            3.8%   6.2%
##           Not Very        0     1            0.0%   2.1%
##           Not At All      1     1            1.9%   2.1%
##
## Imp_Support_Parents           Fishers Exact p-value=0.2244
## #
##           Gender
## Imp_Support_Treat_Givers Female Male Prop % by col Female Male
##           Extremely      28    22           53.8%  45.8%
##           Very           21    18           40.4%  37.5%
##           Somewhat        2     8            3.8%  16.7%
##           Not At All      1     0            1.9%   0.0%
##

```

```

## Imp_Support_Treat_Givers Fishers Exact p-value=0.1236
## #
## Gender
## Imp_Support_Siblings Female Male Prop % by col Female Male
## Extremely 22 13 42.3% 27.1%
## Very 18 20 34.6% 41.7%
## Somewhat 5 12 9.6% 25.0%
## Not Very 3 0 5.8% 0.0%
## Not At All 4 3 7.7% 6.2%
##
## Imp_Support_Siblings Fishers Exact p-value=0.0815
## #
## Gender
## Imp_Support_Teacher Female Male Prop % by col Female Male
## Extremely 22 14 42.3% 29.2%
## Very 19 20 36.5% 41.7%
## Somewhat 7 11 13.5% 22.9%
## Not Very 3 2 5.8% 4.2%
## Not At All 1 1 1.9% 2.1%
##
## Imp_Support_Teacher Fishers Exact p-value=0.5827
## #

```

Children Importance of Support By Cleft_Type

Determine if Cleft_Type had a relationship with importance of support provided by: Parents, Treatment Givers, Siblings and Teachers.

```

## Cleft_Type
## Imp_Support_Parents Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely 7 24 37 53.8% 70.6% 69.8%
## Very 4 7 13 30.8% 20.6% 24.5%
## Somewhat 1 1 3 7.7% 2.9% 5.7%
## Not Very 0 1 0 0.0% 2.9% 0.0%
## Not At All 1 1 0 7.7% 2.9% 0.0%
##
## Imp_Support_Parents Fishers Exact p-value=0.4328
## #
## Cleft_Type
## Imp_Support_Treat_Givers Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely 4 17 29 30.8% 50.0% 54.7%
## Very 7 13 19 53.8% 38.2% 35.8%
## Somewhat 2 3 5 15.4% 8.8% 9.4%
## Not At All 0 1 0 0.0% 2.9% 0.0%
##
## Imp_Support_Treat_Givers Fishers Exact p-value=0.5572
## #
## Cleft_Type
## Imp_Support_Siblings Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely 4 10 21 30.8% 29.4% 39.6%
## Very 5 11 22 38.5% 32.4% 41.5%
## Somewhat 3 6 8 23.1% 17.6% 15.1%
## Not Very 0 3 0 0.0% 8.8% 0.0%
## Not At All 1 4 2 7.7% 11.8% 3.8%
##
## Imp_Support_Siblings Fishers Exact p-value=0.3675
## #
## Cleft_Type
## Imp_Support_Teacher Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely 5 10 21 38.5% 29.4% 39.6%
## Very 3 12 24 23.1% 35.3% 45.3%
## Somewhat 5 5 8 38.5% 14.7% 15.1%
## Not Very 0 5 0 0.0% 14.7% 0.0%
## Not At All 0 2 0 0.0% 5.9% 0.0%
##
## Imp_Support_Teacher Fishers Exact p-value=0.0212
## #

```

Children pairwise comparison of Importance of Support

Determine if there were relationships between each pair of importance of support variables.

```

## Imp_Support_Teacher
## Imp_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
## Extremely 28 4 2 1 0 35
## Very 3 29 6 0 0 38
## Somewhat 2 5 8 2 0 17

```

```

##           Not Very           0    0           1           2           0    3
##           Not At All         3    1           1           0           2    7
##           Total              36   39          18           5           2   100
##
## Imp_Support_Siblings v Imp_Support_Teacher           Wilcox Paired p-value=0.4092
## #
##           Imp_Support_Treat_Givers
## Imp_Support_Siblings Extremely Very Somewhat Not At All Total
##           Extremely          27    6           2           0           35
##           Very                13   22           3           0           38
##           Somewhat            5    7           5           0           17
##           Not Very             1    2           0           0           3
##           Not At All           4    2           0           1           7
##           Total                50   39          10           1          100
##
## Imp_Support_Siblings v Imp_Support_Treat_Givers     Wilcox Paired p-value=0.0002
## #
##           Imp_Support_Parents
## Imp_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##           Extremely          33    0           1           0           1           35
##           Very                22   16           0           0           0           38
##           Somewhat            6    7           4           0           0           17
##           Not Very             2    1           0           0           0           3
##           Not At All           5    0           0           1           1           7
##           Total                68   24           5           1           2          100
##
## Imp_Support_Siblings v Imp_Support_Parents           Wilcox Paired p-value=0.0000
## #
##           Imp_Support_Treat_Givers
## Imp_Support_Teacher Extremely Very Somewhat Not At All Total
##           Extremely          29    4           3           0           36
##           Very                11   27           1           0           39
##           Somewhat            6    6           6           0           18
##           Not Very             4    1           0           0           5
##           Not At All           0    1           0           1           2
##           Total                50   39          10           1          100
##
## Imp_Support_Teacher v Imp_Support_Treat_Givers     Wilcox Paired p-value=0.0010
## #
##           Imp_Support_Parents
## Imp_Support_Teacher Extremely Very Somewhat Not Very Not At All Total
##           Extremely          33    0           1           1           1           36
##           Very                24   15           0           0           0           39
##           Somewhat            6    8           4           0           0           18
##           Not Very             4    1           0           0           0           5
##           Not At All           1    0           0           0           1           2
##           Total                68   24           5           1           2          100
##
## Imp_Support_Teacher v Imp_Support_Parents           Wilcox Paired p-value=0.0000
## #
##           Imp_Support_Parents
## Imp_Support_Treat_Givers Extremely Very Somewhat Not Very Not At All Total
##           Extremely          46    3           0           1           0           50
##           Very                20   19           0           0           0           39
##           Somewhat            2    2           5           0           1           10
##           Not At All           0    0           0           0           1           1
##           Total                68   24           5           1           2          100
##
## Imp_Support_Treat_Givers v Imp_Support_Parents     Wilcox Paired p-value=0.0040
## #

```

**** There were Significant differences for importance of support within Children for all tests except for Siblings vs Teacher.****

Interestingly, Imp_Support_Siblings was rated *lower* in importance than the others and Parents were rated *higher*.

Teens Importance of Physical Attributes By Gender

Determine if Gender had a relationship with importance of physical attributes: facial appearance, teeth appearance, speech and hearing.

```
##                               Gender
## Imp_Facial_Appearance Female Male Prop % by col Female Male
##     Extremely      12     7      31.6%  11.1%
##     Very           14    22      36.8%  34.9%
##     Somewhat       10    23      26.3%  36.5%
##     Not Very        1     7       2.6%  11.1%
##     Not At All     1     4       2.6%   6.3%
##
## Imp_Facial_Appearance          Fishers Exact p-value=0.0725
## #
##                               Gender
## Imp_Teeth_Appearance Female Male Prop % by col Female Male
##     Extremely      19     9      50.0%  14.3%
##     Very           13    30      34.2%  47.6%
##     Somewhat        3    14       7.9%  22.2%
##     Not Very        2     7       5.3%  11.1%
##     Not At All     1     3       2.6%   4.8%
##
## Imp_Teeth_Appearance          Fishers Exact p-value=0.0025
## #
##                               Gender
## Imp_Speech      Female Male Prop % by col Female Male
##     Extremely     13    11      34.2%  17.5%
##     Very           16    30      42.1%  47.6%
##     Somewhat        6    16      15.8%  25.4%
##     Not Very        2     3       5.3%   4.8%
##     Not At All     1     3       2.6%   4.8%
##
## Imp_Speech          Fishers Exact p-value=0.3747
## #
##                               Gender
## Imp_Hearing      Female Male Prop % by col Female Male
##     Extremely     10    18      26.3%  28.6%
##     Very           18    26      47.4%  41.3%
##     Somewhat        4    11      10.5%  17.5%
##     Not Very        2     2       5.3%   3.2%
##     Not At All     4     6      10.5%   9.5%
##
## Imp_Hearing          Fishers Exact p-value=0.8532
## #
```

Teens Importance of Physical Attributes By Cleft_Type

Determine if Cleft_Type had a relationship with importance of physical attributes: facial appearance, teeth appearance, speech and hearing.

```
##                               Cleft Type
## Imp Facial Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##     Extremely        2    13     4      15.4%  23.6%  12.1%
##     Very              5    20    11     38.5%  36.4%  33.3%
##     Somewhat          3    15    15     23.1%  27.3%  45.5%
##     Not Very          2     6     0     15.4%  10.9%  0.0%
##     Not At All       1     1     3     7.7%   1.8%  9.1%
##
## Imp_Facial_Appearance          Fishers Exact p-value=0.1344
## #
##                               Cleft_Type
## Imp_Teeth_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##     Extremely        4    14    10     30.8%  25.5%  30.3%
##     Very              4    22    17     30.8%  40.0%  51.5%
##     Somewhat          2    13     2     15.4%  23.6%  6.1%
##     Not Very          2     5     2     15.4%   9.1%  6.1%
##     Not At All       1     1     2     7.7%   1.8%  6.1%
##
## Imp_Teeth_Appearance          Fishers Exact p-value=0.3403
## #
##                               Cleft Type
## Imp_Speech      Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##     Extremely      2    12     10     15.4%  21.8%  30.3%
##     Very            5    27    14     38.5%  49.1%  42.4%
```

```

## Somewhat 4 11 7 30.8% 20.0% 21.2%
## Not Very 1 3 1 7.7% 5.5% 3.0%
## Not At All 1 2 1 7.7% 3.6% 3.0%
##
## Imp_Speech Fishers Exact p-value=0.8813
## #
## Cleft_Type
## Imp_Hearing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely 2 18 8 15.4% 32.7% 24.2%
## Very 6 21 17 46.2% 38.2% 51.5%
## Somewhat 2 7 6 15.4% 12.7% 18.2%
## Not Very 1 3 0 7.7% 5.5% 0.0%
## Not At All 2 6 2 15.4% 10.9% 6.1%
##
## Imp_Hearing Fishers Exact p-value=0.6259
## #

```

Teens pairwise comparison of Importance of Physical Attributes

Determine if there was a relationship between each pair of importance of physical attributes variables.

```

## Imp_Teeth_Appearance
## Imp_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
## Extremely 18 1 0 0 0 19
## Very 6 26 3 1 0 36
## Somewhat 3 16 12 2 0 33
## Not Very 1 0 2 5 0 8
## Not At All 0 0 0 1 4 5
## Total 28 43 17 9 4 101
##
## Imp_Facial_Appearance v Imp_Teeth_Appearance Wilcox Paired p-value=0.0005
## #
## Imp_Speech
## Imp_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
## Extremely 9 8 2 0 0 19
## Very 5 25 5 1 0 36
## Somewhat 9 12 11 1 0 33
## Not Very 1 1 2 3 1 8
## Not At All 0 0 2 0 3 5
## Total 24 46 22 5 4 101
##
## Imp_Facial_Appearance v Imp_Speech Wilcox Paired p-value=0.0121
## #
## Imp_Hearing
## Imp_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
## Extremely 9 7 2 0 1 19
## Very 7 23 3 1 2 36
## Somewhat 10 12 8 2 1 33
## Not Very 2 1 1 1 3 8
## Not At All 0 1 1 0 3 5
## Total 28 44 15 4 10 101
##
## Imp_Facial_Appearance v Imp_Hearing Wilcox Paired p-value=0.0744
## #
## Imp_Speech
## Imp_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
## Extremely 11 11 5 1 0 28
## Very 9 28 6 0 0 43
## Somewhat 2 5 9 1 0 17
## Not Very 2 2 1 3 1 9
## Not At All 0 0 1 0 3 4
## Total 24 46 22 5 4 101
##
## Imp_Teeth_Appearance v Imp_Speech Wilcox Paired p-value=0.8939
## #
## Imp_Hearing
## Imp_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
## Extremely 11 13 2 0 2 28
## Very 11 26 5 0 1 43
## Somewhat 3 3 7 2 2 17
## Not Very 3 2 0 2 2 9

```

```

##           Not At All           0    0           1    0           3    4
##           Total                28  44           15    4           10   101
##
## Imp_Teeth_Appearance v Imp_Hearing           Wilcoxon Paired p-value=0.7357
## #
##           Imp_Hearing
## Imp_Speech  Extremely  Very  Somewhat  Not Very  Not At All  Total
##   Extremely      20    3           1    0           0    24
##   Very            6   35           3    1           1    46
##   Somewhat        2    5           11   1           3    22
##   Not Very         0    1           0    2           2    5
##   Not At All      0    0           0    0           4    4
##   Total           28   44           15    4           10   101
##
## Imp_Speech v Imp_Hearing           Wilcoxon Paired p-value=0.5200
## #

```

There was a Significant difference for importance within Teens for Facial Appearance vs Teeth Appearance. Imp_Facial_Appearance was rated *lower* in importance Teeth Appearance.

Teens Importance of Support By Gender

Determine if Gender had a relationship with importance of support provided by: Parents, Treatment Givers, Siblings and Teachers.

```

##           Gender
## Imp_Support_Parents Female Male  Prop % by col Female Male
##   Extremely      24    35           63.2%  55.6%
##   Very            10    18           26.3%  28.6%
##   Somewhat         0     5           0.0%   7.9%
##   Not Very         2     2           5.3%   3.2%
##   Not At All       2     3           5.3%   4.8%
##
## Imp_Support_Parents           Fishers Exact p-value=0.4986
## #
##           Gender
## Imp_Support_Treat_Givers Female Male  Prop % by col Female Male
##   Extremely      19    23           50.0%  36.5%
##   Very            14    27           36.8%  42.9%
##   Somewhat         0     7           0.0%  11.1%
##   Not Very         2     3           5.3%   4.8%
##   Not At All       3     3           7.9%   4.8%
##
## Imp_Support_Treat_Givers           Fishers Exact p-value=0.1704
## #
##           Gender
## Imp_Support_Siblings Female Male  Prop % by col Female Male
##   Extremely      14    19           36.8%  30.2%
##   Very            12    22           31.6%  34.9%
##   Somewhat         7    14           18.4%  22.2%
##   Not Very         1     2           2.6%   3.2%
##   Not At All       4     6           10.5%   9.5%
##
## Imp_Support_Siblings           Fishers Exact p-value=0.9518
## #
##           Gender
## Imp_Support_Teacher Female Male  Prop % by col Female Male
##   Extremely       9    11           23.7%  17.5%
##   Very             9    16           23.7%  25.4%
##   Somewhat        11    25           28.9%  39.7%
##   Not Very         6     6           15.8%   9.5%
##   Not At All       3     5           7.9%   7.9%
##
## Imp_Support_Teacher           Fishers Exact p-value=0.7176
## #

```


Teens Importance of Support By Cleft_Type

Determine if Cleft_Type had a relationship with importance of support provided by: Parents, Treatment Givers, Siblings and Teachers.

```
##          Cleft_Type
## Imp_Support_Parents Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely      8      29      22      61.5%  52.7%  66.7%
##      Very           3      16       9      23.1%  29.1%  27.3%
##      Somewhat       0       4       1       0.0%   7.3%   3.0%
##      Not Very       1       3       0       7.7%   5.5%   0.0%
##      Not At All     1       3       1       7.7%   5.5%   3.0%
##
## Imp_Support_Parents          Fishers Exact p-value=0.7778
## #
##          Cleft_Type
## Imp_Support_Treat_Givers Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-on-
ly
##      Extremely      3      23      16      23.1%  41.8%  48.5%
##      Very           6      21      14      46.2%  38.2%  42.4%
##      Somewhat       2       4       1      15.4%   7.3%   3.0%
##      Not Very       1       4       0       7.7%   7.3%   0.0%
##      Not At All     1       3       2       7.7%   5.5%   6.1%
##
## Imp_Support_Treat_Givers          Fishers Exact p-value=0.4922
## #
##          Cleft_Type
## Imp_Support_Siblings Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely      2      18      13      15.4%  32.7%  39.4%
##      Very           6      16      12      46.2%  29.1%  36.4%
##      Somewhat       3      12       6      23.1%  21.8%  18.2%
##      Not Very       0       3       0       0.0%   5.5%   0.0%
##      Not At All     2       6       2      15.4%  10.9%   6.1%
##
## Imp_Support_Siblings          Fishers Exact p-value=0.6775
## #
##          Cleft_Type
## Imp_Support_Teacher Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely      1      13       6       7.7%  23.6%  18.2%
##      Very           2      10      13      15.4%  18.2%  39.4%
##      Somewhat       5      21      10      38.5%  38.2%  30.3%
##      Not Very       3       6       3      23.1%  10.9%   9.1%
##      Not At All     2       5       1      15.4%   9.1%   3.0%
##
## Imp_Support_Teacher          Fishers Exact p-value=0.2918
## #
```

Teens pairwise comparison of Importance of Support

Determine if there were relationships between each pair of importance of support variables.

```
##          Imp_Support_Teacher
## Imp_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##      Extremely      16       6       7       4       0      33
##      Very           4      16      11       3       0      34
##      Somewhat       0       2      12       4       3      21
##      Not Very       0       1       2       0       0       3
##      Not At All     0       0       4       1       5      10
##      Total          20      25      36      12       8     101
##
## Imp_Support_Siblings v Imp_Support_Teacher          Wilcox Paired p-value=0.0010
## #
##          Imp_Support_Treat_Givers
## Imp_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##      Extremely      27       4       2       0       0      33
##      Very           11      21       1       1       0      34
##      Somewhat       2      16       0       2       1      21
##      Not Very       0       0       1       2       0       3
##      Not At All     2       0       3       0       5      10
##      Total          42      41       7       5       6     101
##
## Imp_Support_Siblings v Imp_Support_Treat_Givers          Wilcox Paired p-value=0.0032
## #
##          Imp_Support_Parents
## Imp_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##      Extremely      33       0       0       0       0      33
##      Very           17      17       0       0       0      34
```

```

##           Somewhat           5  10           4           2           0  21
##           Not Very           1   0           1           1           0   3
##           Not At All         3   1           0           1           5  10
##           Total              59  28           5           4           5  101
##
## Imp_Support_Siblings v Imp_Support_Parents           Wilcox Paired p-value=0.0000
## #
##           Imp_Support_Treat_Givers
## Imp_Support_Teacher Extremely Very Somewhat Not Very Not At All Total
##           Extremely          19   1           0           0           0  20
##           Very                10  12           0           2           1  25
##           Somewhat            9  21           3           1           2  36
##           Not Very             3   6           3           0           0  12
##           Not At All           1   1           1           2           3   8
##           Total               42  41           7           5           6  101
##
## Imp_Support_Teacher v Imp_Support_Treat_Givers       Wilcox Paired p-value=0.0000
## #
##           Imp_Support_Parents
## Imp_Support_Teacher Extremely Very Somewhat Not Very Not At All Total
##           Extremely          20   0           0           0           0  20
##           Very               16   7           2           0           0  25
##           Somewhat          17  15           1           2           1  36
##           Not Very           5   5           1           0           1  12
##           Not At All         1   1           1           2           3   8
##           Total              59  28           5           4           5  101
##
## Imp_Support_Teacher v Imp_Support_Parents           Wilcox Paired p-value=0.0000
## #
##           Imp_Support_Parents
## Imp_Support_Treat_Givers Extremely Very Somewhat Not Very Not At All Total
##           Extremely          39   3           0           0           0  42
##           Very               15  22           3           1           0  41
##           Somewhat            4   2           0           0           1   7
##           Not Very            0   1           2           2           0   5
##           Not At All          1   0           0           1           4   6
##           Total              59  28           5           4           5  101
##
## Imp_Support_Treat_Givers v Imp_Support_Parents       Wilcox Paired p-value=0.0046
## #

```

**** There were Significant differences for importance of support within Teens for all tests.****

Adults Importance of Physical Attributes By Gender

Determine if Gender had a relationship with importance of physical attributes: facial appearance, teeth appearance, speech and hearing.

```

##           Gender
## Imp_Facial_Appearance Female Male Prop % by col Female Male
##           Extremely          27  12           31.0%  16.9%
##           Very                32  24           36.8%  33.8%
##           Somewhat            24  23           27.6%  32.4%
##           Not Very             4   7           4.6%   9.9%
##           Not At All           0   5           0.0%   7.0%
##
## Imp_Facial_Appearance           Fishers Exact p-value=0.0218
## #
##           Gender
## Imp_Teeth_Appearance Female Male Prop % by col Female Male
##           Extremely          33  12           37.9%  16.9%
##           Very                34  30           39.1%  42.3%
##           Somewhat            15  20           17.2%  28.2%
##           Not Very             5   5           5.7%   7.0%
##           Not At All           0   4           0.0%   5.6%
##

```

```

## Imp_Teeth_Appearance Fishers Exact p-value=0.0076
## #
## Gender
## Imp_Speech Female Male Prop % by col Female Male
## Extremely 44 30 50.6% 42.3%
## Very 30 21 34.5% 29.6%
## Somewhat 9 14 10.3% 19.7%
## Not Very 2 3 2.3% 4.2%
## Not At All 2 3 2.3% 4.2%
##
## Imp_Speech Fishers Exact p-value=0.3742
## #
## Gender
## Imp_Hearing Female Male Prop % by col Female Male
## Extremely 44 29 50.6% 40.8%
## Very 29 23 33.3% 32.4%
## Somewhat 9 6 10.3% 8.5%
## Not Very 1 6 1.1% 8.5%
## Not At All 4 7 4.6% 9.9%
##
## Imp_Hearing Fishers Exact p-value=0.1326
## #

```

Adults Importance of Physical Attributes By Cleft_Type

Determine if Cleft_Type had a relationship with importance of physical attributes: facial appearance, teeth appearance, speech and hearing.

```

## Cleft_Type
## Imp_Facial_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely 3 25 11 12.0% 31.6% 20.4%
## Very 11 26 19 44.0% 32.9% 35.2%
## Somewhat 10 21 16 40.0% 26.6% 29.6%
## Not Very 1 5 5 4.0% 6.3% 9.3%
## Not At All 0 2 3 0.0% 2.5% 5.6%
##
## Imp_Facial_Appearance Fishers Exact p-value=0.4828
## #
## Cleft_Type
## Imp_Teeth_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely 7 23 15 28.0% 29.1% 27.8%
## Very 13 29 22 52.0% 36.7% 40.7%
## Somewhat 4 21 10 16.0% 26.6% 18.5%
## Not Very 1 5 4 4.0% 6.3% 7.4%
## Not At All 0 1 3 0.0% 1.3% 5.6%
##
## Imp_Teeth_Appearance Fishers Exact p-value=0.7714
## #
## Cleft_Type
## Imp_Speech Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely 10 36 28 40.0% 45.6% 51.9%
## Very 6 31 14 24.0% 39.2% 25.9%
## Somewhat 5 10 8 20.0% 12.7% 14.8%
## Not Very 3 1 1 12.0% 1.3% 1.9%
## Not At All 1 1 3 4.0% 1.3% 5.6%
##
## Imp_Speech Fishers Exact p-value=0.1481
## #
## Cleft_Type
## Imp_Hearing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely 10 36 27 40.0% 45.6% 50.0%
## Very 9 27 16 36.0% 34.2% 29.6%
## Somewhat 1 9 5 4.0% 11.4% 9.3%
## Not Very 2 3 2 8.0% 3.8% 3.7%
## Not At All 3 4 4 12.0% 5.1% 7.4%
##
## Imp_Hearing Fishers Exact p-value=0.8468
## #

```

Adults pairwise comparison of Importance of Physical Attributes

Determine if there was a relationship between each pair of importance of physical attributes variables.

```

##                               Imp_Teeth_Appearance
## Imp_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely          30   6           2           1           0   39
##           Very              10  36           8           1           1   56
##           Somewhat          5  17           21          4           0   47
##           Not Very          0   4           3           4           0   11
##           Not At All        0   1           1           0           3    5
##           Total             45  64           35          10           4  158
##
## Imp_Facial_Appearance v Imp_Teeth_Appearance           Wilcox Paired p-value=0.0295
## #
##                               Imp_Speech
## Imp_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely          32   4           1           1           1   39
##           Very              23  21           9           2           1   56
##           Somewhat          16  20           11          0           0   47
##           Not Very          2   5           1           2           1   11
##           Not At All        1   1           1           0           2    5
##           Total             74  51           23          5           5  158
##
## Imp_Facial_Appearance v Imp_Speech           Wilcox Paired p-value=0.0000
## #
##                               Imp_Hearing
## Imp_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely          29   3           3           1           3   39
##           Very              21  24           6           4           1   56
##           Somewhat          21  17           5           2           2   47
##           Not Very          2   6           1           0           2   11
##           Not At All        0   2           0           0           3    5
##           Total             73  52           15          7           11  158
##
## Imp_Facial_Appearance v Imp_Hearing           Wilcox Paired p-value=0.0006
## #
##                               Imp_Speech
## Imp_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely          32   9           3           0           1   45
##           Very              26  26           8           3           1   64
##           Somewhat          13  11           10          1           0   35
##           Not Very          2   5           1           1           1   10
##           Not At All        1   0           1           0           2    4
##           Total             74  51           23          5           5  158
##
## Imp_Teeth_Appearance v Imp_Speech           Wilcox Paired p-value=0.0007
## #
##                               Imp_Hearing
## Imp_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely          31   8           3           1           2   45
##           Very              25  28           6           2           3   64
##           Somewhat          14  14           6           1           0   35
##           Not Very          3   2           0           2           3   10
##           Not At All        0   0           0           1           3    4
##           Total             73  52           15          7           11  158
##
## Imp_Teeth_Appearance v Imp_Hearing           Wilcox Paired p-value=0.0129
## #
##                               Imp_Hearing
## Imp_Speech      Extremely Very Somewhat Not Very Not At All Total
##           Extremely          55  13           1           4           1   74
##           Very              14  30           5           1           1   51
##           Somewhat          4   6           9           1           3   23
##           Not Very          0   2           0           1           2    5
##           Not At All        0   1           0           0           4    5
##           Total             73  52           15          7           11  158
##
## Imp_Speech v Imp_Hearing           Wilcox Paired p-value=0.3148
## #

```

There were Significant differences for importance of physical attributes within Adults for all tests except for Face & Teeth Appearance, and Speech & Hearing.

Interestingly, Imp_Facial_Appearance was rated *lower* in importance than the other attributes.

Adults Importance of Support By Gender

Determine if Gender had a relationship with importance of support provided by: Parents, Treatment Givers, Siblings and Employers.

```
##                               Gender
## Imp_Support_Parents Female Male Prop % by col Female Male
##     Extremely      57    29      65.5%  40.8%
##     Very           20    24      23.0%  33.8%
##     Somewhat       7     11      8.0%   15.5%
##     Not Very       1     2       1.1%   2.8%
##     Not At All    2     5       2.3%   7.0%
##
## Imp_Support_Parents      Fishers Exact p-value=0.0233
## #
##                               Gender
## Imp_Support_Treat_Givers Female Male Prop % by col Female Male
##     Extremely      31    22      35.6%  31.0%
##     Very           40    26      46.0%  36.6%
##     Somewhat      11    18      12.6%  25.4%
##     Not Very       4     1       4.6%   1.4%
##     Not At All    1     4       1.1%   5.6%
##
## Imp_Support_Treat_Givers      Fishers Exact p-value=0.0849
## #
##                               Gender
## Imp_Support_Siblings Female Male Prop % by col Female Male
##     Extremely      37    17      42.5%  23.9%
##     Very           26    24      29.9%  33.8%
##     Somewhat      14    14      16.1%  19.7%
##     Not Very       5     6       5.7%   8.5%
##     Not At All    5     10      5.7%  14.1%
##
## Imp_Support_Siblings      Fishers Exact p-value=0.0990
## #
##                               Gender
## Imp_Support_Employer Female Male Prop % by col Female Male
##     Extremely      19     7      21.8%   9.9%
##     Very           23    19      26.4%  26.8%
##     Somewhat      28    24      32.2%  33.8%
##     Not Very      10    11      11.5%  15.5%
##     Not At All    7     10      8.0%  14.1%
##
## Imp_Support_Teacher      Fishers Exact p-value=0.2629
## #
```

Adults Importance of Support By Cleft_Type

Determine if Cleft_Type had a relationship with importance of support provided by: Parents, Treatment Givers, Siblings and Employers.

```
##                               Cleft Type
## Imp_Support_Parents Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##     Extremely      13    41    32      52.0%  51.9%  59.3%
##     Very           5     26    13      20.0%  32.9%  24.1%
##     Somewhat       6     7     5       24.0%   8.9%   9.3%
##     Not Very       1     2     0       4.0%   2.5%   0.0%
##     Not At All    0     3     4       0.0%   3.8%   7.4%
##
## Imp_Support_Parents      Fishers Exact p-value=0.2827
## #
##                               Cleft_Type
## Imp_Support_Treat_Givers Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-on
ly
##     Extremely      7     30    16      28.0%  38.0%  29.6%
##     Very           10    31    25      40.0%  39.2%  46.3%
```

```

##          Somewhat      7      13      9      28.0%      16.5%      16.7%
##          Not Very      1       3       1       4.0%       3.8%       1.9%
##          Not At All    0       2       3       0.0%       2.5%       5.6%
##
## Imp_Support_Treat_Givers          Fishers Exact p-value=0.7778
## #
##          Cleft_Type
## Imp_Support_Siblings Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          Extremely      8      28      18      32.0%      35.4%      33.3%
##          Very            9      24      17      36.0%      30.4%      31.5%
##          Somewhat       4      14      10      16.0%      17.7%      18.5%
##          Not Very       3       5       3      12.0%       6.3%       5.6%
##          Not At All     1       8       6       4.0%      10.1%      11.1%
##
## Imp_Support_Siblings          Fishers Exact p-value=0.9728
## #
##          Cleft_Type
## Imp_Support_Employer Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          Extremely      6       8      12      24.0%      10.1%      22.2%
##          Very            3      24      15      12.0%      30.4%      27.8%
##          Somewhat       7      32      13      28.0%      40.5%      24.1%
##          Not Very       7       7       7      28.0%       8.9%      13.0%
##          Not At All     2       8       7       8.0%      10.1%      13.0%
##
## Imp_Support_Teacher          Fishers Exact p-value=0.0614
## #

```

Adults pairwise comparison of Importance of Support

Determine if there were relationships between each pair of importance of support variables.

```

##          Imp_Support_Employer
## Imp_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##          Extremely      20      14      16      3       1      54
##          Very            5      20      16      6       3      50
##          Somewhat       1       5      14      6       2      28
##          Not Very       0       1       2      4       4      11
##          Not At All     0       2       4      2       7      15
##          Total          26      42      52      21      17      158
##
## Imp_Support_Siblings v Imp_Support_Employer          Wilcoxon Paired p-value=0.0000
## #
##          Imp_Support_Treat_Givers
## Imp_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##          Extremely      35      13      6       0       0      54
##          Very            7      31      11      1       0      50
##          Somewhat       5      14      7       1       1      28
##          Not Very       1       5      3       2       0      11
##          Not At All     5       3      2       1       4      15
##          Total          53      66      29      5       5      158
##
## Imp_Support_Siblings v Imp_Support_Treat_Givers      Wilcoxon Paired p-value=0.0204
## #
##          Imp_Support_Parents
## Imp_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##          Extremely      52       2       0       0       0      54
##          Very            20      27      3       0       0      50
##          Somewhat       7       9      12      0       0      28
##          Not Very       3       4       2       2       0      11
##          Not At All     4       2       1       1       7      15
##          Total          86      44      18      3       7      158
##
## Imp_Support_Siblings v Imp_Support_Parents          Wilcoxon Paired p-value=0.0000
## #
##          Imp_Support_Treat_Givers
## Imp_Support_Employer Extremely Very Somewhat Not Very Not At All Total
##          Extremely      21       5       0       0       0      26
##          Very            11      26      5       0       0      42
##          Somewhat       17      16      17      2       0      52
##          Not Very       1      12      4       3       1      21
##          Not At All     3       7      3       0       4      17
##          Total          53      66      29      5       5      158
##
## Imp_Support_Employer v Imp_Support_Treat_Givers      Wilcoxon Paired p-value=0.0000
## #

```

```

##                               Imp_Support_Parents
## Imp_Support_Employer Extremely Very Somewhat Not Very Not At All Total
##           Extremely      25    0         1         0         0    26
##           Very           25   16         1         0         0    42
##           Somewhat      25   17         9         1         0    52
##           Not Very       5    8         5         2         1    21
##           Not At All     6    3         2         0         6    17
##           Total          86   44        18         3         7   158
##
## Imp_Support_Employer v Imp_Support_Parents      Wilcoxon Paired p-value=0.0000
## #
##                               Imp_Support_Parents
## Imp_Support_Treat_Givers Extremely Very Somewhat Not Very Not At All Total
##           Extremely      43    5         3         0         2    53
##           Very           27   31         7         1         0    66
##           Somewhat      14    7         7         1         0    29
##           Not Very       2    1         0         1         1     5
##           Not At All     0    0         1         0         4     5
##           Total          86   44        18         3         7   158
##
## Imp_Support_Treat_Givers v Imp_Support_Parents  Wilcoxon Paired p-value=0.0005
## #

```

**** There were Significant differences for importance of support within Adults for all tests.****

Satisfaction with Physical Attributes and Support

Satisfaction ratings used the following Likert scale: 1=Extremely, 2=Very, 3=Somewhat, 4=Not Very, 5=Not At All.

For pairwise comparisons use paired Wilcoxon-Mann-Whitney U Test for each combination of the following:

Imp_Facial_Appearance, Imp_Teeth_Appearance, Imp_Speech, Imp_Hearing and Imp_Support_Siblings, Imp_Support_Teacher, Imp_Support_Treat_Givers, Imp_Support_Parents
 Note: Use Wilcoxon as Chi-square has cells with estimated counts < 5 and Fisher's exact test cannot handle the complexity. This is a paired test as we are comparing ratings by the same person. Adjust the p-values using the Holm correction as we are re-using the same variables in multiple tests.

Children Satisfaction with Physical Attributes By Gender

Determine if Gender had a relationship with satisfaction with physical attributes: facial appearance, teeth appearance, speech and hearing.

```

##                               Gender
## Sat_Facial_Appearance Female Male Prop % by col Female Male
##           Extremely      16    11      30.8%  22.9%
##           Very           16    19      30.8%  39.6%
##           Somewhat      12    14      23.1%  29.2%
##           Not Very       6     4      11.5%   8.3%
##           Not At All     2     0       3.8%   0.0%
##
## Sat_Facial_Appearance      Fishers Exact p-value=0.5450
## #
##                               Gender
## Sat_Teeth_Appearance Female Male Prop % by col Female Male
##           Extremely      14     9      26.9%  18.8%
##           Very           10    14      19.2%  29.2%
##           Somewhat      18    15      34.6%  31.2%
##           Not Very       5     9       9.6%  18.8%
##           Not At All     5     1       9.6%   2.1%
##
## Sat_Teeth_Appearance      Fishers Exact p-value=0.2406
## #
##                               Gender
## Sat_Speech      Female Male Prop % by col Female Male

```

```

##      Extremely      11      9      21.2%  18.8%
##      Very          20     18      38.5%  37.5%
##      Somewhat     14     12      26.9%  25.0%
##      Not Very      5      7       9.6%  14.6%
##      Not At All    2      2       3.8%   4.2%
##
## Sat_Speech                      Fishers Exact p-value=0.9736
## #
##                               Gender
## Sat_Hearing  Female Male  Prop % by col Female Male
##      Extremely  15     12      28.8%  25.0%
##      Very       17     20      32.7%  41.7%
##      Somewhat   16     9       30.8%  18.8%
##      Not Very    2      3       3.8%   6.2%
##      Not At All  2      4       3.8%   8.3%
##
## Sat_Hearing                      Fishers Exact p-value=0.5228
## #

```

Children Satisfaction with Physical Attributes By Cleft_Type

Determine if Cleft_Type had a relationship with satisfaction with physical attributes: facial appearance, teeth appearance, speech and hearing.

```

##                               Cleft_Type
## Sat_Facial_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely        1      7      19      7.7%  20.6%  35.8%
##      Very             5     10     20     38.5%  29.4%  37.7%
##      Somewhat         3     12     11     23.1%  35.3%  20.8%
##      Not Very         4      3      3     30.8%   8.8%   5.7%
##      Not At All       0      2      0      0.0%   5.9%   0.0%
##
## Sat_Facial_Appearance          Fishers Exact p-value=0.0500
## #
##                               Cleft_Type
## Sat_Teeth_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely        0      7     16      0.0%  20.6%  30.2%
##      Very             5      7     12     38.5%  20.6%  22.6%
##      Somewhat         4      9     20     30.8%  26.5%  37.7%
##      Not Very         3      6      5     23.1%  17.6%   9.4%
##      Not At All       1      5      0      7.7%  14.7%   0.0%
##
## Sat Teeth Appearance          Fishers Exact p-value=0.0200
## #
##                               Cleft_Type
## Sat_Speech Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely        4      6     10     30.8%  17.6%  18.9%
##      Very             7     12     19     53.8%  35.3%  35.8%
##      Somewhat         2     11     13     15.4%  32.4%  24.5%
##      Not Very         0      2     10      0.0%   5.9%  18.9%
##      Not At All       0      3      1      0.0%   8.8%   1.9%
##
## Sat_Speech                      Fishers Exact p-value=0.2866
## #
##                               Cleft_Type
## Sat Hearing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely        3     12     12     23.1%  35.3%  22.6%
##      Very             5     12     20     38.5%  35.3%  37.7%
##      Somewhat         3      5     17     23.1%  14.7%  32.1%
##      Not Very         1      2      2      7.7%   5.9%   3.8%
##      Not At All       1      3      2      7.7%   8.8%   3.8%
##
## Sat Hearing                      Fishers Exact p-value=0.6132
## #

```

Children pairwise comparison of satisfaction with Physical Attributes

Determine if there was a relationship between each pair of satisfaction with physical attributes variables.

```

##                               Sat_Teeth_Appearance
## Sat_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##      Extremely          17      3      3      2      2      27
##      Very               5     16     13      1      0      35
##      Somewhat           1      1     15      8      1      26
##      Not Very           0      4      2      3      1      10

```



```

##           Not At All           0    0           0           0           2    2
##           Total                23   24           33           14           6   100
##
## Sat_Facial_Appearance v Sat_Teeth_Appearance           Wilcox Paired p-value=0.0091
## #
##           Sat_Speech
## Sat_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely           11    8           4           2           2   27
##           Very                 7   19           7           2           0   35
##           Somewhat             2    7           11          4           2   26
##           Not Very              0    4           3           3           0   10
##           Not At All            0    0           1           1           0    2
##           Total                 20   38           26          12           4   100
##
## Sat_Facial_Appearance v Sat_Speech           Wilcox Paired p-value=0.2318
## #
##           Sat_Hearing
## Sat_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely           15    4           5           1           2   27
##           Very                 6   18           9           1           1   35
##           Somewhat             3   11           8           2           2   26
##           Not Very              1    4           3           1           1   10
##           Not At All            2    0           0           0           0    2
##           Total                 27   37           25           5           6   100
##
## Sat_Facial_Appearance v Sat_Hearing           Wilcox Paired p-value=0.9267
## #
##           Sat_Speech
## Sat_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely           12    8           2           0           1   23
##           Very                 5   12           6           1           0   24
##           Somewhat             2   12           13          6           0   33
##           Not Very              1    5           3           4           1   14
##           Not At All            0    1           2           1           2    6
##           Total                 20   38           26          12           4   100
##
## Sat_Teeth_Appearance v Sat_Speech           Wilcox Paired p-value=0.1486
## #
##           Sat_Hearing
## Sat_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely           14    4           4           0           1   23
##           Very                 4   15           4           1           0   24
##           Somewhat             3   15           14          0           1   33
##           Not Very              3    3           2           4           2   14
##           Not At All            3    0           1           0           2    6
##           Total                 27   37           25           5           6   100
##
## Sat_Teeth_Appearance v Sat_Hearing           Wilcox Paired p-value=0.0294
## #
##           Sat_Hearing
## Sat_Speech   Extremely Very Somewhat Not Very Not At All Total
##           Extremely           14    3           3           0           0   20
##           Very                 6   23           6           2           1   38
##           Somewhat             4   10           11          1           0   26
##           Not Very              3    1           5           2           1   12
##           Not At All            0    0           0           0           4    4
##           Total                 27   37           25           5           6   100
##
## Sat_Speech v Sat_Hearing           Wilcox Paired p-value=0.1471
## #

```

**** There were no Significant differences for Satisfaction with physical attributes within Children for all tests.****

Two tests were significant if unadjusted p-values were considered.

Children Satisfaction with Support By Gender

Determine if Gender had a relationship with Satisfaction with support provided by: Parents, Treatment Givers, Siblings and Teachers.

```
##                               Gender
## Sat_Support_Parents Female Male Prop % by col Female Male
##      Extremely      35      32      67.3% 66.7%
##      Very           9       14      17.3% 29.2%
##      Somewhat       4        2       7.7%  4.2%
##      Not Very       1         0       1.9%  0.0%
##      Not At All     3         0       5.8%  0.0%
##
## Sat_Support_Parents           Fishers Exact p-value=0.2058
## #
##                               Gender
## Sat_Support_Treat_Givers Female Male Prop % by col Female Male
##      Extremely      29      19      55.8% 39.6%
##      Very           19      23      36.5% 47.9%
##      Somewhat       4         6       7.7% 12.5%
##
## Sat_Support_Treat_Givers       Fishers Exact p-value=0.2782
## #
##                               Gender
## Sat_Support_Siblings Female Male Prop % by col Female Male
##      Extremely      20      12      38.5% 25.0%
##      Very           13      17      25.0% 35.4%
##      Somewhat       8       14      15.4% 29.2%
##      Not Very       5         2       9.6%  4.2%
##      Not At All     6         3      11.5%  6.2%
##
## Sat_Support_Siblings           Fishers Exact p-value=0.1863
## #
##                               Gender
## Sat_Support_Teacher Female Male Prop % by col Female Male
##      Extremely      22         8      42.3% 16.7%
##      Very           14        19      26.9% 39.6%
##      Somewhat       9         15      17.3% 31.2%
##      Not Very       4         4       7.7%  8.3%
##      Not At All     3         2       5.8%  4.2%
##
## Sat_Support_Teacher           Fishers Exact p-value=0.0548
## #
```

Children Satisfaction with Support By Cleft_Type

Determine if Cleft_Type had a relationship with Satisfaction with support provided by: Parents, Treatment Givers, Siblings and Teachers.

```
##                               Cleft_Type
## Sat_Support_Parents Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely      7       21       39      53.8% 61.8% 73.6%
##      Very           2         9       12      15.4% 26.5% 22.6%
##      Somewhat       3         2         1      23.1%  5.9%  1.9%
##      Not Very       0         1         0       0.0%  2.9%  0.0%
##      Not At All     1         1         1       7.7%  2.9%  1.9%
##
## Sat_Support_Parents           Fishers Exact p-value=0.1164
## #
##                               Cleft Type
## Sat_Support_Treat_Givers Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-on
ly
##      Extremely      5       17       26      38.5% 50.0% 49.1%
##      Very           5       13       24      38.5% 38.2% 45.3%
##      Somewhat       3         4         3      23.1% 11.8%  5.7%
##
## Sat_Support_Treat_Givers       Fishers Exact p-value=0.4048
## #
##                               Cleft_Type
## Sat_Support_Siblings Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely      3         9       20      23.1% 26.5% 37.7%
##      Very           2         9       19      15.4% 26.5% 35.8%
##      Somewhat       6         8         8      46.2% 23.5% 15.1%
##      Not Very       0         4         3       0.0% 11.8%  5.7%
##      Not At All     2         4         3      15.4% 11.8%  5.7%
```

```
##
## Sat_Support_Siblings                               Fishers Exact p-value=0.2128
## #
##          Cleft_Type
## Sat Support Teacher Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely      2      10      18      15.4%      29.4%      34.0%
##      Very            2      12      19      15.4%      35.3%      35.8%
##      Somewhat       6       6      12      46.2%      17.6%      22.6%
##      Not Very       1       4       3       7.7%      11.8%      5.7%
##      Not At All    2       2       1      15.4%      5.9%      1.9%
##
## Sat Support Teacher                               Fishers Exact p-value=0.2079
## #
```

Children pairwise comparison of Satisfaction with Support

Determine if there were relationships between each pair of Satisfaction with support variables.

```
##          Sat_Support_Teacher
## Sat_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##      Extremely      21     6     3     1     1     32
##      Very            1    22     5     2     0     30
##      Somewhat       2     4    14     1     1     22
##      Not Very       1     1     2     3     0     7
##      Not At All    5     0     0     1     3     9
##      Total         30    33    24     8     5    100
##
## Sat_Support_Siblings v Sat_Support_Teacher      Wilcox Paired p-value=0.8714
## #
##          Sat_Support_Treat_Givers
## Sat_Support_Siblings Extremely Very Somewhat Total
##      Extremely      28     3     1     32
##      Very            6    22     2     30
##      Somewhat       9     8     5     22
##      Not Very       1     5     1     7
##      Not At All    4     4     1     9
##      Total         48    42    10    100
##
## Sat_Support_Siblings v Sat_Support_Treat_Givers  Wilcox Paired p-value=0.0000
## #
##          Sat_Support_Parents
## Sat_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##      Extremely      31     0     1     0     0     32
##      Very            14    16     0     0     0     30
##      Somewhat       14     4     4     0     0     22
##      Not Very       3     3     0     1     0     7
##      Not At All    5     0     1     0     3     9
##      Total         67    23     6     1     3    100
##
## Sat_Support_Siblings v Sat_Support_Parents      Wilcox Paired p-value=0.0000
## #
##          Sat_Support_Treat_Givers
## Sat_Support_Teacher Extremely Very Somewhat Total
##      Extremely      26     3     1     30
##      Very            12    21     0     33
##      Somewhat       5    12     7     24
##      Not Very       3     5     0     8
##      Not At All    2     1     2     5
##      Total         48    42    10    100
##
## Sat_Support_Teacher v Sat_Support_Treat_Givers  Wilcox Paired p-value=0.0000
## #
##          Sat_Support_Parents
## Sat_Support_Teacher Extremely Very Somewhat Not Very Not At All Total
##      Extremely      29     0     1     0     0     30
##      Very            21    11     0     1     0     33
##      Somewhat       10     9     5     0     0     24
##      Not Very       4     3     0     0     1     8
##      Not At All    3     0     0     0     2     5
##      Total         67    23     6     1     3    100
```

```
##
## Sat_Support_Teacher v Sat_Support_Parents      Wilcox Paired p-value=0.0000
## #
##           Sat_Support_Parents
## Sat_Support_Treat_Givers Extremely Very Somewhat Not Very Not At All Total
##           Extremely      45   1       1       0       1       48
##           Very           18  20       2       1       1       42
##           Somewhat       4   2       3       0       1       10
##           Total          67  23       6       1       3       100
##
## Sat_Support_Treat_Givers v Sat_Support_Parents  Wilcox Paired p-value=0.0995
## #
```

**** There were Significant differences for Satisfaction with support within Children for all tests except for Siblings v Teacher, and Treatment Givers v Parents.****

Teens Satisfaction with Physical Attributes By Gender

Determine if Gender had a relationship with satisfaction with physical attributes: facial appearance, teeth appearance, speech and hearing.

```
##           Gender
## Sat_Facial_Appearance Female Male Prop % by col Female Male
##           Extremely      7   14      18.4% 22.2%
##           Very           12   12      36.8% 19.0%
##           Somewhat       12   23      31.6% 36.5%
##           Not Very        4   13      10.5% 20.6%
##           Not At All      1    1       2.6%  1.6%
##
## Sat_Facial_Appearance      Fishers Exact p-value=0.2762
## #
##           Gender
## Sat_Teeth_Appearance Female Male Prop % by col Female Male
##           Extremely      6   16      15.8% 25.4%
##           Very           13   18      34.2% 28.6%
##           Somewhat       12   17      31.6% 27.0%
##           Not Very        4   11      10.5% 17.5%
##           Not At All      3    1       7.9%  1.6%
##
## Sat_Teeth_Appearance      Fishers Exact p-value=0.3487
## #
##           Gender
## Sat_Speech      Female Male Prop % by col Female Male
##           Extremely      4   11      10.5% 17.5%
##           Very           18   14      47.4% 22.2%
##           Somewhat       14   22      36.8% 34.9%
##           Not Very        1   13       2.6% 20.6%
##           Not At All      1    3       2.6%  4.8%
##
## Sat_Speech      Fishers Exact p-value=0.0164
## #
##           Gender
## Sat_Hearing      Female Male Prop % by col Female Male
##           Extremely      5   12      13.2% 19.0%
##           Very           20   24      52.6% 38.1%
##           Somewhat       10   21      26.3% 33.3%
##           Not Very        0    6       0.0%  9.5%
##           Not At All      3    0       7.9%  0.0%
##
## Sat_Hearing      Fishers Exact p-value=0.0307
## #
```

Teens Satisfaction with Physical Attributes By Cleft_Type

Determine if Cleft_Type had a relationship with satisfaction with physical attributes: facial appearance, teeth appearance, speech and hearing.

```

##                               Cleft_Type
## Sat_Facial_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely        6         6           9           46.2%    10.9%    27.3%
##      Very             4        12          10           30.8%    21.8%    30.3%
##      Somewhat        2        22          11           15.4%    40.0%    33.3%
##      Not Very        0        14           3            0.0%    25.5%    9.1%
##      Not At All     1         1           0            7.7%    1.8%    0.0%
##
##                               Fishers Exact p-value=0.0122
## #
##                               Cleft_Type
## Sat Teeth Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely        6         8           8           46.2%    14.5%    24.2%
##      Very             4        15          12           30.8%    27.3%    36.4%
##      Somewhat        2        20           7           15.4%    36.4%    21.2%
##      Not Very        0        12           3            0.0%    21.8%    9.1%
##      Not At All     1         0           3            7.7%    0.0%    9.1%
##
##                               Fishers Exact p-value=0.0189
## #
##                               Cleft_Type
## Sat_Speech Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely        6         4           5           46.2%    7.3%    15.2%
##      Very             4        14          14           30.8%    25.5%    42.4%
##      Somewhat        2        22          12           15.4%    40.0%    36.4%
##      Not Very        1        12           1            7.7%    21.8%    3.0%
##      Not At All     0         3           1            0.0%    5.5%    3.0%
##
##                               Fishers Exact p-value=0.0108
## #
##                               Cleft_Type
## Sat_Hearing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely        6         6           5           46.2%    10.9%    15.2%
##      Very             6        22          16           46.2%    40.0%    48.5%
##      Somewhat        1        19          11            7.7%    34.5%    33.3%
##      Not Very        0         6           0            0.0%    10.9%    0.0%
##      Not At All     0         2           1            0.0%    3.6%    3.0%
##
##                               Fishers Exact p-value=0.0545
## #

```

Teens pairwise comparison of satisfaction with Physical Attributes

Determine if there was a relationship between each pair of satisfaction with physical attributes variables.

```

##                               Sat_Teeth_Appearance
## Sat_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##      Extremely        13     4         4         0         0     21
##      Very             6     17        2         1         0     26
##      Somewhat        1     8        20        4         2     35
##      Not Very        2     2         3         9         1     17
##      Not At All     0     0         0         1         1     2
##      Total          22    31        29        15        4    101
##
##                               Wilcox Paired p-value=0.7446
## #
##                               Sat_Speech
## Sat_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##      Extremely        7     10         4         0         0     21
##      Very             4     8         10        3         1     26
##      Somewhat        2     9         19        4         1     35
##      Not Very        2     4         3         6         2     17
##      Not At All     0     1         0         1         0     2
##      Total          15    32        36        14        4    101
##
##                               Wilcox Paired p-value=0.4984
## #
##                               Sat_Hearing
## Sat_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##      Extremely        9     8         4         0         0     21
##      Very             4    13         8         1         0     26
##      Somewhat        3    14        12        3         3     35
##      Not Very        1     8         6         2         0     17
##      Not At All     0     1         1         0         0     2
##      Total          17    44        31        6         3    101

```

```

##
## Sat_Facial_Appearance v Sat_Hearing           Wilcox Paired p-value=0.1232
## #
##           Sat_Speech
## Sat_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely      8  10      4      0      0      22
##           Very           5  12     10      3      1      31
##           Somewhat      1   7     16      5      0      29
##           Not Very      1   2      4      5      3      15
##           Not At All    0   1      2      1      0      4
##           Total        15  32     36     14      4     101
##
## Sat_Teeth_Appearance v Sat_Speech           Wilcox Paired p-value=0.2479
## #
##           Sat_Hearing
## Sat_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely      8  11      3      0      0      22
##           Very           5  16      9      1      0      31
##           Somewhat      3   9     14      2      1      29
##           Not Very      1   7      3      3      1      15
##           Not At All    0   1      2      0      1      4
##           Total        17  44     31      6      3     101
##
## Sat_Teeth_Appearance v Sat_Hearing           Wilcox Paired p-value=0.1844
## #
##           Sat_Hearing
## Sat_Speech   Extremely Very Somewhat Not Very Not At All Total
##   Extremely      12   3      0      0      0      15
##   Very           4  22      6      0      0      32
##   Somewhat      1  12     19      1      3      36
##   Not Very      0   5      6      3      0      14
##   Not At All    0   2      0      2      0      4
##   Total        17  44     31      6      3     101
##
## Sat_Speech v Sat_Hearing           Wilcox Paired p-value=0.0071
## #

```

**** There was a Significant difference for importance within Teens for Sat_Speech vs Sat_Hearing.****
Speech was rated *lower* in satisfaction than hearing.

Teens Satisfaction with Support By Gender

Determine if Gender had a relationship with Satisfaction with support provided by: Parents, Treatment Givers, Siblings and Teachers.

```

##           Gender
## Sat_Support_Parents Female Male Prop % by col Female Male
##           Extremely      23   36      60.5%  57.1%
##           Very           10   18      26.3%  28.6%
##           Somewhat       2    7       5.3%  11.1%
##           Not Very       0    2       0.0%   3.2%
##           Not At All     3    0       7.9%   0.0%
##
## Sat_Support_Parents           Fishers Exact p-value=0.1485
## #
##           Gender
## Sat_Support_Treat_Givers Female Male Prop % by col Female Male
##           Extremely      21   22      55.3%  34.9%
##           Very           15   32      39.5%  50.8%
##           Somewhat       0    8       0.0%  12.7%
##           Not Very       1    1       2.6%   1.6%
##           Not At All     1    0       2.6%   0.0%
##
## Sat_Support_Treat_Givers           Fishers Exact p-value=0.0169
## #
##           Gender
## Sat_Support_Siblings Female Male Prop % by col Female Male

```

```

##           Extremely      12      15           31.6%  23.8%
##           Very           10      21           26.3%  33.3%
##           Somewhat       9       19           23.7%  30.2%
##           Not Very        2       6            5.3%   9.5%
##           Not At All     5       2           13.2%   3.2%
##
## Sat_Support_Siblings           Fishers Exact p-value=0.2944
## #
##           Gender
## Sat_Support_Teacher Female Male Prop % by col Female Male
##           Extremely        6      8           15.8%  12.7%
##           Very              8     10           21.1%  15.9%
##           Somewhat         11     31           28.9%  49.2%
##           Not Very          7     12           18.4%  19.0%
##           Not At All        6      2           15.8%   3.2%
##
## Sat_Support_Teacher           Fishers Exact p-value=0.1085
## #

```

Teens Satisfaction with Support By Cleft_Type

Determine if Cleft_Type had a relationship with Satisfaction with support provided by: Parents, Treatment Givers, Siblings and Teachers.

```

##           Cleft_Type
## Sat_Support_Parents Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           Extremely      9     29           21           69.2%  52.7%  63.6%
##           Very            4     15           9            30.8%  27.3%  27.3%
##           Somewhat        0      7           2            0.0%  12.7%   6.1%
##           Not Very         0      2           0            0.0%   3.6%   0.0%
##           Not At All      0      2           1            0.0%   3.6%   3.0%
##
## Sat_Support_Parents           Fishers Exact p-value=0.8804
## #
##           Cleft_Type
## Sat_Support_Treat_Givers Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-on
ly
##           Extremely      4     21           18           30.8%  38.2%  54.5%
##           Very            7     27           13           53.8%  49.1%  39.4%
##           Somewhat        2      5           1            15.4%   9.1%   3.0%
##           Not Very         0      2           0            0.0%   3.6%   0.0%
##           Not At All      0      0           1            0.0%   0.0%   3.0%
##
## Sat_Support_Treat_Givers           Fishers Exact p-value=0.3953
## #
##           Cleft_Type
## Sat_Support_Siblings Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           Extremely      3     15           9            23.1%  27.3%  27.3%
##           Very            7     13           11           53.8%  23.6%  33.3%
##           Somewhat        3     15           10           23.1%  27.3%  30.3%
##           Not Very         0      7           1            0.0%  12.7%   3.0%
##           Not At All      0      5           2            0.0%   9.1%   6.1%
##
## Sat_Support_Siblings           Fishers Exact p-value=0.5508
## #
##           Cleft_Type
## Sat_Support_Teacher Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           Extremely      1      7           6            7.7%  12.7%  18.2%
##           Very            3      7           8            23.1%  12.7%  24.2%
##           Somewhat        7     22           13           53.8%  40.0%  39.4%
##           Not Very         2     14           3            15.4%  25.5%   9.1%
##           Not At All      0      5           3            0.0%   9.1%   9.1%
##
## Sat_Support_Teacher           Fishers Exact p-value=0.5325
## #

```

Teens pairwise comparison of Satisfaction with Support

Determine if there were relationships between each pair of Satisfaction with support variables.

```

##           Sat_Support_Teacher
## Sat_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##           Extremely      10      6          9          2          0      27
##           Very           2     11         13          5          0      31
##           Somewhat       2      1         17          6          2      28
##           Not Very        0      0          1          6          1      8
##           Not At All      0      0          2          0          5      7
##           Total          14     18         42         19          8     101

```

```

##
## Sat_Support_Siblings v Sat_Support_Teacher      Wilcox Paired p-value=0.0000
## #
##           Sat_Support_Treat_Givers
## Sat_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##           Extremely      22   4       1       0       0       27
##           Very           13  17       1       0       0       31
##           Somewhat       5   20       3       0       0       28
##           Not Very       0   5        2       1       0        8
##           Not At All     3   1        1       1       1        7
##           Total          43  47       8       2       1       101
##
## Sat_Support_Siblings v Sat_Support_Treat_Givers  Wilcox Paired p-value=0.0000
## #
##           Sat_Support_Parents
## Sat_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##           Extremely      27   0       0       0       0       27
##           Very           17  14       0       0       0       31
##           Somewhat       9   12       7       0       0       28
##           Not Very       3   2        1       2       0        8
##           Not At All     3   0        1       0       3        7
##           Total          59  28       9       2       3       101
##
## Sat_Support_Siblings v Sat_Support_Parents      Wilcox Paired p-value=0.0000
## #
##           Sat_Support_Treat_Givers
## Sat_Support_Teacher Extremely Very Somewhat Not Very Not At All Total
##           Extremely      13   1       0       0       0       14
##           Very           11   7       0       0       0       18
##           Somewhat      13  24       5       0       0       42
##           Not Very       4  11       3       1       0       19
##           Not At All     2   4        0       1       1        8
##           Total          43  47       8       2       1       101
##
## Sat_Support_Teacher v Sat_Support_Treat_Givers  Wilcox Paired p-value=0.0000
## #
##           Sat_Support_Parents
## Sat_Support_Teacher Extremely Very Somewhat Not Very Not At All Total
##           Extremely      14   0       0       0       0       14
##           Very           13   5       0       0       0       18
##           Somewhat      23  14       5       0       0       42
##           Not Very       7   7        4       1       0       19
##           Not At All     2   2        0       1       3        8
##           Total          59  28       9       2       3       101
##
## Sat_Support_Teacher v Sat_Support_Parents      Wilcox Paired p-value=0.0000
## #
##           Sat_Support_Parents
## Sat_Support_Treat_Givers Extremely Very Somewhat Not Very Not At All Total
##           Extremely      39   4       0       0       0       43
##           Very           17  23       5       1       1       47
##           Somewhat       3   1        4       0       0        8
##           Not Very       0   0        0       1       1        2
##           Not At All     0   0        0       0       1        1
##           Total          59  28       9       2       3       101
##
## Sat_Support_Treat_Givers v Sat_Support_Parents  Wilcox Paired p-value=0.1638
## #

```

** There were Significant differences for Satisfaction with support within Teens for all tests except Treatment Givers vs Parents.**

Adults Satisfaction with Physical Attributes By Gender

Determine if Gender had a relationship with satisfaction with physical attributes: facial appearance, teeth appearance, speech and hearing.


```

##                               Gender
## Sat_Facial_Appearance Female Male Prop % by col Female Male
##           Extremely      13     10           14.9%  14.1%
##           Very           29     23           33.3%  32.4%
##           Somewhat      33     21           37.9%  29.6%
##           Not Very       8      13           9.2%  18.3%
##           Not At All     4       4           4.6%  5.6%
##
## Sat_Facial_Appearance           Fishers Exact p-value=0.4978
## #
##                               Gender
## Sat_Teeth_Appearance Female Male Prop % by col Female Male
##           Extremely      25     16           28.7%  22.5%
##           Very           31     23           35.6%  32.4%
##           Somewhat      21     19           24.1%  26.8%
##           Not Very       8       7           9.2%  9.9%
##           Not At All     2       6           2.3%  8.5%
##
## Sat_Teeth_Appearance           Fishers Exact p-value=0.4625
## #
##                               Gender
## Sat_Speech      Female Male Prop % by col Female Male
##           Extremely      29     15           33.3%  21.1%
##           Very           33     18           37.9%  25.4%
##           Somewhat      16     28           18.4%  39.4%
##           Not Very       5       6           5.7%  8.5%
##           Not At All     4       4           4.6%  5.6%
##
## Sat_Speech           Fishers Exact p-value=0.0278
## #
##                               Gender
## Sat_Hearing      Female Male Prop % by col Female Male
##           Extremely      34     24           39.1%  33.8%
##           Very           29     21           33.3%  29.6%
##           Somewhat      13     16           14.9%  22.5%
##           Not Very       9       5           10.3%  7.0%
##           Not At All     2       5           2.3%  7.0%
##
## Sat_Hearing           Fishers Exact p-value=0.3982
## #

```

Adults Satisfaction with Physical Attributes By Cleft_Type

Determine if Cleft_Type had a relationship with satisfaction with physical attributes: facial appearance, teeth appearance, speech and hearing.

```

##                               Cleft_Type
## Sat_Facial_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           Extremely      3       9       11           12.0%  11.4%  20.4%
##           Very           9      25      18           36.0%  31.6%  33.3%
##           Somewhat      8      29      17           32.0%  36.7%  31.5%
##           Not Very       3      12       6           12.0%  15.2%  11.1%
##           Not At All     2       4       2           8.0%   5.1%   3.7%
##
## Sat_Facial_Appearance           Fishers Exact p-value=0.9114
## #
##                               Cleft_Type
## Sat Teeth Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           Extremely      5      22      14           20.0%  27.8%  25.9%
##           Very           11     24      19           44.0%  30.4%  35.2%
##           Somewhat      6      23      11           24.0%  29.1%  20.4%
##           Not Very       1       5       9           4.0%   6.3%  16.7%
##           Not At All     2       5       1           8.0%   6.3%   1.9%
##
## Sat_Teeth_Appearance           Fishers Exact p-value=0.3912
## #
##                               Cleft_Type
## Sat_Speech      Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           Extremely      14      16      14           56.0%  20.3%  25.9%
##           Very           5      25      21           20.0%  31.6%  38.9%
##           Somewhat      3      29      12           12.0%  36.7%  22.2%
##           Not Very       2       8       1           8.0%  10.1%   1.9%
##           Not At All     1       1       6           4.0%   1.3%  11.1%
##

```

```

## Sat_Speech                               Fishers Exact p-value=0.0015
## #
##           Cleft_Type
## Sat_Hearing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Extremely   10      28      20      40.0%  35.4%  37.0%
## Very        10      25      15      40.0%  31.6%  27.8%
## Somewhat    3      15      11      12.0%  19.0%  20.4%
## Not Very    1       8       5       4.0%  10.1%  9.3%
## Not At All  1       3       3       4.0%   3.8%   5.6%
##
## Sat_Hearing                               Fishers Exact p-value=0.9675
## #

```

Adults pairwise comparison of satisfaction with Physical Attributes

Determine if there was a relationship between each pair of satisfaction with physical attributes variables.

```

##           Sat_Teeth_Appearance
## Sat_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely      15      6      1      0      1      23
##           Very           16     28      4      4      0      52
##           Somewhat       6     13     29      5      1      54
##           Not Very       4      4      6      5      2      21
##           Not At All     0      3      0      1      4       8
##           Total          41     54     40     15      8     158
##
## Sat_Facial_Appearance v Sat_Teeth_Appearance      Wilcoxon Paired p-value=0.0016
## #
##           Sat_Speech
## Sat_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely      13      4      4      1      1      23
##           Very           16     21     11      3      1      52
##           Somewhat      11     17     21      3      2      54
##           Not Very       3      5      8      4      1      21
##           Not At All     1      4      0      0      3       8
##           Total          44     51     44     11      8     158
##
## Sat_Facial_Appearance v Sat_Speech                Wilcoxon Paired p-value=0.0020
## #
##           Sat_Hearing
## Sat_Facial_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely      17      3      1      1      1      23
##           Very           20     21      6      4      1      52
##           Somewhat      16     15     14      5      4      54
##           Not Very       5      6      6      4      0      21
##           Not At All     0      5      2      0      1       8
##           Total          58     50     29     14      7     158
##
## Sat_Facial_Appearance v Sat_Hearing                Wilcoxon Paired p-value=0.0000
## #
##           Sat_Speech
## Sat_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely      19     13      8      1      0      41
##           Very           14     25     11      3      1      54
##           Somewhat       8      7     19      5      1      40
##           Not Very       2      5      4      1      3      15
##           Not At All     1      1      2      1      3       8
##           Total          44     51     44     11      8     158
##
## Sat_Teeth_Appearance v Sat_Speech                Wilcoxon Paired p-value=0.6546
## #
##           Sat_Hearing
## Sat_Teeth_Appearance Extremely Very Somewhat Not Very Not At All Total
##           Extremely      27      9      4      1      0      41
##           Very           15     27      6      5      1      54
##           Somewhat       9      8     15      5      3      40
##           Not Very       6      4      3      2      0      15
##           Not At All     1      2      1      1      3       8
##           Total          58     50     29     14      7     158

```

```
##
## Sat_Teeth_Appearance v Sat_Hearing          Wilcoxon Paired p-value=0.0534
## #
##           Sat_Hearing
## Sat_Speech  Extremely Very Somewhat Not Very Not At All Total
##   Extremely      34    5         4         1         0        44
##   Very           12   33         5         1         0        51
##   Somewhat       10    6        17         8         3        44
##   Not Very        1    3         2         3         2        11
##   Not At All     1    3         1         1         2         8
##   Total          58   50        29        14         7       158
##
## Sat_Speech v Sat_Hearing          Wilcoxon Paired p-value=0.0631
## #
```

**** There were Significant differences for Satisfaction with physical attributes within Adults with facial appearance being lowest.****

Adults Satisfaction with Support By Gender

Determine if Gender had a relationship with Satisfaction with support provided by: Parents, Treatment Givers, Siblings and Employers.

```
##           Gender
## Sat_Support_Parents Female Male  Prop % by col Female Male
##   Extremely      54    41         62.1%  57.7%
##   Very           23    16         26.4%  22.5%
##   Somewhat        6     7         6.9%   9.9%
##   Not Very         1     5         1.1%   7.0%
##   Not At All      3     2         3.4%   2.8%
##
## Sat_Support_Parents          Fishers Exact p-value=0.3706
## #
##           Gender
## Sat_Support_Treat_Givers Female Male  Prop % by col Female Male
##   Extremely      42    20         48.3%  28.2%
##   Very           31    33         35.6%  46.5%
##   Somewhat       10    14         11.5%  19.7%
##   Not Very        3     1         3.4%   1.4%
##   Not At All      1     3         1.1%   4.2%
##
## Sat_Support_Treat_Givers          Fishers Exact p-value=0.0479
## #
##           Gender
## Sat_Support_Siblings Female Male  Prop % by col Female Male
##   Extremely      35    24         40.2%  33.8%
##   Very           26    22         29.9%  31.0%
##   Somewhat       16    15         18.4%  21.1%
##   Not Very        2     5         2.3%   7.0%
##   Not At All      8     5         9.2%   7.0%
##
## Sat_Support_Siblings          Fishers Exact p-value=0.6174
## #
##           Gender
## Sat_Support_Employer Female Male  Prop % by col Female Male
##   Extremely      31    15         35.6%  21.1%
##   Very           28    15         32.2%  21.1%
##   Somewhat       12    24         13.8%  33.8%
##   Not Very        3     8         3.4%  11.3%
##   Not At All     13     9         14.9%  12.7%
##
## Sat_Support_Employer          Fishers Exact p-value=0.0046
## #
```

Adults Satisfaction with Support By Cleft_Type

Determine if Cleft_Type had a relationship with Satisfaction with support provided by: Parents, Treatment Givers, Siblings and Employers.

```
##                               Cleft_Type
## Sat_Support_Parents Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely      17      45      33      68.0%      57.0%      61.1%
##      Very           6      20      13      24.0%      25.3%      24.1%
##      Somewhat       2       7       4       8.0%      8.9%      7.4%
##      Not Very       0       4       2       0.0%      5.1%      3.7%
##      Not At All    0       3       2       0.0%      3.8%      3.7%
##
## Sat_Support_Parents                               Fishers Exact p-value=0.9943
## #
##                               Cleft_Type
## Sat_Support_Treat_Givers Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-on
ly
##      Extremely      12      27      23      48.0%      34.2%      42.6%
##      Very           9      33      22      36.0%      41.8%      40.7%
##      Somewhat       3      14       7      12.0%      17.7%      13.0%
##      Not Very       1       3       0       4.0%      3.8%      0.0%
##      Not At All    0       2       2       0.0%      2.5%      3.7%
##
## Sat_Support_Treat_Givers                           Fishers Exact p-value=0.7815
## #
##                               Cleft_Type
## Sat_Support_Siblings Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely      13      28      18      52.0%      35.4%      33.3%
##      Very           6      24      18      24.0%      30.4%      33.3%
##      Somewhat       5      13      13      20.0%      16.5%      24.1%
##      Not Very       0       6       1       0.0%      7.6%      1.9%
##      Not At All    1       8       4       4.0%      10.1%      7.4%
##
## Sat_Support_Siblings                               Fishers Exact p-value=0.5884
## #
##                               Cleft_Type
## Sat_Support_Employer Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Extremely      10      19      17      40.0%      24.1%      31.5%
##      Very           7      22      14      28.0%      27.8%      25.9%
##      Somewhat       6      21       9      24.0%      26.6%      16.7%
##      Not Very       2       7       2       8.0%      8.9%      3.7%
##      Not At All    0      10      12      0.0%      12.7%      22.2%
##
## Sat_Support_Employer                               Fishers Exact p-value=0.1634
## #
```

Adults pairwise comparison of Satisfaction with Suport

Determine if there were relationships between each pair of Satisfaction with support variables.

```
##                               Sat_Support_Employer
## Sat_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##      Extremely      36      11       6       2       4      59
##      Very           5      24      13       3       3      48
##      Somewhat       3       8       8       5       7      31
##      Not Very       1       0       4       1       1       7
##      Not At All    1       0       5       0       7      13
##      Total         46      43      36      11      22     158
##
## Sat_Support_Siblings v Sat_Support_Employer           Wilcox Paired p-value=0.0016
## #
##                               Sat_Support_Treat_Givers
## Sat_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##      Extremely      39      15       5       0       0      59
##      Very           11      29       7       1       0      48
##      Somewhat       9      14       7       1       0      31
##      Not Very       1       3       2       0       1       7
##      Not At All    2       3       3       2       3      13
##      Total         62      64      24       4       4     158
##
## Sat_Support_Siblings v Sat_Support_Treat_Givers       Wilcox Paired p-value=0.0034
## #
##                               Sat_Support_Parents
## Sat_Support_Siblings Extremely Very Somewhat Not Very Not At All Total
##      Extremely      59       0       0       0       0      59
##      Very           18      28       1       1       0      48
##      Somewhat       12       9       9       1       0      31
##      Not Very       2       0       1       4       0       7
```

```

##           Not At All           4    2           2           0           5    13
##           Total              95   39           13           6           5   158
##
## Sat_Support_Siblings v Sat_Support_Parents           Wilcox Paired p-value=0.0000
## #
##           Sat_Support_Treat_Givers
## Sat_Support_Employer Extremely Very Somewhat Not Very Not At All Total
##           Extremely          36    8           1           1           0    46
##           Very              10   27           5           1           0    43
##           Somewhat          6   15           12          2           1    36
##           Not Very          4    5           2           0           0    11
##           Not At All        6    9           4           0           3    22
##           Total            62   64           24          4           4   158
##
## Sat_Support_Employer v Sat_Support_Treat_Givers           Wilcox Paired p-value=0.0000
## #
##           Sat_Support_Parents
## Sat_Support_Employer Extremely Very Somewhat Not Very Not At All Total
##           Extremely          42    2           1           1           0    46
##           Very              21   20           2           0           0    43
##           Somewhat          16   11           6           2           1    36
##           Not Very          7    2           1           1           0    11
##           Not At All        9    4           3           2           4    22
##           Total            95   39           13          6           5   158
##
## Sat_Support_Employer v Sat_Support_Parents           Wilcox Paired p-value=0.0000
## #
##           Sat_Support_Parents
## Sat_Support_Treat_Givers Extremely Very Somewhat Not Very Not At All Total
##           Extremely          55    5           1           1           0    62
##           Very              29   24           7           3           1    64
##           Somewhat          11    8           4           1           0    24
##           Not Very          0    2           1           0           1     4
##           Not At All        0    0           0           1           3     4
##           Total            95   39           13          6           5   158
##
## Sat_Support_Treat_Givers v Sat_Support_Parents           Wilcox Paired p-value=0.0013
## #

```

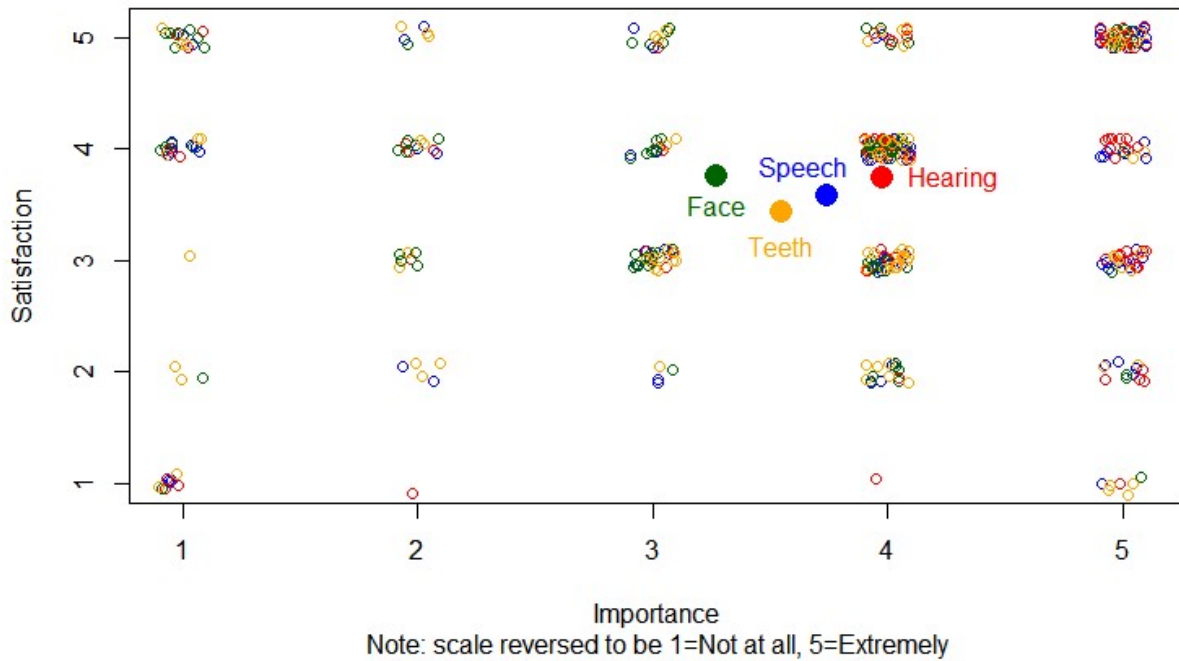
**** There were Significant differences for Satisfaction with support within Adults for all tests.****

Importance vs Satisfaction Plots

Plot Importance vs Satisfaction with jitter to see x,y scatter plot. This was abandoned (not included in final paper) as graphs were too messy. Instead plots of mean values was done using Excel (see Master spreadsheet). Note that the order has been reversed so that the more important (i.e. Extremely) is on the RHS and at the top. This makes it easier to interpret.

Children Physical Attributes Plot

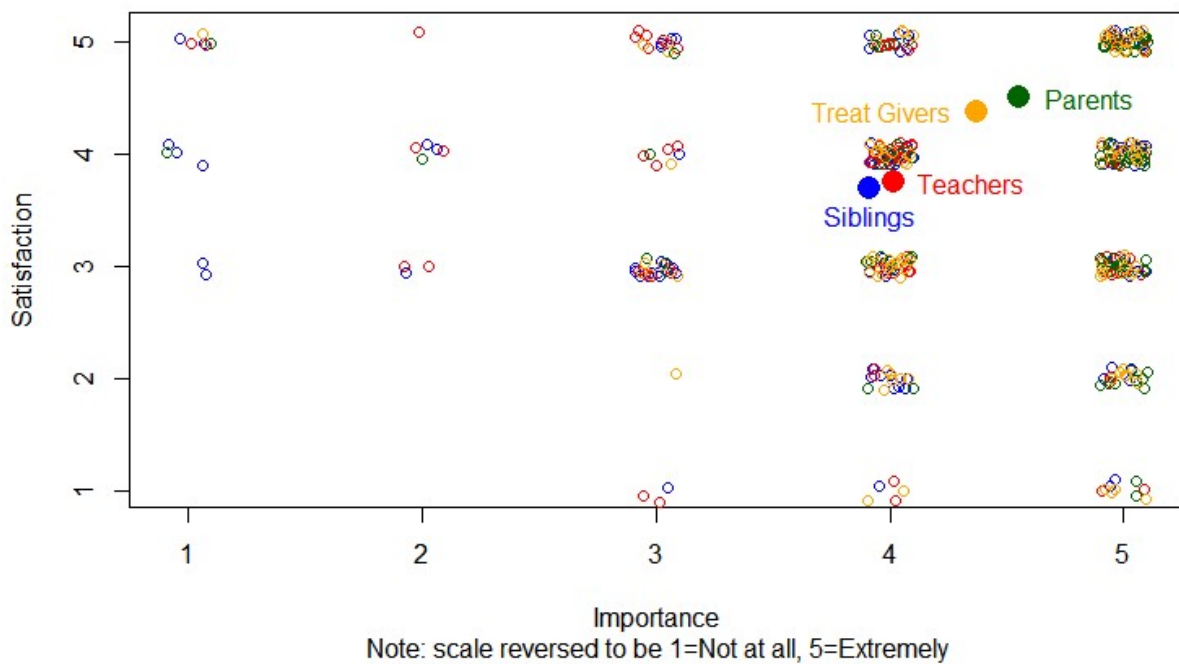
Children Importance vs Satisfaction for Physical Attributes



Hearing and speech were the most important and facial appearance was least important. Very even for satisfaction.

Children Support Plot

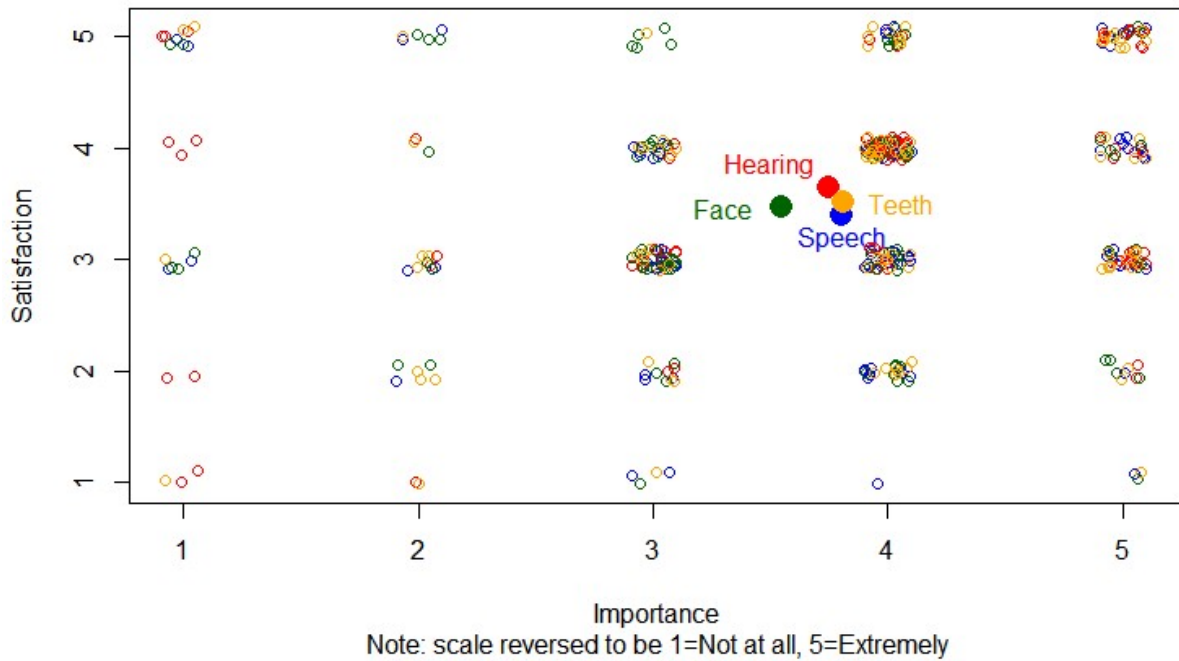
Children Importance vs Satisfaction for Support



Parents and Treatment Givers were the most important and had highest satisfaction ratings.

Teens Physical Attributes Plot

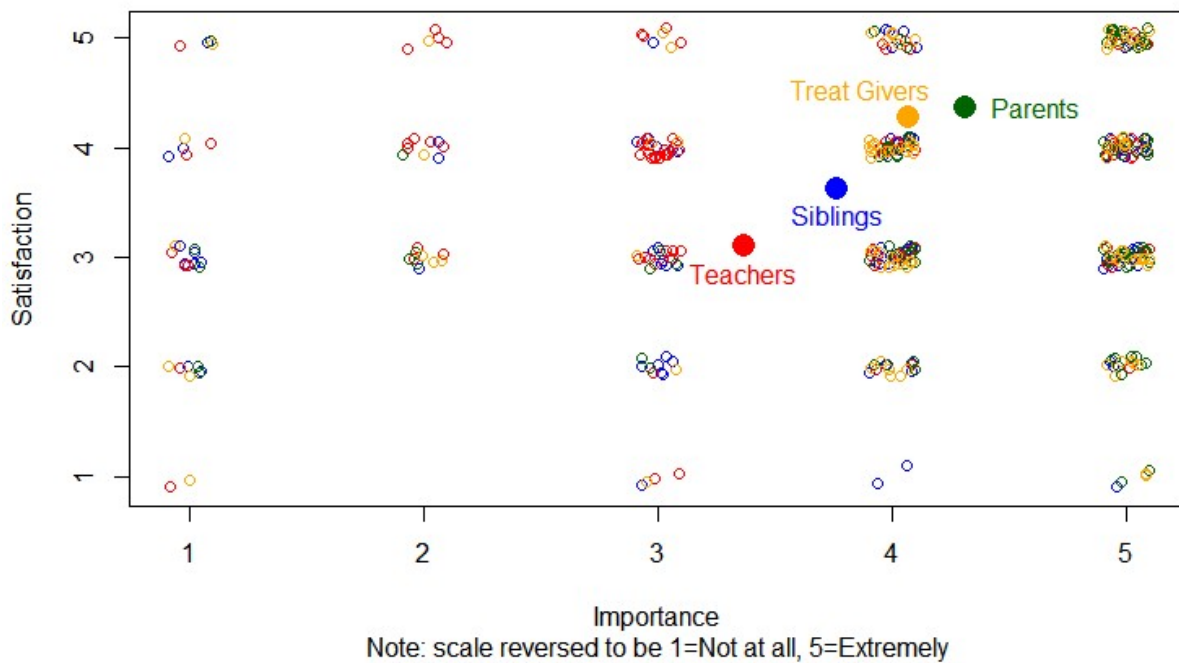
Teens Importance vs Satisfaction for Physical Attributes



Means are closely clumped together, although facial appearance was rated less important overall.

Teens Support Plot

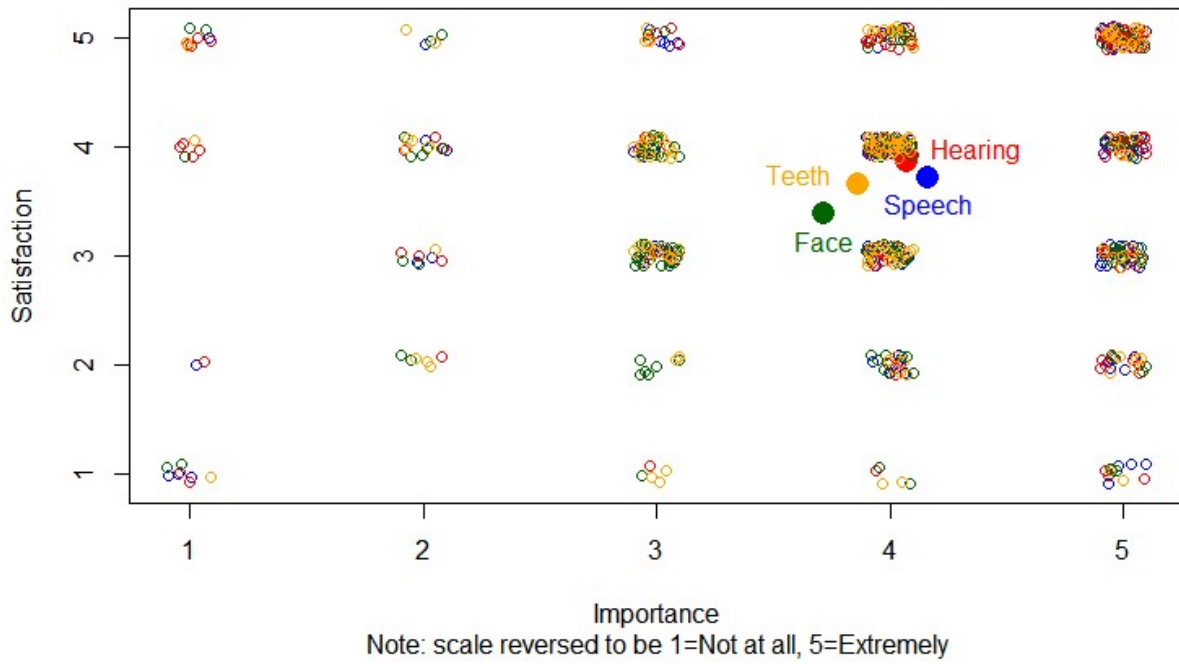
Teens Importance vs Satisfaction for Support



As with Children, Teens rated Parents and Treatment Givers highly. Teachers were lowest.

Adults Physical Attributes Plot

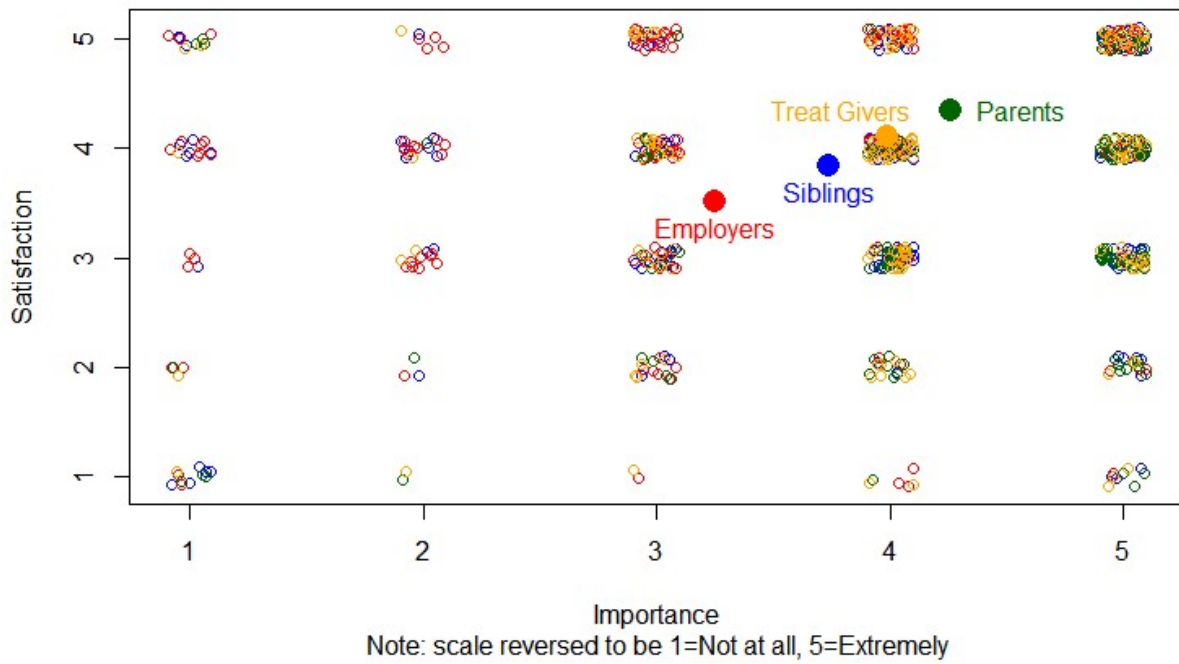
Adults Importance vs Satisfaction for Physical Attributes



As with Children and Teens, facial appearance was rated the lowest in importance.

Adults Support Plot

Adults Importance vs Satisfaction for Support

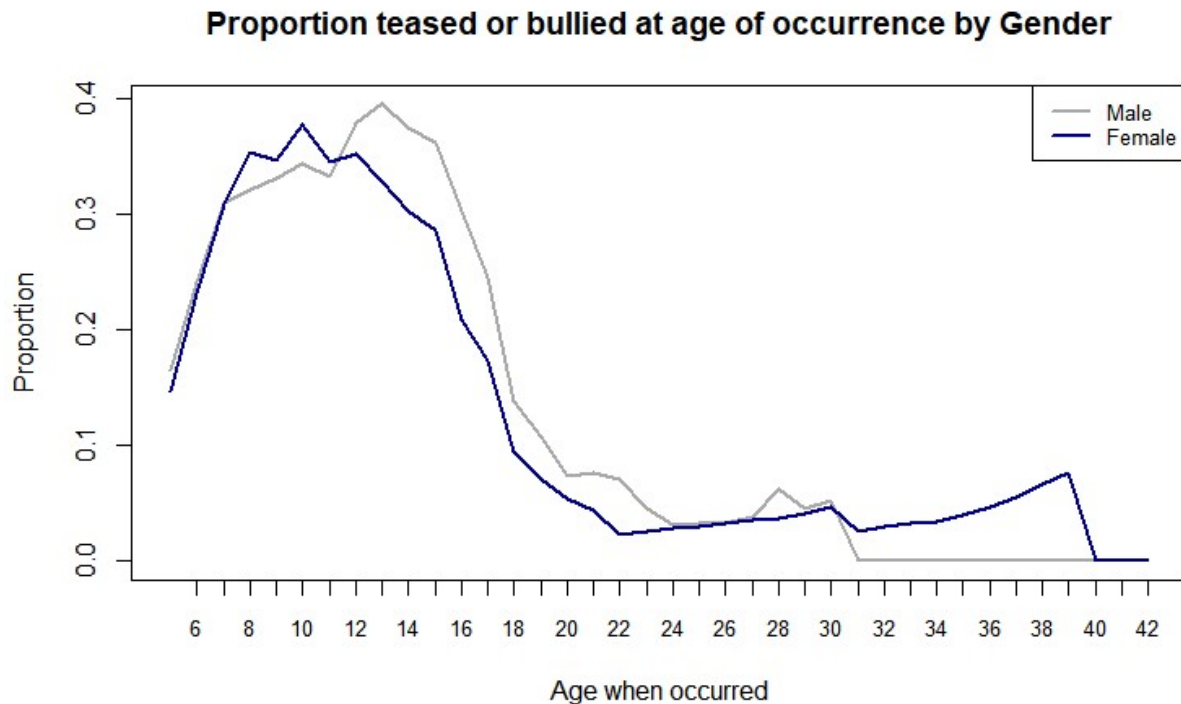


As with Children and Teens, the Adults rated Parents and Treatment Givers highly.

Teased or Bullied

The master database spreadsheet contains a tab called Bullying Data. It contains the proportion of study participants across all age groups who reported teasing or bullying at each age by Gender and Cleft_Type. Assuming this data approximates continuous distributions, the Kolmogorov-Smirnov test was used to determine if there were differences between the Gender and Cleft_Type distributions.

Teased or Bullied By Gender



Use the Kolmogorov-Smirnov Test to test the null hypothesis that genders have the same distributions.

```
##
## Male vs Female                               Kolmg-Smirnov p-value=0.2369
## #
```

There was no significant difference in the distributions for proportion reporting teasing or bullying over age of occurrence by Gender.

Teased or Bullied By Cleft_Type

Use the Kolmogorov-Smirnov Test for each pair of cleft types to test the null hypothesis that pairs of cleft types were sampled from populations with the same distribution.

```
##
## Lip & Palate v Lip-only                       Kolmg-Smirnov p-value=0.0054
## #
##
## Lip & Palate v Palate-only                   Kolmg-Smirnov p-value=0.0234
## #
##
## Lip-only v Palate-only                       Kolmg-Smirnov p-value=0.3688
## #
```

There were significant differences in the distributions for teasing or bullying over age of occurrence by Cleft Type.

The distribution for Lip & Palate Cleft Type was different to Palate-only and Lip-only.

Adults Teased_Bullied and Bullied_Others

For the Adults age-group test for difference by Gender and Cleft_Type for Teased_Bullied (i.e. Have you ever been teased or bullied because of your cleft?) and Bullied_Others (i.e. Have you ever bullied others?). Also compare Teased_Bullied vs Bullied_Others.

```
##          Gender
## Teased_Bullied Female Male Prop % by col Female Male
##          No      39      26          44.8%  36.6%
##          Yes      48      45          55.2%  63.4%
##
## Teased Bullied By Gender          Chi-squared  p-value=0.2970
## #
##          Cleft_Type
## Teased_Bullied Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      10      18          37          40.0%  22.8%  68.5%
##          Yes      15      61          17          60.0%  77.2%  31.5%
##
## Teased_Bullied By Cleft_Type          Chi-squared  p-value=0.0000
## #
##          Cleft_Type
## Teased_Bullied Remainder Lip & Palate Prop % by col Remainder Lip & Palate
##          No      47      18          59.5%  22.8%
##          Yes      32      61          40.5%  77.2%
##
## Risk Ratio=2.37 CI=(1.63,3.88) p.value=0.0000
## The Relative Risk for Lip & Palate of Cleft_Type is at least 63% higher for Yes than No of Teased_Bullied
##
## RR Teased Bullied Lip & Palate v Remainder          Relative Risk p-value=0.0000
## #
##          Gender
## Bullied_Others Female Male Prop % by col Female Male
##          No      75      59          86.2%  83.1%
##          Yes      12      12          13.8%  16.9%
##
## Bullied Others By Gender          Chi-squared  p-value=0.5882
## #
##          Cleft_Type
## Bullied_Others Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      23      64          47          92.0%  81.0%  87.0%
##          Yes      2      15          7           8.0%  19.0%  13.0%
##
## Bullied Others By Cleft Type          Fishers Exact p-value=0.4300
## #
##          Teased_Bullied
## Bullied_Others No      Yes Prop % by col No      Yes
##          No      60      74          92.3%  79.6%
##          Yes      5      19          7.7%  20.4%
##
## Teased Bullied and Bullied Others          Chi-squared  p-value=0.0282
## #
##
## Risk Ratio=1.43 CI=(1.08,1.83) p.value=0.0411
## The Relative Risk for Yes of Teased Bullied is at least 8% higher for Yes than No of Bullied Others
##
## RR Teased Bullied and Bullied Others          Relative Risk p-value=0.0411
## #
```

There was a significant difference in Adults for Teased_Bullied by Cleft_Type.

Participants with a Cleft Type of Lip & Palate were 63% more likely to be teased or bullied than the other cleft types combined.

There was a significant difference in Teased_Bullied vs Bullied_Others for Adults.

Participants who were teased or bullied were 8% more likely to bully others.

Children Teased or Bullied vs Satisfaction with Physical Attribute

For Children age-group determine if there was a significant relationship between teasing or bullying and level of satisfaction with the physical attributes of speech, hearing, facial appearance and teeth appearance.

```
##          Teased_Bullied
## Sat_Speech No      Yes Prop % by col No      Yes
## Extremely  17      3          24.3%  10.0%
```

```

##      Very      30      8      42.9% 26.7%
##      Somewhat  15     11     21.4% 36.7%
##      Not Very   5      7      7.1% 23.3%
##      Not At All 3      1      4.3%  3.3%
##
## Sat_Speech                               Fishers Exact p-value=0.0373
## #
##           Teased_Bullied
## Sat_Hearing No      Yes  Prop % by col No      Yes
##      Extremely  20     7      28.6% 23.3%
##      Very       29     8      41.4% 26.7%
##      Somewhat   14     11     20.0% 36.7%
##      Not Very    2      3      2.9% 10.0%
##      Not At All 5      1      7.1%  3.3%
##
## Sat_Hearing                               Fishers Exact p-value=0.1712
## #
##           Teased_Bullied
## Sat_Facial_Appearance No      Yes  Prop % by col No      Yes
##      Extremely    21     6      30.0% 20.0%
##      Very         29     6      41.4% 20.0%
##      Somewhat     17     9      24.3% 30.0%
##      Not Very      3      7      4.3% 23.3%
##      Not At All   0      2      0.0%  6.7%
##
## Sat_Facial_Appearance                     Fishers Exact p-value=0.0033
## #
##           Teased_Bullied
## Sat_Teeth_Appearance No      Yes  Prop % by col No      Yes
##      Extremely    21     2      30.0%  6.7%
##      Very         15     9      21.4% 30.0%
##      Somewhat     26     7      37.1% 23.3%
##      Not Very      7      7      10.0% 23.3%
##      Not At All   1      5      1.4% 16.7%
##
## Sat_Teeth_Appearance                       Fishers Exact p-value=0.0013
## #

```

Teens Teased or Bullied vs Satisfaction with Physical Attribute

For Teens age-group determine if there was a significant relationship between teasing or bullying and level of satisfaction with the physical attributes of speech, hearing, facial appearance and teeth appearance.

```

##           Teased_Bullied
## Sat_Speech No      Yes  Prop % by col No      Yes
##      Extremely  10     5      25.0%  8.2%
##      Very       18     14     45.0% 23.0%
##      Somewhat   10     26     25.0% 42.6%
##      Not Very    2     12     5.0% 19.7%
##      Not At All 0      4      0.0%  6.6%
##
## Teased_Bullied v Sat_Speech               Fishers Exact p-value=0.0018
## #
##           Teased_Bullied
## Sat_Hearing No      Yes  Prop % by col No      Yes
##      Extremely  12     5      30.0%  8.2%
##      Very       19     25     47.5% 41.0%
##      Somewhat    9     22     22.5% 36.1%
##      Not Very    0      6      0.0%  9.8%
##      Not At All 0      3      0.0%  4.9%
##
## Teased_Bullied v Sat_Hearing               Fishers Exact p-value=0.0048
## #
##           Teased_Bullied
## Sat_Facial_Appearance No      Yes  Prop % by col No      Yes
##      Extremely   13     8      32.5% 13.1%
##      Very        11     15     27.5% 24.6%

```

```

##           Somewhat      13      22           32.5%  36.1%
##           Not Very       3       14           7.5%  23.0%
##           Not At All     0        2           0.0%   3.3%
##
## Teased_Bullied v Sat_Facial_Appearance      Fishers Exact p-value=0.0525
## #
##           Teased_Bullied
## Sat_Teeth_Appearance No      Yes  Prop % by col No      Yes
##           Extremely     11     11           27.5%  18.0%
##           Very           16     15           40.0%  24.6%
##           Somewhat       9      20           22.5%  32.8%
##           Not Very       3      12           7.5%  19.7%
##           Not At All     1       3           2.5%   4.9%
##
## Teased_Bullied v Sat_Teeth_Appearance      Fishers Exact p-value=0.1640
## #

```

Adults Teased or Bullied vs Satisfaction with Physical Attribute

For Adults age-group determine if there was a significant relationship between teasing or bullying and level of satisfaction with the physical attributes of speech, hearing, facial appearance and teeth appearance.

```

##           Teased_Bullied
## Sat_Speech   No      Yes  Prop % by col No      Yes
##   Extremely  17     27           26.2%  29.0%
##   Very       27     24           41.5%  25.8%
##   Somewhat   15     29           23.1%  31.2%
##   Not Very   2      9            3.1%   9.7%
##   Not At All 4      4            6.2%   4.3%
##
## Teased_Bullied v Sat_Speech      Fishers Exact p-value=0.1622
## #
##           Teased_Bullied
## Sat_Hearing  No      Yes  Prop % by col No      Yes
##   Extremely  25     33           38.5%  35.5%
##   Very       21     29           32.3%  31.2%
##   Somewhat   9      20           13.8%  21.5%
##   Not Very   5      9            7.7%   9.7%
##   Not At All 5      2            7.7%   2.2%
##
## Teased_Bullied v Sat_Hearing      Fishers Exact p-value=0.4032
## #
##           Teased_Bullied
## Sat_Facial_Appearance No      Yes  Prop % by col No      Yes
##   Extremely    15     8           23.1%   8.6%
##   Very         25     27           38.5%  29.0%
##   Somewhat     17     37           26.2%  39.8%
##   Not Very     6      15           9.2%  16.1%
##   Not At All   2       6            3.1%   6.5%
##
## Teased_Bullied v Sat_Facial_Appearance      Fishers Exact p-value=0.0299
## #
##           Teased_Bullied
## Sat_Teeth_Appearance No      Yes  Prop % by col No      Yes
##   Extremely    19     22           29.2%  23.7%
##   Very         28     26           43.1%  28.0%
##   Somewhat     9      31           13.8%  33.3%
##   Not Very     7      8           10.8%   8.6%
##   Not At All   2       6            3.1%   6.5%
##
## Teased_Bullied v Sat_Teeth_Appearance      Fishers Exact p-value=0.0386
## #

```

There were significant differences found for teased or bullied vs satisfaction with physical attributes.

Relative Risk Teased or Bullied vs Satisfaction with Speech

For each age-group calculate the relative risk for being Teased or Bullied by satisfaction with Speech (Satisfied = Extremely + Very, and Not Satisfied = Not Very + Not At All). The somewhat ratings were not included as these could be either.

```
##
## Risk Ratio=2.89 CI=(1.26,6.64) p.value=0.0213
## The Relative Risk for Not Satisfied of Speech_Satisfaction is at least 26% higher for Yes than No of Children_Teased_Bullied
##
## RR Teased_Bullied v Speech Satisfaction Relative Risk p-value=0.0213
## #
##
## Risk Ratio=6.86 CI=(1.71,27.44) p.value=0.0006
## The Relative Risk for Not Satisfied of Speech_Satisfaction is at least 71% higher for Yes than No of Teens_Teased_Bullied
##
## RR Teased_Bullied v Speech Satisfaction Relative Risk p-value=0.0006
## #
##
##           Speech_Satisfaction
## Adults_Teased_Bullied Satisfied Not Satisfied Prop % by col Satisfied Not Satisfied
##
##           No      44      6      46.3%      31.6%
##           Yes      51      13     53.7%      68.4%
##
## Risk Ratio=1.69 CI=(0.72,5.47) p.value=0.3135
## Lower CI <=1 for Not Satisfied of Speech_Satisfaction indicates no significant difference between Yes and No
##
## RR Teased_Bullied v Speech Satisfaction Relative Risk p-value=0.3135
## #
```

Treatment Best, Worst, Prepared, Own Decisions

Compare the following treatment related variables for Teens and Adults age-group by Gender and Cleft_Type.

- Treat_Best_Part = One of: Outcome, Options, Staff, Finished
- Treat_Worst_Part = One of: Pain, Number, Staff, Reminder
- Treat_Prepared = Have you felt adequately prepared for the treatment? Y or N
- Treat_Own_Decisions= Opportunity to make decisions on your own treatment? Y or N

Teens Treatment By Gender

Determine if Gender had a relationship with Treatment variables.

```
##           Gender
## Treat_Best_Part Female Male Prop % by col Female Male
##           Finished      1      4      2.7%      6.5%
##           Options       4     11     10.8%     17.7%
##           Outcome      29     43     78.4%     69.4%
##           Staff         3      4      8.1%      6.5%
##
## Treat_Best_Part Fishers Exact p-value=0.6883
## #
##           Gender
## Treat_Worst_Part Female Male Prop % by col Female Male
##           Number     13     21     34.2%     36.2%
##           Pain        24     33     63.2%     56.9%
##           Reminder     1      2      2.6%      3.4%
##           Staff        0      2      0.0%      3.4%
##
## Treat_Worst_Part Fishers Exact p-value=0.8396
## #
```

```

##          Gender
## Treat_Prepared Female Male Prop % by col Female Male
##           No      0      3           0.0%  4.8%
##           Yes     38     60          100.0% 95.2%
##
## Treat_Prepared          Fishers Exact p-value=0.2889
## #
##          Gender
## Treat_Own_Decisions Female Male Prop % by col Female Male
##           No      7      9           18.4% 14.3%
##           Yes     31     54           81.6% 85.7%
##
## Treat_Own_Decisions          Fishers Exact p-value=0.5861
## #

```

There were no significant differences in treatment for Teens age group by Gender.

Teens Treatment By Cleft_Type

Determine if Cleft_Type had a relationship with Treatment variables.

```

##          Cleft_Type
## Treat_Best_Part Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           Finished  0      3      2           0.0%  5.6%  6.1%
##           Options   0     11     4           0.0% 20.4% 12.1%
##           Outcome   12    36    24          100.0% 66.7% 72.7%
##           Staff     0      4      3           0.0%  7.4%  9.1%
##
## Teens Treat_Best_Part          Fishers Exact p-value=0.5221
## #
##          Cleft_Type
## Treat_Worst_Part Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           Number    5     15    14           45.5% 27.8% 45.2%
##           Pain       6     36    15           54.5% 66.7% 48.4%
##           Reminder   0      1      2           0.0%  1.9%  6.5%
##           Staff     0      2      0           0.0%  3.7%  0.0%
##
## Teens Treat Worst Part          Fishers Exact p-value=0.3808
## #
##          Cleft Type
## Treat_Prepared Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      0      3      0           0.0%  5.5%  0.0%
##           Yes    13    52    33          100.0% 94.5% 100.0%
##
## Teens Treat_Prepared          Fishers Exact p-value=0.5317
## #
##          Cleft Type
## Treat_Own_Decisions Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      2      9      5           15.4% 16.4% 15.2%
##           Yes    11    46    28           84.6% 83.6% 84.8%
##
## Teens Treat Own Decisions          Fishers Exact p-value=1.0000
## #

```

There were no significant differences in treatment for Teens age group by Cleft_Type.

Adults Treatment By Gender

Determine if Gender had a relationship with Treatment variables.

```

##          Gender
## Treat_Best_Part Female Male Prop % by col Female Male
##           Finished  18     9           20.7% 12.7%
##           Options   7      8           8.0% 11.3%
##           Outcome   44    44           50.6% 62.0%
##           Staff    18    10           20.7% 14.1%
##
## Treat_Best_Part          Chi-squared p-value=0.2873
## #
##          Gender
## Treat_Worst_Part Female Male Prop % by col Female Male
##           Number    30    30           42.9% 46.9%
##           Pain      32    22           45.7% 34.4%
##           Reminder   6      9           8.6% 14.1%
##           Staff     2      3           2.9%  4.7%

```

```
##
## Treat_Worst_Part Fishers Exact p-value=0.4869
## #
## Gender
## Treat_Prepared Female Male Prop % by col Female Male
## No 10 9 11.5% 12.7%
## Yes 77 62 88.5% 87.3%
##
## Treat_Prepared Chi-squared p-value=0.8203
## #
## Gender
## Treat_Own_Decisions Female Male Prop % by col Female Male
## No 46 28 52.9% 39.4%
## Yes 41 43 47.1% 60.6%
##
## Treat_Own_Decisions Chi-squared p-value=0.0922
## #
```

There were no significant differences in treatment for Adults age group by Gender.

Adults Treatment By Cleft_Type

Determine if Cleft_Type had a relationship with Treatment variables.

```
## Cleft_Type
## Treat_Best_Part Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Finished 2 12 13 8.0% 15.2% 24.1%
## Options 5 8 2 20.0% 10.1% 3.7%
## Outcome 12 47 29 48.0% 59.5% 53.7%
## Staff 6 12 10 24.0% 15.2% 18.5%
##
## Treat_Best_Part Fishers Exact p-value=0.1736
## #
## Cleft_Type
## Treat_Worst_Part Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Number 8 26 26 40.0% 37.1% 59.1%
## Pain 9 32 13 45.0% 45.7% 29.5%
## Reminder 3 9 3 15.0% 12.9% 6.8%
## Staff 0 3 2 0.0% 4.3% 4.5%
##
## Treat_Worst_Part Fishers Exact p-value=0.3190
## #
## Cleft_Type
## Treat_Prepared Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 4 11 4 16.0% 13.9% 7.4%
## Yes 21 68 50 84.0% 86.1% 92.6%
##
## Treat_Prepared Fishers Exact p-value=0.4100
## #
## Cleft_Type
## Treat_Own_Decisions Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 11 34 29 44.0% 43.0% 53.7%
## Yes 14 45 25 56.0% 57.0% 46.3%
##
## Treat_Own_Decisions Chi-squared p-value=0.4581
## #
```

There were no significant differences in treatment for Adults age group Cleft_Type.

Teens v Adults Treatment

Compare treatment for Teens vs Adults age-groups using these variables:

* Treat_Prepared = Have you felt adequately prepared for the treatment? Y or N

* Treat_Own_Decisions= Opportunity to make decisions on your own treatment? Y or N

Do not test by Gender or Cleft_Type as these are not significantly different within each age-group (see prior tests).

The null is that the proportion who are not prepared and prepared for teens is the same as for adults.

Alternative is prop teens who are not prepared is less than the prop adults not prepared.

```

##           Age_Group
## Treat_Prepared Teens Adults Prop % by col Teens Adults
##           No      3      19              3.0%  12.0%
##           Yes     98     139             97.0%  88.0%
##
## Treat_Prepared                Chi-squared   p-value=0.0108
## #
##           Age_Group
## Treat_Prepared Adults Teens Prop % by col Adults Teens
##           No      19      3              12.0%  3.0%
##           Yes     139     98             88.0%  97.0%
##
## Risk Ratio=3.03  CI=(1.38,Inf)  p.value=0.0112
## The Relative Risk for Teens of Age_Group is at least 38% higher for Yes than No
of Treat_Prepared
##
## RR Treat_Prepared                Relative Risk p-value=0.0112
## #
##           Age_Group
## Treat_Own_Decisions Teens Adults Prop % by col Teens Adults
##           No      16      74              15.8%  46.8%
##           Yes     85      84             84.2%  53.2%
##
## Treat_Own_Decisions                Chi-squared   p-value=0.0000
## #
##           Age_Group
## Treat_Own_Decisions Adults Teens Prop % by col Adults Teens
##           No      74      16              46.8%  15.8%
##           Yes     84      85             53.2%  84.2%
##
## Risk Ratio=2.83  CI=(1.88,4.97)  p.value=0.0000
## The Relative Risk for Teens of Age_Group is at least 88% higher for Yes than No
of Treat_Own_Decisions
##
## RR Treat_Own_Decisions                Relative Risk p-value=0.0000
## #

```

**** There were significant differences between Teens and Adults age groups for Treat_Prepared and Treat_Own_Decisions.****

Teens were more prepared for treatment and were more involved in treatment decisions in comparison with the Adults.

Fears, Chew Properly, Smile

Compare the following variables for each age-group by Gender and Cleft_Type:

- Fear_Of_Anaesthetic = Have you suffered from Fear of having an Anaesthetic? Y or N
- Fear_Of_Dentist = Have you ever suffered from Fear of going to the Dentist? Y or N
- Chew_Properly = Can you chew food properly? Y or N
- Happy_With_Smile = Are you happy with your smile? Y or N

Children Fears By Gender

Determine if Gender had a relationship with Fears, Chew Properly, Smile variables.

```

##           Gender
## Fear_Of_Anaesthetic Female Male Prop % by col Female Male
##           No      27      30              51.9%  62.5%
##           Yes     25      18              48.1%  37.5%
##
## Fear_Of_Anaesthetic                Chi-squared   p-value=0.2858
## #
##           Gender
## Fear_Of_Dentist Female Male Prop % by col Female Male
##           No      42      41              80.8%  85.4%

```



```

##           Yes      10      7           19.2%  14.6%
##
## Fear_Of_Dentist           Chi-squared  p-value=0.5365
## #
##           Gender
## Chew_Properly Female Male  Prop % by col Female Male
##           No      5      8           9.6%  16.7%
##           Yes     47     40           90.4%  83.3%
##
## Chew_Properly           Chi-squared  p-value=0.2949
## #
##           Gender
## Happy_With_Smile Female Male  Prop % by col Female Male
##           No      16     12           30.8%  25.0%
##           Yes     36     36           69.2%  75.0%
##
## Happy_With_Smile           Chi-squared  p-value=0.5209
## #

```

There were no significant differences in Fears etc. for Children age group Gender.

Children Fears By Cleft_Type

Determine if Cleft_Type had a relationship with Fears, Chew Properly, Smile variables.

```

##           Cleft_Type
## Fear Of Anaesthetic Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      9      18      30           69.2%  52.9%  56.6%
##           Yes     4      16      23           30.8%  47.1%  43.4%
##
## Fear_Of_Anaesthetic           Chi-squared  p-value=0.5989
## #
##           Cleft_Type
## Fear_Of_Dentist Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No     12     28     43           92.3%  82.4%  81.1%
##           Yes     1      6      10           7.7%  17.6%  18.9%
##
## Fear_Of_Dentist           Fishers Exact p-value=0.7575
## #
##           Cleft_Type
## Chew Properly Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      0      3      10           0.0%  8.8%  18.9%
##           Yes    13     31     43           100.0%  91.2%  81.1%
##
## Chew Properly           Fishers Exact p-value=0.1576
## #
##           Cleft_Type
## Happy_With_Smile Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      7      11     10           53.8%  32.4%  18.9%
##           Yes     6      23     43           46.2%  67.6%  81.1%
##
## Happy With Smile           Fishers Exact p-value=0.0405
## #
##           Cleft_Type
## Happy_With_Smile Remainder Palate-only Prop % by col Remainder Palate-only
##           No     18     10           38.3%  18.9%
##           Yes    29     43           61.7%  81.1%
##
## Risk Ratio=1.67  CI=(1.05,3.24)  p.value=0.0441
## The Relative Risk for Palate-only of Cleft_Type is at least 5% higher for Yes than No of Happy_With_Smile
##
## RR Happy_With_Smile Palate-only v Remainder           Relative Risk p-value=0.0441
## #

```

There was one significant difference found for Children Happy_With_Smile by Cleft_Type.

Children participants with the Palate-only cleft type were more likely to be happy with their smile, however the significance was marginal (0.0405) as was the relative risk (6% higher).

Teens Fears, Chew Properly, Smile By Gender

Determine if Gender had a relationship with Fears, Chew Properly, Smile variables.

```

##           Gender
## Fear_Of_Anaesthetic Female Male  Prop % by col Female Male

```

```

##           No      21      39           55.3%  61.9%
##           Yes      17      24           44.7%  38.1%
##
## Fear_Of_Anaesthetic           Chi-squared  p-value=0.5102
## #
##           Gender
## Fear_Of_Dentist Female Male  Prop % by col Female Male
##           No      30      45           78.9%  71.4%
##           Yes      8      18           21.1%  28.6%
##
## Fear_Of_Dentist           Chi-squared  p-value=0.4025
## #
##           Gender
## Chew_Properly Female Male  Prop % by col Female Male
##           No      7      9           18.4%  14.3%
##           Yes     31     54           81.6%  85.7%
##
## Chew_Properly           Chi-squared  p-value=0.5814
## #
##           Gender
## Happy_With_Smile Female Male  Prop % by col Female Male
##           No      17      26           44.7%  41.3%
##           Yes     21     37           55.3%  58.7%
##
## Happy_With_Smile           Chi-squared  p-value=0.7328
## #

```

Teens Fears, Chew Properly, Smile By Cleft_Type

Determine if Cleft_Type had a relationship with Fears, Chew Properly, Smile variables.

```

##           Cleft_Type
## Fear Of Anaesthetic Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      10      31      19           76.9%  56.4%  57.6%
##           Yes      3      24      14           23.1%  43.6%  42.4%
##
## Fear_Of_Anaesthetic           Chi-squared  p-value=0.3846
## #
##           Cleft_Type
## Fear_Of_Dentist Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N      11      38      26           84.6%  69.1%  78.8%
##           Y      2      17      7           15.4%  30.9%  21.2%
##
## Fear_Of_Dentist           Fishers Exact p-value=0.4525
## #
##           Cleft_Type
## Chew_Properly Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      0      11      5           0.0%  20.0%  15.2%
##           Yes     13     44     28           100.0%  80.0%  84.8%
##
## Chew_Properly           Fishers Exact p-value=0.2172
## #
##           Cleft_Type
## Happy_With_Smile Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      4      30      9           30.8%  54.5%  27.3%
##           Yes      9      25     24           69.2%  45.5%  72.7%
##
## Happy With Smile           Chi-squared  p-value=0.0284
## #
##           Cleft_Type
## Happy_With_Smile Remainder Palate-only Prop % by col Remainder Palate-only
##           No      34      9           50.0%  27.3%
##           Yes     34     24           50.0%  72.7%
##
## Risk Ratio=1.98  CI=(1.08,4.63)  p.value=0.0341
## The Relative Risk for Palate-only of Cleft_Type is at least 8% higher for Yes than No of Happy_With_Smil
##
## RR Happy_With_Smile Palate-only v Remainder           Relative Risk p-value=0.0341
## #

```

There was one significant difference found for Teens Happy_With_Smile by Cleft_Type.

Teens with the Palate-only cleft type were more likely to be happy with their smile, however the significance was marginal (0.0329), although the relative risk was 11% higher than for the other two cleft types combined.

Adults Fears, Chew Properly, Smile By Gender

Determine if Gender had a relationship with Fears, Chew Properly, Smile variables.

```
##
##          Gender
## Fear_Of_Anaesthetic Female Male Prop % by col Female Male
##                No      65      62          74.7%  87.3%
##                Yes      22       9          25.3%  12.7%
##
## Fear_Of_Anaesthetic          Chi-squared   p-value=0.0471
## #
##          Gender
## Fear_Of_Dentist Female Male Prop % by col Female Male
##                No      63      51          72.4%  71.8%
##                Yes      24      20          27.6%  28.2%
##
## Fear_Of_Dentist          Chi-squared   p-value=0.9352
## #
##          Gender
## Chew_Properly Female Male Prop % by col Female Male
##                No       4       2           4.6%   2.8%
##                Yes      83      69          95.4%  97.2%
##
## Chew_Properly          Fishers Exact p-value=0.6914
## #
##          Gender
## Happy_With_Smile Female Male Prop % by col Female Male
##                No      28      22          32.2%  31.0%
##                Yes      59      49          67.8%  69.0%
##
## Happy_With_Smile          Chi-squared   p-value=0.8720
## #
```

There was one significant difference in Fear_Of_Anaesthetic for Adults age group by Gender.

Females were more likely to fear anaesthetic than males, however the result was marginal ($p=0.0471$).

Adults Fears, Chew Properly, Smile By Cleft_Type

Determine if Cleft_Type had a relationship with Fears, Chew Properly, Smile variables.

```
##
##          Cleft_Type
## Fear_Of_Anaesthetic Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##                No      23      60      44          92.0%  75.9%  81.5%
##                Yes       2      19      10           8.0%  24.1%  18.5%
##
## Fear Of Anaesthetic          Fishers Exact p-value=0.2234
## #
##          Cleft_Type
## Fear_Of_Dentist Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##                No      21      60      33          84.0%  75.9%  61.1%
##                Yes       4      19      21          16.0%  24.1%  38.9%
##
## Fear_Of_Dentist          Chi-squared   p-value=0.0611
## #
##          Cleft_Type
## Chew_Properly Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##                No       1       1       4           4.0%   1.3%   7.4%
##                Yes      24      78      50          96.0%  98.7%  92.6%
##
## Chew Properly          Fishers Exact p-value=0.2014
## #
##          Cleft_Type
## Happy_With_Smile Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##                No       7       26      17          28.0%  32.9%  31.5%
##                Yes      18      53      37          72.0%  67.1%  68.5%
##
## Happy_With_Smile          Chi-squared   p-value=0.8991
## #
```

Talk to someone

Compare the following variables each age-group by Gender and Cleft_Type:

- Talk_Appearance = Talk about appearance issues? Y or N (coerce NA to N)

- Talk_Self_Esteem = Talk about self esteem issues? Y or N (coerce NA to N)
- Talk_Social_Skills = Talk about social skills issues? Y or N (coerce NA to N)
- Talk_Teasing = Talk about teasing and bullying issues? Y or N (coerce NA to N)
- Talk_To_Someone = Calculated as Y if any of the above were Y otherwise N

Children talk to someone By Gender

Determine if Gender had a relationship with the Talk variables.

```
##          Gender
## Talk_Appearance Female Male Prop % by col Female Male
##          No      49      45          94.2%  93.8%
##          Yes       3       3           5.8%   6.2%
##
## Talk_Appearance By Gender          Fishers Exact p-value=1.0000
## #
##          Gender
## Talk_Self_Esteem Female Male Prop % by col Female Male
##          No      50      42          96.2%  87.5%
##          Yes       2       6           3.8%  12.5%
##
## Talk_Self_Esteem By Gender          Fishers Exact p-value=0.1486
## #
##          Gender
## Talk_Social_Skills Female Male Prop % by col Female Male
##          No      49      44          94.2%  91.7%
##          Yes       3       4           5.8%   8.3%
##
## Talk_Social_Skills By Gender          Fishers Exact p-value=0.7075
## #
##          Gender
## Talk_Teasing Female Male Prop % by col Female Male
##          No      49      43          94.2%  89.6%
##          Yes       3       5           5.8%  10.4%
##
## Talk_Teasing By Gender          Fishers Exact p-value=0.4754
## #
##          Gender
## Talk_To_Someone Female Male Prop % by col Female Male
##          No      47      40          90.4%  83.3%
##          Yes       5       8           9.6%  16.7%
##
## Talk_To_Someone By Gender          Fishers Exact p-value=0.3771
## #
```

Children talk to someone By Cleft_Type

Determine if Cleft_Type had a relationship with the Talk variables.

```
##          Cleft_Type
## Talk_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      10      33      51          76.9%  97.1%  96.2%
##          Yes       3       1       2          23.1%   2.9%   3.8%
##
## Talk_Appearance          Fishers Exact p-value=0.0350
## #
##          Cleft_Type
## Talk_Self_Esteem Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      11      33      48          84.6%  97.1%  90.6%
##          Yes       2       1       5          15.4%   2.9%   9.4%
##
## Talk_Self_Esteem          Fishers Exact p-value=0.2726
## #
##          Cleft_Type
## Talk_Social_Skills Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      10      33      50          76.9%  97.1%  94.3%
##          Yes       3       1       3          23.1%   2.9%   5.7%
##
## Talk_Social_Skills          Fishers Exact p-value=0.0996
## #
```

```

##           Cleft_Type
## Talk_Teasing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      11      31      50      84.6%  91.2%  94.3%
##           Yes       2       3       3      15.4%   8.8%   5.7%
##
## Talk_Teasing           Fishers Exact p-value=0.3859
## #
##           Cleft_Type
## Talk_To_Someone Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      10      30      47      76.9%  88.2%  88.7%
##           Yes       3       4       6      23.1%  11.8%  11.3%
##
## Talk_To_Someone           Fishers Exact p-value=0.5348
## #

```

There was one significant difference found for Children Talk_Appearance by Cleft_Type. Children with the Lip-only cleft type were more likely to want to talk to someone regarding their appearance than the other cleft types, however the significance was marginal (0.0350).

Teens talk to someone By Gender

Determine if Gender had a relationship with the Talk variables.

```

##           Gender
## Talk_Appearance Female Male Prop % by col Female Male
##           No      29      60      76.3%  95.2%
##           Yes       9       3      23.7%   4.8%
##
## Talk_Appearance           Fishers Exact p-value=0.0085
## #
##           Gender
## Talk_Self_Esteem Female Male Prop % by col Female Male
##           No      28      58      73.7%  92.1%
##           Yes     10       5      26.3%   7.9%
##
## Talk_Self_Esteem           Chi-squared p-value=0.0119
## #
##           Gender
## Talk_Social_Skills Female Male Prop % by col Female Male
##           No      28      59      73.7%  93.7%
##           Yes     10       4      26.3%   6.3%
##
## Talk_Social_Skills           Chi-squared p-value=0.0049
## #
##           Gender
## Talk_Teasing Female Male Prop % by col Female Male
##           No      23      56      60.5%  88.9%
##           Yes     15       7      39.5%  11.1%
##
## Talk_Teasing           Chi-squared p-value=0.0008
## #
##           Gender
## Talk_To_Someone Female Male Prop % by col Female Male
##           No      23      54      60.5%  85.7%
##           Yes     15       9      39.5%  14.3%
##
## Talk_To_Someone           Chi-squared p-value=0.0040
## #

```

There were significant differences in talking to someone for Teens age group by Gender for all tests.

In each case females were more likely to want to talk to someone than males.

Teens talk to someone By Cleft_Type

Determine if Cleft_Type had a relationship with the Talk variables.

```

##           Cleft_Type
## Talk_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only

```

```

##           No      12      48      29      92.3%  87.3%  87.9%
##           Yes       1       7       4       7.7%  12.7%  12.1%
##
## Talk_Appearance                               Fishers Exact p-value=1.0000
## #
##           Cleft_Type
## Talk_Self_Esteem Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      13      43      30      100.0%  78.2%  90.9%
##           Yes       0      12       3       0.0%   21.8%   9.1%
##
## Talk Self Esteem                               Fishers Exact p-value=0.0746
## #
##           Cleft_Type
## Talk_Social_Skills Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      12      45      30      92.3%  81.8%  90.9%
##           Yes       1      10       3       7.7%  18.2%   9.1%
##
## Talk Social Skills                             Fishers Exact p-value=0.5070
## #
##           Cleft_Type
## Talk_Teasing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      12      39      28      92.3%  70.9%  84.8%
##           Yes       1      16       5       7.7%  29.1%  15.2%
##
## Talk Teasing                                  Fishers Exact p-value=0.1589
## #
##           Cleft_Type
## Talk_To_Someone Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           No      12      37      28      92.3%  67.3%  84.8%
##           Yes       1      18       5       7.7%  32.7%  15.2%
##
## Talk_To_Someone                               Fishers Exact p-value=0.0739
## #

```

There were no significant differences in talking to someone for Teens age group by Cleft_Type.

Adults talk to someone By Gender

Determine if Gender had a relationship with the Talk variables.

```

##           Gender
## Talk_Appearance Female Male Prop % by col Female Male
##           No      47      51      54.0%  71.8%
##           Yes      40      20      46.0%  28.2%
##
## Talk_Appearance                               Chi-squared   p-value=0.0218
## #
##           Gender
## Talk_Self_Esteem Female Male Prop % by col Female Male
##           No      51      47      58.6%  66.2%
##           Yes      36      24      41.4%  33.8%
##
## Talk_Self_Esteem                               Chi-squared   p-value=0.3290
## #
##           Gender
## Talk_Social_Skills Female Male Prop % by col Female Male
##           No      52      49      59.8%  69.0%
##           Yes      35      22      40.2%  31.0%
##
## Talk_Social_Skills                             Chi-squared   p-value=0.2287
## #
##           Gender
## Talk_Teasing Female Male Prop % by col Female Male
##           No      60      51      69.0%  71.8%
##           Yes      27      20      31.0%  28.2%
##
## Talk_Teasing                                  Chi-squared   p-value=0.6951
## #
##           Gender
## Talk_To_Someone Female Male Prop % by col Female Male
##           No      20      18      23.0%  25.4%
##           Yes      67      53      77.0%  74.6%
##
## Talk_To_Someone                               Chi-squared   p-value=0.7295
## #

```

There was one significant difference in talking to someone for Adults age group by Gender for Talk_Appearence.

In this case females were more likely to want to talk to someone about their appearance than males, however the significance was marginal (0.0318).

Adults talk to someone By Cleft_Type

Determine if Cleft_Type had a relationship with the Talk variables.

```
##          Cleft_Type
## Talk_Appearence Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      16      46      36          64.0%   58.2%   66.7%
##          Yes      9      33      18          36.0%   41.8%   33.3%
##
## Talk_Appearence          Chi-squared   p-value=0.6008
## #
##          Cleft_Type
## Talk_Self_Esteem Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      15      47      36          60.0%   59.5%   66.7%
##          Yes      10      32      18          40.0%   40.5%   33.3%
##
## Talk_Self_Esteem          Chi-squared   p-value=0.6865
## #
##          Cleft_Type
## Talk_Social_Skills Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      18      49      34          72.0%   62.0%   63.0%
##          Yes      7      30      20          28.0%   38.0%   37.0%
##
## Talk_Social_Skills          Chi-squared   p-value=0.6531
## #
##          Cleft_Type
## Talk_Teasing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      16      57      38          64.0%   72.2%   70.4%
##          Yes      9      22      16          36.0%   27.8%   29.6%
##
## Talk_Teasing          Chi-squared   p-value=0.7392
## #
##          Cleft_Type
## Talk_To_Someone Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          No      6      14      18          24.0%   17.7%   33.3%
##          Yes      19      65      36          76.0%   82.3%   66.7%
##
## Talk To Someone          Chi-squared   p-value=0.1177
## #
```

There were no significant differences in talking to someone for Adults age group by Cleft_Type.

Pamphlets

Compare the following variables for each age-group by Gender and Cleft_Type:

- Pamphlet_Appearence = Would you have found pamphlets helpful for Appearance? Y or N
- Pamphlet_Self_Esteem = Would you have found pamphlets helpful for Self Esteem? Y or N
- Pamphlet_Social_Skills = Would you have found pamphlets helpful for Socail Skills? Y or N
- Pamphlet_Teasing = Would you have found pamphlets helpful for Teased or Bullied? Y or N

Children Pamphlets By Gender

Determine if Gender had a relationship with the Pamplet variables.

```
##          Gender
## Pamphlet_Appearence Female Male Prop % by col Female Male
##          No      46      43          88.5%   89.6%
##          Yes      6      5          11.5%   10.4%
##
## Pamphlet_Appearence          Chi-squared   p-value=0.8578
## #
##          Gender
## Pamphlet_Self_Esteem Female Male Prop % by col Female Male
##          No      47      37          90.4%   77.1%
##          Yes      5      11          9.6%   22.9%
```

```

##
## Pamphlet_Self_Esteem Chi-squared p-value=0.0699
## #
## Gender
## Pamphlet_Social_Skills Female Male Prop % by col Female Male
## No 48 42 92.3% 87.5%
## Yes 4 6 7.7% 12.5%
##
## Pamphlet_Social_Skills Fishers Exact p-value=0.5141
## #
## Gender
## Pamphlet_Teasing Female Male Prop % by col Female Male
## No 43 39 82.7% 81.2%
## Yes 9 9 17.3% 18.8%
##
## Pamphlet_Teasing Chi-squared p-value=0.8512
## #

```

There were no significant difference in Pamphlets for Children age-group by Gender.

Children Pamphlets By Cleft_Type

Determine if Cleft_Type had a relationship with the Pamphlet variables.

```

## Cleft_Type
## Pamphlet Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 9 30 50 69.2% 88.2% 94.3%
## Yes 4 4 3 30.8% 11.8% 5.7%
##
## Pamphlet Appearance Fishers Exact p-value=0.0440
## #
## Cleft Type
## Pamphlet_Self_Esteem Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 11 30 43 84.6% 88.2% 81.1%
## Yes 2 4 10 15.4% 11.8% 18.9%
##
## Pamphlet_Self_Esteem Fishers Exact p-value=0.8019
## #
## Cleft Type
## Pamphlet_Social_Skills Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 10 31 49 76.9% 91.2% 92.5%
## Yes 3 3 4 23.1% 8.8% 7.5%
##
## Pamphlet Social Skills Fishers Exact p-value=0.2839
## #
## Cleft_Type
## Pamphlet_Teasing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 10 28 44 76.9% 82.4% 83.0%
## Yes 3 6 9 23.1% 17.6% 17.0%
##
## Pamphlet_Teasing Fishers Exact p-value=0.8727
## #

```

There was one significant difference in Pamphlet_Teasing for Children age group by Cleft_Type.

Children participants with a Lip-only cleft type were more likely to request pamphlets, however the significance was marginal (0.0440).

Teens Pamphlets By Gender

Determine if Gender had a relationship with the Pamphlet variables.

```

## Gender
## Pamphlet Appearance Female Male Prop % by col Female Male
## No 30 55 78.9% 87.3%
## Yes 8 8 21.1% 12.7%
##
## Pamphlet Appearance Chi-squared p-value=0.2653
## #
## Gender
## Pamphlet_Self_Esteem Female Male Prop % by col Female Male
## No 29 54 76.3% 85.7%
## Yes 9 9 23.7% 14.3%
##

```



```
## Pamphlet_Self_Esteem Chi-squared p-value=0.2318
## #
## Gender
## Pamphlet_Social_Skills Female Male Prop % by col Female Male
## No 28 58 73.7% 92.1%
## Yes 10 5 26.3% 7.9%
##
## Pamphlet_Social_Skills Chi-squared p-value=0.0119
## #
## Gender
## Pamphlet_Teasing Female Male Prop % by col Female Male
## No 26 44 68.4% 69.8%
## Yes 12 19 31.6% 30.2%
##
## Pamphlet_Teasing Chi-squared p-value=0.8808
## #
```

There was one significant difference in Pamphlet_Social_Skills for Teens age-group by Gender.
Female Teens were more likely to request pamphlets on social skills than males.

Teens Pamphlets By Cleft_Type

Determine if Cleft_Type had a relationship with the Pamphlet variables.

```
## Cleft_Type
## Pamphlet_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 11 45 29 84.6% 81.8% 87.9%
## Yes 2 10 4 15.4% 18.2% 12.1%
##
## Pamphlet Appearance Fishers Exact p-value=0.8606
## #
## Cleft_Type
## Pamphlet_Self_Esteem Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 12 42 29 92.3% 76.4% 87.9%
## Yes 1 13 4 7.7% 23.6% 12.1%
##
## Pamphlet_Self_Esteem Fishers Exact p-value=0.3027
## #
## Cleft_Type
## Pamphlet_Social_Skills Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 12 45 29 92.3% 81.8% 87.9%
## Yes 1 10 4 7.7% 18.2% 12.1%
##
## Pamphlet_Social_Skills Fishers Exact p-value=0.6722
## #
## Cleft_Type
## Pamphlet_Teasing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## No 11 33 26 84.6% 60.0% 78.8%
## Yes 2 22 7 15.4% 40.0% 21.2%
##
## Pamphlet_Teasing Fishers Exact p-value=0.0921
## #
```

There were no significant difference in Pamphlets for Teens age-group by Cleft_Type.

Adults Pamphlets By Gender

Determine if Gender had a relationship with the Pamphlet variables.

```
## Gender
## Pamphlet_Appearance Female Male Prop % by col Female Male
## No 44 47 50.6% 66.2%
## Yes 43 24 49.4% 33.8%
##
## Pamphlet_Appearance Chi-squared p-value=0.0481
## #
## Gender
## Pamphlet_Self_Esteem Female Male Prop % by col Female Male
## No 49 42 56.3% 59.2%
## Yes 38 29 43.7% 40.8%
##
```

```

## Pamphlet_Self_Esteem                      Chi-squared    p-value=0.7200
## #
##                               Gender
## Pamphlet_Social_Skills Female Male Prop % by col Female Male
##                               No    49    44          56.3%  62.0%
##                               Yes   38    27          43.7%  38.0%
##
## Pamphlet_Social_Skills                      Chi-squared    p-value=0.4728
## #
##                               Gender
## Pamphlet_Teasing Female Male Prop % by col Female Male
##                               No    58    47          66.7%  66.2%
##                               Yes   29    24          33.3%  33.8%
##
## Pamphlet_Teasing                          Chi-squared    p-value=0.9504
## #

```

There were no significant difference in Pamphlets for Adults age-group by Gender.

Adults Pamphlets By Cleft_Type

Determine if Cleft_Type had a relationship with the Pamphlet variables.

```

##                               Cleft_Type
## Pamphlet_Appearance Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##                               No    14    44    33          56.0%  55.7%  61.1%
##                               Yes   11    35    21          44.0%  44.3%  38.9%
##
## Pamphlet_Appearance                      Chi-squared    p-value=0.8122
## #
##                               Cleft_Type
## Pamphlet_Self_Esteem Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##                               No    13    45    33          52.0%  57.0%  61.1%
##                               Yes   12    34    21          48.0%  43.0%  38.9%
##
## Pamphlet_Self_Esteem                      Chi-squared    p-value=0.7383
## #
##                               Cleft_Type
## Pamphlet_Social_Skills Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##                               No    15    47    31          60.0%  59.5%  57.4%
##                               Yes   10    32    23          40.0%  40.5%  42.6%
##
## Pamphlet_Social_Skills                      Chi-squared    p-value=0.9639
## #
##                               Cleft_Type
## Pamphlet Teasing Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##                               No    15    55    35          60.0%  69.6%  64.8%
##                               Yes   10    24    19          40.0%  30.4%  35.2%
##
## Pamphlet Teasing                          Chi-squared    p-value=0.6416
## #

```

There were no significant difference in Pamphlets for Adults age-group by Cleft_Type.

Analysis Summary

The following table summarises all of the statistical tests conducted in this analysis.

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Children Sample Bias	Study v PMH By Gender	Chi-squared	0.2051		
Children Sample Bias	Study v PMH By Cleft_Type	Chi-squared	0.0573		
Children Sample Bias	Study v PMH By Residence_Area	Chi-squared	0.1017		
Children Sample Bias	Study v PMH By Age	Chi-squared	0.0000		Significant
Teens Sample Bias	Study v PMH By Gender	Chi-squared	0.1209		
Teens Sample Bias	Study v PMH By Cleft_Type	Chi-squared	0.0000		Significant
Teens Sample Bias	Study v PMH By Residence_Area	Chi-squared	0.7574		
Teens Sample Bias	Study v PMH By Age	Chi-squared	0.0001		Significant
Adults Sample Bias	Study v PMH By Gender	Chi-squared	0.0209		Significant
Adults Sample Bias	Study v PMH By Cleft_Type	Chi-squared	0.2291		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Adults Sample Bias	Study v PMH By Residence_Area	Chi-squared	0.0292		Significant
Adults Sample Bias	Study v PMH By ABS Age Group	Chi-squared	0.8601		
Children Impact By Gender	Impact_Academic	Chi-squared	0.5956		
Children Impact By Gender	Impact_Attitude	Chi-squared	0.1932		
Children Impact By Gender	Impact_Friends_Age	Chi-squared	0.4711		
Children Impact By Gender	Impact_Health	Chi-squared	0.9321		
Children Impact By Gender	Impact_Independence	Fishers Exact	1.0000		
Children Impact By Gender	Impact_Photographed	Chi-squared	0.1932		
Children Impact By Gender	Impact_Public_Speaking	Chi-squared	0.4335		
Children Impact By Gender	Impact_Restriction	Chi-squared	0.1825		
Children Impact By Gender	Impact_School	Chi-squared	0.2400		
Children Impact By Gender	Impact_Sport	Fishers Exact	1.0000		
Children Impact By Cleft_Type	Impact_Academic	Fishers Exact	0.7350		
Children Impact By Cleft_Type	Impact_Attitude	Fishers Exact	0.3846		
Children Impact By Cleft_Type	Impact_Friends_Age	Fishers Exact	0.8019		
Children Impact By Cleft_Type	Impact_Health	Fishers Exact	0.6084		
Children Impact By Cleft_Type	Impact_Independence	Fishers Exact	0.7189		
Children Impact By Cleft_Type	Impact_Photographed	Fishers Exact	0.0013		Significant
Children Impact By Cleft_Type	Impact_Public_Speaking	Fishers Exact	0.8718		
Children Impact By Cleft_Type	Impact_Restriction	Fishers Exact	0.2595		
Children Impact By Cleft_Type	Impact_School	Fishers Exact	0.8757		
Children Impact By Cleft_Type	Impact_Sport	Fishers Exact	0.8968		
Teens Impact By Gender	Impact_Academic	Chi-squared	0.6632		
Teens Impact By Gender	Impact_Attitude	Chi-squared	0.4413		
Teens Impact By Gender	Impact_Friends_Age	Chi-squared	0.7489		
Teens Impact By Gender	Impact_Health	Fishers Exact	0.5272		
Teens Impact By Gender	Impact_Independence	Fishers Exact	1.0000		
Teens Impact By Gender	Impact_Photographed	Chi-squared	0.6586		
Teens Impact By Gender	Impact_Public_Speaking	Chi-squared	0.1726		
Teens Impact By Gender	Impact_Restriction	Fishers Exact	1.0000		
Teens Impact By Gender	Impact_School	Chi-squared	0.2752		
Teens Impact By Gender	Impact_Sport	Chi-squared	0.9378		
Teens Impact By Gender	Impact_Getting_Work	Fishers Exact	0.0703		
Teens Impact By Gender	Impact_Special_Relationships	Chi-squared	0.8555		
Teens Impact By Cleft_Type	Impact_Academic	Fishers Exact	0.2806		
Teens Impact By Cleft_Type	Impact_Attitude	Fishers Exact	0.0147		Significant
Teens Impact By Cleft_Type	Impact_Friends_Age	Fishers Exact	0.0046		Significant
Teens Impact By Cleft_Type	Impact_Health	Fishers Exact	0.1274		
Teens Impact By Cleft_Type	Impact_Independence	Fishers Exact	1.0000		
Teens Impact By Cleft_Type	Impact_Photographed	Fishers Exact	0.0002		Significant
Teens Impact By Cleft_Type	Impact_Public_Speaking	Fishers Exact	0.0010		Significant
Teens Impact By Cleft_Type	Impact_Restriction	Fishers Exact	0.1850		
Teens Impact By Cleft_Type	Impact_School	Fishers Exact	0.0004		Significant
Teens Impact By Cleft_Type	Impact_Sport	Fishers Exact	0.2538		
Teens Impact By Cleft_Type	Impact_Getting_Work	Fishers Exact	0.1850		
Teens Impact By Cleft_Type	Impact_Special_Relationships	Fishers Exact	0.0059		Significant
Adults Impact By Gender	Impact_Academic	Chi-squared	0.0908		
Adults Impact By Gender	Impact_Attitude	Chi-squared	0.1244		
Adults Impact By Gender	Impact_Friends_Age	Chi-squared	0.2104		
Adults Impact By Gender	Impact_Health	Chi-squared	0.1134		
Adults Impact By Gender	Impact_Independence	Chi-squared	0.6349		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Adults Impact By Gender	Impact_Photographed	Chi-squared	0.0436		Significant
Adults Impact By Gender	Impact_Public_Speaking	Chi-squared	0.4702		
Adults Impact By Gender	Impact_Restriction	Chi-squared	0.8370		
Adults Impact By Gender	Impact_School	Chi-squared	0.3956		
Adults Impact By Gender	Impact_Sport	Chi-squared	0.9165		
Adults Impact By Gender	Impact_Getting_Work	Chi-squared	0.9550		
Adults Impact By Gender	Impact_Special_Relationships	Chi-squared	0.0677		
Adults Impact By Cleft_Type	Impact_Academic	Fishers Exact	0.1759		
Adults Impact By Cleft_Type	Impact_Attitude	Fishers Exact	0.4205		
Adults Impact By Cleft_Type	Impact_Friends_Age	Fishers Exact	0.3249		
Adults Impact By Cleft_Type	Impact_Health	Fishers Exact	0.3405		
Adults Impact By Cleft_Type	Impact_Independence	Fishers Exact	0.8980		
Adults Impact By Cleft_Type	Impact_Photographed	Fishers Exact	0.0005		Significant
Adults Impact By Cleft_Type	Impact_Public_Speaking	Fishers Exact	0.7297		
Adults Impact By Cleft_Type	Impact_Restriction	Fishers Exact	0.3509		
Adults Impact By Cleft_Type	Impact_School	Fishers Exact	0.0181		Significant
Adults Impact By Cleft_Type	Impact_Sport	Fishers Exact	0.4652		
Adults Impact By Cleft_Type	Impact_Getting_Work	Fishers Exact	0.1163		
Adults Impact By Cleft_Type	Impact_Special_Relationships	Fishers Exact	0.8041		
Children Imp Phys Attrib By Gender	Imp_Facial_Appearance	Fishers Exact	0.0039		Significant
Children Imp Phys Attrib By Gender	Imp_Teeth_Appearance	Fishers Exact	0.5013		
Children Imp Phys Attrib By Gender	Imp_Speech	Fishers Exact	0.9686		
Children Imp Phys Attrib By Gender	Imp_Hearing	Fishers Exact	0.8793		
Children Imp Phys Attrib By Cleft_Type	Imp_Facial_Appearance	Fishers Exact	0.1643		
Children Imp Phys Attrib By Cleft_Type	Imp_Teeth_Appearance	Fishers Exact	0.5932		
Children Imp Phys Attrib By Cleft_Type	Imp_Speech	Fishers Exact	0.3668		
Children Imp Phys Attrib By Cleft_Type	Imp_Hearing	Fishers Exact	0.3565		
Children Imp Phys Attrib Pairwise	Imp_Facial_Appearance v Imp_Teeth_Appearance	Wilcox Paired	0.0100	0.0299	Significant
Children Imp Phys Attrib Pairwise	Imp_Facial_Appearance v Imp_Speech	Wilcox Paired	0.0029	0.0114	Significant
Children Imp Phys Attrib Pairwise	Imp_Facial_Appearance v Imp_Hearing	Wilcox Paired	0.0000	0.0001	Significant
Children Imp Phys Attrib Pairwise	Imp_Teeth_Appearance v Imp_Speech	Wilcox Paired	0.1628	0.1628	
Children Imp Phys Attrib Pairwise	Imp_Teeth_Appearance v Imp_Hearing	Wilcox Paired	0.0021	0.0103	Significant
Children Imp Phys Attrib Pairwise	Imp_Speech v Imp_Hearing	Wilcox Paired	0.0235	0.0471	Significant
Children Imp Support By Gender	Imp_Support_Parents	Fishers Exact	0.2244		
Children Imp Support By Gender	Imp_Support_Treat_Givers	Fishers Exact	0.1236		
Children Imp Support By Gender	Imp_Support_Siblings	Fishers Exact	0.0815		
Children Imp Support By Gender	Imp_Support_Teacher	Fishers Exact	0.5827		
Children Imp Support By Cleft_Type	Imp_Support_Parents	Fishers Exact	0.4328		
Children Imp Support By Cleft_Type	Imp_Support_Treat_Givers	Fishers Exact	0.5572		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Children Imp Support By Cleft_Type	Imp_Support_Siblings	Fishers Exact	0.3675		
Children Imp Support By Cleft_Type	Imp_Support_Teacher	Fishers Exact	0.0212		Significant
Children Imp Support Pairwise	Imp_Support_Siblings v Imp_Support_Teacher	Wilcox Paired	0.4092	0.4092	
Children Imp Support Pairwise	Imp_Support_Siblings v Imp_Support_Treat_Givers	Wilcox Paired	0.0002	0.0010	Significant
Children Imp Support Pairwise	Imp_Support_Siblings v Imp_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Children Imp Support Pairwise	Imp_Support_Teacher v Imp_Support_Treat_Givers	Wilcox Paired	0.0010	0.0031	Significant
Children Imp Support Pairwise	Imp_Support_Teacher v Imp_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Children Imp Support Pairwise	Imp_Support_Treat_Givers v Imp_Support_Parents	Wilcox Paired	0.0040	0.0080	Significant
Teens Imp Phys Attrib By Gender	Imp_Facial_Appearance	Fishers Exact	0.0725		
Teens Imp Phys Attrib By Gender	Imp_Teeth_Appearance	Fishers Exact	0.0025		Significant
Teens Imp Phys Attrib By Gender	Imp_Speech	Fishers Exact	0.3747		
Teens Imp Phys Attrib By Gender	Imp_Hearing	Fishers Exact	0.8532		
Teens Imp Phys Attrib By Cleft_Type	Imp_Facial_Appearance	Fishers Exact	0.1344		
Teens Imp Phys Attrib By Cleft_Type	Imp_Teeth_Appearance	Fishers Exact	0.3403		
Teens Imp Phys Attrib By Cleft_Type	Imp_Speech	Fishers Exact	0.8813		
Teens Imp Phys Attrib By Cleft_Type	Imp_Hearing	Fishers Exact	0.6259		
Teens Imp Phys Attrib Pairwise	Imp_Facial_Appearance v Imp_Teeth_Appearance	Wilcox Paired	0.0005	0.0031	Significant
Teens Imp Phys Attrib Pairwise	Imp_Facial_Appearance v Imp_Speech	Wilcox Paired	0.0121	0.0604	
Teens Imp Phys Attrib Pairwise	Imp_Facial_Appearance v Imp_Hearing	Wilcox Paired	0.0744	0.2976	
Teens Imp Phys Attrib Pairwise	Imp_Teeth_Appearance v Imp_Speech	Wilcox Paired	0.8939	1.0000	
Teens Imp Phys Attrib Pairwise	Imp_Teeth_Appearance v Imp_Hearing	Wilcox Paired	0.7357	1.0000	
Teens Imp Phys Attrib Pairwise	Imp_Speech v Imp_Hearing	Wilcox Paired	0.5200	1.0000	
Teens Imp Support By Gender	Imp_Support_Parents	Fishers Exact	0.4986		
Teens Imp Support By Gender	Imp_Support_Treat_Givers	Fishers Exact	0.1704		
Teens Imp Support By Gender	Imp_Support_Siblings	Fishers Exact	0.9518		
Teens Imp Support By Gender	Imp_Support_Teacher	Fishers Exact	0.7176		
Teens Imp Support By Cleft_Type	Imp_Support_Parents	Fishers Exact	0.7778		
Teens Imp Support By Cleft_Type	Imp_Support_Treat_Givers	Fishers Exact	0.4922		
Teens Imp Support By Cleft_Type	Imp_Support_Siblings	Fishers Exact	0.6775		
Teens Imp Support By Cleft_Type	Imp_Support_Teacher	Fishers Exact	0.2918		
Teens Imp Support Pairwise	Imp_Support_Siblings v Imp_Support_Teacher	Wilcox Paired	0.0010	0.0029	Significant

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Teens Imp Support Pairwise	Imp_Support_Siblings v Imp_Support_Treat_Givers	Wilcox Paired	0.0032	0.0065	Significant
Teens Imp Support Pairwise	Imp_Support_Siblings v Imp_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Teens Imp Support Pairwise	Imp_Support_Teacher v Imp_Support_Treat_Givers	Wilcox Paired	0.0000	0.0000	Significant
Teens Imp Support Pairwise	Imp_Support_Teacher v Imp_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Teens Imp Support Pairwise	Imp_Support_Treat_Givers v Imp_Support_Parents	Wilcox Paired	0.0046	0.0065	Significant
Adults Imp Phys Attrib By Gender	Imp_Facial_Appearance	Fishers Exact	0.0218		Significant
Adults Imp Phys Attrib By Gender	Imp_Teeth_Appearance	Fishers Exact	0.0076		Significant
Adults Imp Phys Attrib By Gender	Imp_Speech	Fishers Exact	0.3742		
Adults Imp Phys Attrib By Gender	Imp_Hearing	Fishers Exact	0.1326		
Adults Imp Phys Attrib By Cleft_Type	Imp_Facial_Appearance	Fishers Exact	0.4828		
Adults Imp Phys Attrib By Cleft_Type	Imp_Teeth_Appearance	Fishers Exact	0.7714		
Adults Imp Phys Attrib By Cleft_Type	Imp_Speech	Fishers Exact	0.1481		
Adults Imp Phys Attrib By Cleft_Type	Imp_Hearing	Fishers Exact	0.8468		
Adults Imp Phys Attrib Pairwise	Imp_Facial_Appearance v Imp_Teeth_Appearance	Wilcox Paired	0.0295	0.0589	
Adults Imp Phys Attrib Pairwise	Imp_Facial_Appearance v Imp_Speech	Wilcox Paired	0.0000	0.0000	Significant
Adults Imp Phys Attrib Pairwise	Imp_Facial_Appearance v Imp_Hearing	Wilcox Paired	0.0006	0.0031	Significant
Adults Imp Phys Attrib Pairwise	Imp_Teeth_Appearance v Imp_Speech	Wilcox Paired	0.0007	0.0031	Significant
Adults Imp Phys Attrib Pairwise	Imp_Teeth_Appearance v Imp_Hearing	Wilcox Paired	0.0129	0.0388	Significant
Adults Imp Phys Attrib Pairwise	Imp_Speech v Imp_Hearing	Wilcox Paired	0.3148	0.3148	
Adults Imp Support By Gender	Imp_Support_Parents	Fishers Exact	0.0233		Significant
Adults Imp Support By Gender	Imp_Support_Treat_Givers	Fishers Exact	0.0849		
Adults Imp Support By Gender	Imp_Support_Siblings	Fishers Exact	0.0990		
Adults Imp Support By Gender	Imp_Support_Teacher	Fishers Exact	0.2629		
Adults Imp Support By Cleft_Type	Imp_Support_Parents	Fishers Exact	0.2827		
Adults Imp Support By Cleft_Type	Imp_Support_Treat_Givers	Fishers Exact	0.7778		
Adults Imp Support By Cleft_Type	Imp_Support_Siblings	Fishers Exact	0.9728		
Adults Imp Support By Cleft_Type	Imp_Support_Teacher	Fishers Exact	0.0614		
Adults Imp Support Pairwise	Imp_Support_Siblings v Imp_Support_Employer	Wilcox Paired	0.0000	0.0000	Significant
Adults Imp Support Pairwise	Imp_Support_Siblings v Imp_Support_Treat_Givers	Wilcox Paired	0.0204	0.0204	Significant
Adults Imp Support Pairwise	Imp_Support_Siblings v Imp_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Adults Imp Support Pairwise	Imp_Support_Employer v Imp_Support_Treat_Givers	Wilcox Paired	0.0000	0.0000	Significant

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Adults Imp Support Pairwise	Imp_Support_Employer v Imp_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Adults Imp Support Pairwise	Imp_Support_Treat_Givers v Imp_Support_Parents	Wilcox Paired	0.0005	0.0010	Significant
Children Sat Phys Attrib By Gender	Sat_Facial_Appearance	Fishers Exact	0.5450		
Children Sat Phys Attrib By Gender	Sat_Teeth_Appearance	Fishers Exact	0.2406		
Children Sat Phys Attrib By Gender	Sat_Speech	Fishers Exact	0.9736		
Children Sat Phys Attrib By Gender	Sat_Hearing	Fishers Exact	0.5228		
Children Sat Phys Attrib By Cleft_Type	Sat_Facial_Appearance	Fishers Exact	0.0500		Significant
Children Sat Phys Attrib By Cleft_Type	Sat_Teeth_Appearance	Fishers Exact	0.0200		Significant
Children Sat Phys Attrib By Cleft_Type	Sat_Speech	Fishers Exact	0.2866		
Children Sat Phys Attrib By Cleft_Type	Sat_Hearing	Fishers Exact	0.6132		
Children Sat Phys Attrib Pairwise	Sat_Facial_Appearance v Sat_Teeth_Appearance	Wilcox Paired	0.0091	0.0548	
Children Sat Phys Attrib Pairwise	Sat_Facial_Appearance v Sat_Speech	Wilcox Paired	0.2318	0.5885	
Children Sat Phys Attrib Pairwise	Sat_Facial_Appearance v Sat_Hearing	Wilcox Paired	0.9267	0.9267	
Children Sat Phys Attrib Pairwise	Sat_Teeth_Appearance v Sat_Speech	Wilcox Paired	0.1486	0.5885	
Children Sat Phys Attrib Pairwise	Sat_Teeth_Appearance v Sat_Hearing	Wilcox Paired	0.0294	0.1468	
Children Sat Phys Attrib Pairwise	Sat_Speech v Sat_Hearing	Wilcox Paired	0.1471	0.5885	
Children Sat Support By Gender	Sat_Support_Parents	Fishers Exact	0.2058		
Children Sat Support By Gender	Sat_Support_Treat_Givers	Fishers Exact	0.2782		
Children Sat Support By Gender	Sat_Support_Siblings	Fishers Exact	0.1863		
Children Sat Support By Gender	Sat_Support_Teacher	Fishers Exact	0.0548		
Children Sat Support By Cleft_Type	Sat_Support_Parents	Fishers Exact	0.1164		
Children Sat Support By Cleft_Type	Sat_Support_Treat_Givers	Fishers Exact	0.4048		
Children Sat Support By Cleft_Type	Sat_Support_Siblings	Fishers Exact	0.2128		
Children Sat Support By Cleft_Type	Sat_Support_Teacher	Fishers Exact	0.2079		
Children Sat Support Pairwise	Sat_Support_Siblings v Sat_Support_Teacher	Wilcox Paired	0.8714	0.8714	
Children Sat Support Pairwise	Sat_Support_Siblings v Sat_Support_Treat_Givers	Wilcox Paired	0.0000	0.0000	Significant
Children Sat Support Pairwise	Sat_Support_Siblings v Sat_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Children Sat Support Pairwise	Sat_Support_Teacher v Sat_Support_Treat_Givers	Wilcox Paired	0.0000	0.0000	Significant
Children Sat Support Pairwise	Sat_Support_Teacher v Sat_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Children Sat Support Pairwise	Sat_Support_Treat_Givers v Sat_Support_Parents	Wilcox Paired	0.0995	0.1990	
Teens Sat Phys Attrib By Gender	Sat_Facial_Appearance	Fishers Exact	0.2762		
Teens Sat Phys Attrib By Gender	Sat_Teeth_Appearance	Fishers Exact	0.3487		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Teens Sat Phys Attrib By Gender	Sat_Speech	Fishers Exact	0.0164		Significant
Teens Sat Phys Attrib By Gender	Sat_Hearing	Fishers Exact	0.0307		Significant
Teens Sat Phys Attrib By Cleft_Type	Sat_Facial_Appearance	Fishers Exact	0.0122		Significant
Teens Sat Phys Attrib By Cleft_Type	Sat_Teeth_Appearance	Fishers Exact	0.0189		Significant
Teens Sat Phys Attrib By Cleft_Type	Sat_Speech	Fishers Exact	0.0108		Significant
Teens Sat Phys Attrib By Cleft_Type	Sat_Hearing	Fishers Exact	0.0545		
Teens Sat Phys Attrib Pairwise	Sat_Facial_Appearance v Sat_Teeth_Appearance	Wilcox Paired	0.7446	0.9967	
Teens Sat Phys Attrib Pairwise	Sat_Facial_Appearance v Sat_Speech	Wilcox Paired	0.4984	0.9967	
Teens Sat Phys Attrib Pairwise	Sat_Facial_Appearance v Sat_Hearing	Wilcox Paired	0.1232	0.6162	
Teens Sat Phys Attrib Pairwise	Sat_Teeth_Appearance v Sat_Speech	Wilcox Paired	0.2479	0.7438	
Teens Sat Phys Attrib Pairwise	Sat_Teeth_Appearance v Sat_Hearing	Wilcox Paired	0.1844	0.7377	
Teens Sat Phys Attrib Pairwise	Sat_Speech v Sat_Hearing	Wilcox Paired	0.0071	0.0426	Significant
Teens Sat Support By Gender	Sat_Support_Parents	Fishers Exact	0.1485		
Teens Sat Support By Gender	Sat_Support_Treat_Givers	Fishers Exact	0.0169		Significant
Teens Sat Support By Gender	Sat_Support_Siblings	Fishers Exact	0.2944		
Teens Sat Support By Gender	Sat_Support_Teacher	Fishers Exact	0.1085		
Teens Sat Support By Cleft_Type	Sat_Support_Parents	Fishers Exact	0.8804		
Teens Sat Support By Cleft_Type	Sat_Support_Treat_Givers	Fishers Exact	0.3953		
Teens Sat Support By Cleft_Type	Sat_Support_Siblings	Fishers Exact	0.5508		
Teens Sat Support By Cleft_Type	Sat_Support_Teacher	Fishers Exact	0.5325		
Teens Sat Support Pairwise	Sat_Support_Siblings v Sat_Support_Teacher	Wilcox Paired	0.0000	0.0000	Significant
Teens Sat Support Pairwise	Sat_Support_Siblings v Sat_Support_Treat_Givers	Wilcox Paired	0.0000	0.0000	Significant
Teens Sat Support Pairwise	Sat_Support_Siblings v Sat_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Teens Sat Support Pairwise	Sat_Support_Teacher v Sat_Support_Treat_Givers	Wilcox Paired	0.0000	0.0000	Significant
Teens Sat Support Pairwise	Sat_Support_Teacher v Sat_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Teens Sat Support Pairwise	Sat_Support_Treat_Givers v Sat_Support_Parents	Wilcox Paired	0.1638	0.1638	
Adults Sat Phys Attrib By Gender	Sat_Facial_Appearance	Fishers Exact	0.4978		
Adults Sat Phys Attrib By Gender	Sat_Teeth_Appearance	Fishers Exact	0.4625		
Adults Sat Phys Attrib By Gender	Sat_Speech	Fishers Exact	0.0278		Significant
Adults Sat Phys Attrib By Gender	Sat_Hearing	Fishers Exact	0.3982		
Adults Sat Phys Attrib By Cleft_Type	Sat_Facial_Appearance	Fishers Exact	0.9114		
Adults Sat Phys Attrib By Cleft_Type	Sat_Teeth_Appearance	Fishers Exact	0.3912		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Adults Sat Phys Attrib By Cleft_Type	Sat_Speech	Fishers Exact	0.0015		Significant
Adults Sat Phys Attrib By Cleft_Type	Sat_Hearing	Fishers Exact	0.9675		
Adults Sat Phys Attrib Pairwise	Sat_Facial_Appearance v Sat_Teeth_Appearance	Wilcox Paired	0.0016	0.0078	Significant
Adults Sat Phys Attrib Pairwise	Sat_Facial_Appearance v Sat_Speech	Wilcox Paired	0.0020	0.0082	Significant
Adults Sat Phys Attrib Pairwise	Sat_Facial_Appearance v Sat_Hearing	Wilcox Paired	0.0000	0.0001	Significant
Adults Sat Phys Attrib Pairwise	Sat_Teeth_Appearance v Sat_Speech	Wilcox Paired	0.6546	0.6546	
Adults Sat Phys Attrib Pairwise	Sat_Teeth_Appearance v Sat_Hearing	Wilcox Paired	0.0534	0.1602	
Adults Sat Phys Attrib Pairwise	Sat_Speech v Sat_Hearing	Wilcox Paired	0.0631	0.1602	
Adults Sat Support By Gender	Sat_Support_Parents	Fishers Exact	0.3706		
Adults Sat Support By Gender	Sat_Support_Treat_Givers	Fishers Exact	0.0479		Significant
Adults Sat Support By Gender	Sat_Support_Siblings	Fishers Exact	0.6174		
Adults Sat Support By Gender	Sat_Support_Employer	Fishers Exact	0.0046		Significant
Adults Sat Support By Cleft_Type	Sat_Support_Parents	Fishers Exact	0.9943		
Adults Sat Support By Cleft_Type	Sat_Support_Treat_Givers	Fishers Exact	0.7815		
Adults Sat Support By Cleft_Type	Sat_Support_Siblings	Fishers Exact	0.5884		
Adults Sat Support By Cleft_Type	Sat_Support_Employer	Fishers Exact	0.1634		
Adults Sat Support Pairwise	Sat_Support_Siblings v Sat_Support_Employer	Wilcox Paired	0.0016	0.0038	Significant
Adults Sat Support Pairwise	Sat_Support_Siblings v Sat_Support_Treat_Givers	Wilcox Paired	0.0034	0.0038	Significant
Adults Sat Support Pairwise	Sat_Support_Siblings v Sat_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Adults Sat Support Pairwise	Sat_Support_Employer v Sat_Support_Treat_Givers	Wilcox Paired	0.0000	0.0000	Significant
Adults Sat Support Pairwise	Sat_Support_Employer v Sat_Support_Parents	Wilcox Paired	0.0000	0.0000	Significant
Adults Sat Support Pairwise	Sat_Support_Treat_Givers v Sat_Support_Parents	Wilcox Paired	0.0013	0.0038	Significant
All Age Teased/Bullied By Gender	Male vs Female	Kolmg-Smirnov	0.2369		
All Age Teased/Bullied By Cleft_Type	Lip & Palate v Lip-only	Kolmg-Smirnov	0.0054		Significant
All Age Teased/Bullied By Cleft_Type	Lip & Palate v Palate-only	Kolmg-Smirnov	0.0234		Significant
All Age Teased/Bullied By Cleft_Type	Lip-only v Palate-only	Kolmg-Smirnov	0.3688		
Adults Teased/Bullied	Teased_Bullied By Gender	Chi-squared	0.2970		
Adults Teased/Bullied	Bullied_Others By Gender	Chi-squared	0.5882		
Adults Teased/Bullied	Teased_Bullied By Cleft_Type	Chi-squared	0.0000		Significant
Adults Teased/Bullied	RR Teased_Bullied Lip & Palate v Remainder	Relative Risk	0.0000		Significant
Adults Teased/Bullied	Bullied_Others By Cleft_Type	Fishers Exact	0.4300		
Adults Teased/Bullied	Teased_Bullied and Bullied_Others	Chi-squared	0.0282		Significant
Adults Teased/Bullied	RR Teased_Bullied and Bullied_Others	Relative Risk	0.0411		Significant
Children Teased_Bullied v Sat Phys Attrib	Sat_Speech	Fishers Exact	0.0373		Significant

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Children Teased_Bullied v Sat Phys Attrib	Sat_Hearing	Fishers Exact	0.1712		
Children Teased_Bullied v Sat Phys Attrib	Sat_Facial_Appearance	Fishers Exact	0.0033		Significant
Children Teased_Bullied v Sat Phys Attrib	Sat_Teeth_Appearance	Fishers Exact	0.0013		Significant
Teens Teased_Bullied v Sat Phys Attrib	Teased_Bullied v Sat_Speech	Fishers Exact	0.0018		Significant
Teens Teased_Bullied v Sat Phys Attrib	Teased_Bullied v Sat_Hearing	Fishers Exact	0.0048		Significant
Teens Teased_Bullied v Sat Phys Attrib	Teased_Bullied v Sat_Facial_Appearance	Fishers Exact	0.0525		
Teens Teased_Bullied v Sat Phys Attrib	Teased_Bullied v Sat_Teeth_Appearance	Fishers Exact	0.1640		
Adults Teased_Bullied v Sat Phys Attrib			0.0000		Significant
Children Tease or Bullied Rel Risk	RR Teased_Bullied v Speech Satisfaction	Relative Risk	0.0213		Significant
Teens Tease or Bullied Rel Risk	RR Teased_Bullied v Speech Satisfaction	Relative Risk	0.0006		Significant
Adults Tease or Bullied Rel Risk	RR Teased_Bullied v Speech Satisfaction	Relative Risk	0.3135		
Teens Treatment By Gender	Treat_Best_Part	Fishers Exact	0.6883		
Teens Treatment By Gender	Treat_Worst_Part	Fishers Exact	0.8396		
Teens Treatment By Gender	Treat_Prepared	Fishers Exact	0.2889		
Teens Treatment By Gender	Treat_Own_Decisions	Fishers Exact	0.5861		
Teens Treatment By Cleft_Type	Teens Treat_Best_Part	Fishers Exact	0.5221		
Teens Treatment By Cleft_Type	Teens Treat_Worst_Part	Fishers Exact	0.3808		
Teens Treatment By Cleft_Type	Teens Treat_Prepared	Fishers Exact	0.5317		
Teens Treatment By Cleft_Type	Teens Treat_Own_Decisions	Fishers Exact	1.0000		
Adults Treatment By Gender	Treat_Best_Part	Chi-squared	0.2873		
Adults Treatment By Gender	Treat_Worst_Part	Fishers Exact	0.4869		
Adults Treatment By Gender	Treat_Prepared	Chi-squared	0.8203		
Adults Treatment By Gender	Treat_Own_Decisions	Chi-squared	0.0922		
Adults Treatment By Cleft_Type	Treat_Best_Part	Fishers Exact	0.1736		
Adults Treatment By Cleft_Type	Treat_Worst_Part	Fishers Exact	0.3190		
Adults Treatment By Cleft_Type	Treat_Prepared	Fishers Exact	0.4100		
Adults Treatment By Cleft_Type	Treat_Own_Decisions	Chi-squared	0.4581		
Treatment for Teens vs Adults	Treat_Prepared	Chi-squared	0.0108		Significant
Treatment for Teens vs Adults	RR Treat_Prepared	Relative Risk	0.0112		Significant
Treatment for Teens vs Adults	Treat_Own_Decisions	Chi-squared	0.0000		Significant
Treatment for Teens vs Adults	RR Treat_Own_Decisions	Relative Risk	0.0000		Significant
Children Fears By Gender	Fear_Of_Anaesthetic	Chi-squared	0.2858		
Children Fears By Gender	Fear_Of_Dentist	Chi-squared	0.5365		
Children Fears By Gender	Chew_Properly	Chi-squared	0.2949		
Children Fears By Gender	Happy_With_Smile	Chi-squared	0.5209		
Children Fears By Cleft_Type	Fear_Of_Anaesthetic	Chi-squared	0.5989		
Children Fears By Cleft_Type	Fear_Of_Dentist	Fishers Exact	0.7575		
Children Fears By Cleft_Type	Chew_Properly	Fishers Exact	0.1576		
Children Fears By Cleft_Type	Happy_With_Smile	Fishers Exact	0.0405		Significant
Children Fears By Cleft_Type	RR Happy_With_Smile Palate-only v Remainder	Relative Risk	0.0441		Significant
Teens Fears By Gender	Fear_Of_Anaesthetic	Chi-squared	0.5102		
Teens Fears By Gender	Fear_Of_Dentist	Chi-squared	0.4025		
Teens Fears By Gender	Chew_Properly	Chi-squared	0.5814		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Teens Fears By Gender	Happy_With_Smile	Chi-squared	0.7328		
Teens Fears By Cleft_Type	Fear_Of_Anaesthetic	Chi-squared	0.3846		
Teens Fears By Cleft_Type	Fear_Of_Dentist	Fishers Exact	0.4525		
Teens Fears By Cleft_Type	Chew_Properly	Fishers Exact	0.2172		
Teens Fears By Cleft_Type	Happy_With_Smile	Chi-squared	0.0284		Significant
Teens Fears By Cleft_Type	RR Happy_With_Smile Palate-only v Remainder	Relative Risk	0.0341		Significant
Adults Fears By Gender	Fear_Of_Anaesthetic	Chi-squared	0.0471		Significant
Adults Fears By Gender	Fear_Of_Dentist	Chi-squared	0.9352		
Adults Fears By Gender	Chew_Properly	Fishers Exact	0.6914		
Adults Fears By Gender	Happy_With_Smile	Chi-squared	0.8720		
Adults Fears By Cleft_Type	Fear_Of_Anaesthetic	Fishers Exact	0.2234		
Adults Fears By Cleft_Type	Fear_Of_Dentist	Chi-squared	0.0611		
Adults Fears By Cleft_Type	Chew_Properly	Fishers Exact	0.2014		
Adults Fears By Cleft_Type	Happy_With_Smile	Chi-squared	0.8991		
Children Talk By Gender	Talk_Appearance By Gender	Fishers Exact	1.0000		
Children Talk By Gender	Talk_Self_Esteem By Gender	Fishers Exact	0.1486		
Children Talk By Gender	Talk_Social_Skills By Gender	Fishers Exact	0.7075		
Children Talk By Gender	Talk_Teasing By Gender	Fishers Exact	0.4754		
Children Talk By Gender	Talk_To_Someone By Gender	Fishers Exact	0.3771		
Children Talk By Cleft_Type	Talk_Appearance	Fishers Exact	0.0350		Significant
Children Talk By Cleft_Type	Talk_Self_Esteem	Fishers Exact	0.2726		
Children Talk By Cleft_Type	Talk_Social_Skills	Fishers Exact	0.0996		
Children Talk By Cleft_Type	Talk_Teasing	Fishers Exact	0.3859		
Children Talk By Cleft_Type	Talk_To_Someone	Fishers Exact	0.5348		
Teens Talk By Gender	Talk_Appearance	Fishers Exact	0.0085		Significant
Teens Talk By Gender	Talk_Self_Esteem	Chi-squared	0.0119		Significant
Teens Talk By Gender	Talk_Social_Skills	Chi-squared	0.0049		Significant
Teens Talk By Gender	Talk_Teasing	Chi-squared	0.0008		Significant
Teens Talk By Gender	Talk_To_Someone	Chi-squared	0.0040		Significant
Teens Talk By Cleft_Type	Talk_Appearance	Fishers Exact	1.0000		
Teens Talk By Cleft_Type	Talk_Self_Esteem	Fishers Exact	0.0746		
Teens Talk By Cleft_Type	Talk_Social_Skills	Fishers Exact	0.5070		
Teens Talk By Cleft_Type	Talk_Teasing	Fishers Exact	0.1589		
Teens Talk By Cleft_Type	Talk_To_Someone	Fishers Exact	0.0739		
Adults Talk By Gender	Talk_Appearance	Chi-squared	0.0218		Significant
Adults Talk By Gender	Talk_Self_Esteem	Chi-squared	0.3290		
Adults Talk By Gender	Talk_Social_Skills	Chi-squared	0.2287		
Adults Talk By Gender	Talk_Teasing	Chi-squared	0.6951		
Adults Talk By Gender	Talk_To_Someone	Chi-squared	0.7295		
Adults Talk By Cleft_Type	Talk_Appearance	Chi-squared	0.6008		
Adults Talk By Cleft_Type	Talk_Self_Esteem	Chi-squared	0.6865		
Adults Talk By Cleft_Type	Talk_Social_Skills	Chi-squared	0.6531		
Adults Talk By Cleft_Type	Talk_Teasing	Chi-squared	0.7392		
Adults Talk By Cleft_Type	Talk_To_Someone	Chi-squared	0.1177		
Children Pamphlets By Gender	Pamphlet_Appearance	Chi-squared	0.8578		
Children Pamphlets By Gender	Pamphlet_Self_Esteem	Chi-squared	0.0699		
Children Pamphlets By Gender	Pamphlet_Social_Skills	Fishers Exact	0.5141		
Children Pamphlets By Gender	Pamphlet_Teasing	Chi-squared	0.8512		
Children Pamphlets	Pamphlet_Appearance	Fishers Exact	0.0440		Significant
Children Pamphlets	Pamphlet_Self_Esteem	Fishers Exact	0.8019		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Children Pamphlets	Pamphlet_Social_Skills	Fishers Exact	0.2839		
Children Pamphlets	Pamphlet_Teasing	Fishers Exact	0.8727		
Teens Pamphlets By Gender	Pamphlet_Appearance	Chi-squared	0.2653		
Teens Pamphlets By Gender	Pamphlet_Self_Esteem	Chi-squared	0.2318		
Teens Pamphlets By Gender	Pamphlet_Social_Skills	Chi-squared	0.0119		Significant
Teens Pamphlets By Gender	Pamphlet_Teasing	Chi-squared	0.8808		
Teens Pamphlets By Cleft_Type	Pamphlet_Appearance	Fishers Exact	0.8606		
Teens Pamphlets By Cleft_Type	Pamphlet_Self_Esteem	Fishers Exact	0.3027		
Teens Pamphlets By Cleft_Type	Pamphlet_Social_Skills	Fishers Exact	0.6722		
Teens Pamphlets By Cleft_Type	Pamphlet_Teasing	Fishers Exact	0.0921		
Adults Pamphlets By Gender	Pamphlet_Appearance	Chi-squared	0.0481		Significant
Adults Pamphlets By Gender	Pamphlet_Self_Esteem	Chi-squared	0.7200		
Adults Pamphlets By Gender	Pamphlet_Social_Skills	Chi-squared	0.4728		
Adults Pamphlets By Gender	Pamphlet_Teasing	Chi-squared	0.9504		
Adults Pamphlets By Cleft_Type	Pamphlet_Appearance	Chi-squared	0.8122		
Adults Pamphlets By Cleft_Type	Pamphlet_Self_Esteem	Chi-squared	0.7383		
Adults Pamphlets By Cleft_Type	Pamphlet_Social_Skills	Chi-squared	0.9639		
Adults Pamphlets By Cleft_Type	Pamphlet_Teasing	Chi-squared	0.6416		

Data Analysis for Chapter 6 Paper 3. Adult specific life outcomes of cleft lip and palate in a Western Australian cohort.

Background

Three age-appropriate versions of the Cleft Research Questionnaire (CRQ) were developed to capture psychosocial impacts of cleft amongst current and former patients across three age-groups: Children, Adolescents and Adults. Many of the questions were the same for all three versions of the CRQ, however the Adults version contained additional questions regarding occupation, annual income, highest education level attained, living arrangements, relationships, psychosocial issues and health lifestyle choices. The purpose of this document was to conduct an analysis of these adult specific questions to identify similarities and differences by Gender, Cleft Type, Area of Residence and Age Group. This was primarily done using hypothesis tests.

For count data, the Chi-squared hypothesis test for independence of variables was unreliable (i.e. cells had expected values < 5) hence Fisher's Exact test was used. The Wilcoxon signed rank test was used to check for a significant difference in location (median). In some cases where a significant difference was found, the Odds Ratio and the Relative Risk were calculated.

Notes:

Alpha level of 0.05 (i.e. 95% Confidence Level) was used for all hypothesis tests.

This analysis was developed with R version: 3.4.1 and RStudio version: 1.0.143 using RMarkdown version:1.6.

Age Distribution Study v ABS WA 2014

Compare counts for each age in years for this study against ABS population counts for Western Australia in 2014.

```
##      Age Distribution Females Study v ABS
## Age  Study ABS      Prop % by col Study  ABS
##  22    10 17277          11.5%    4.4%
##  23     6 18501           6.9%    4.7%
##  24     3 19492           3.4%    5.0%
##  25     7 20055           8.0%    5.1%
##  26     6 20113           6.9%    5.1%
##  27     1 20485           1.1%    5.2%
##  28     6 20614           6.9%    5.2%
##  29     5 20454           5.7%    5.2%
##  30     5 20185           5.7%    5.1%
##  31     4 19887           4.6%    5.1%
##  32     4 19244           4.6%    4.9%
##  33     1 18673           1.1%    4.7%
##  34     4 18112           4.6%    4.6%
##  35     4 17860           4.6%    4.5%
##  36     3 17168           3.4%    4.4%
##  37     3 17095           3.4%    4.3%
##  38     2 17190           2.3%    4.4%
##  39     4 17315           4.6%    4.4%
##  40     2 17427           2.3%    4.4%
##  41     3 17696           3.4%    4.5%
##  42     4 18773           4.6%    4.8%
##
## By Gender Females                               Fishers Exact p-value=0.4738
## #
##      Age Distribution Males Study v ABS
## Age  Study ABS      Prop % by col Study  ABS
##  22     6 18503           8.5%    4.4%
```

```

##      23      2 19701      2.8%  4.7%
##      24      2 21071      2.8%  5.0%
##      25      1 21366      1.4%  5.1%
##      26      8 21776     11.3%  5.2%
##      27      4 22258      5.6%  5.3%
##      28      4 22612      5.6%  5.4%
##      29      6 22376      8.5%  5.3%
##      30      5 21855      7.0%  5.2%
##      31      3 21777      4.2%  5.2%
##      32      2 20883      2.8%  5.0%
##      33      4 20049      5.6%  4.8%
##      34      1 19189      1.4%  4.6%
##      35      3 18692      4.2%  4.5%
##      36      4 18163      5.6%  4.3%
##      37      3 17647      4.2%  4.2%
##      38      2 17914      2.8%  4.3%
##      39      1 17876      1.4%  4.3%
##      40      3 17788      4.2%  4.2%
##      41      3 18599      4.2%  4.4%
##      42      4 19586      5.6%  4.7%
##
## By Gender Males                               Fishers Exact p-value=0.7191
## #
##      Age Distribution All Study v ABS
## Age  Study ABS  Prop % by col Study  ABS
## 22    16 35780     10.1%  4.4%
## 23     8 38202      5.1%  4.7%
## 24     5 40563      3.2%  5.0%
## 25     8 41421      5.1%  5.1%
## 26    14 41889      8.9%  5.2%
## 27     5 42743      3.2%  5.3%
## 28    10 43226      6.3%  5.3%
## 29    11 42830      7.0%  5.3%
## 30    10 42040      6.3%  5.2%
## 31     7 41664      4.4%  5.1%
## 32     6 40127      3.8%  4.9%
## 33     5 38722      3.2%  4.8%
## 34     5 37301      3.2%  4.6%
## 35     7 36552      4.4%  4.5%
## 36     7 35331      4.4%  4.3%
## 37     6 34742      3.8%  4.3%
## 38     4 35104      2.5%  4.3%
## 39     5 35191      3.2%  4.3%
## 40     5 35215      3.2%  4.3%
## 41     6 36295      3.8%  4.5%
## 42     8 38359      5.1%  4.7%
##
## By Gender All                               Fishers Exact p-value=0.3808
## #

```

There were no significant differences for Age Distribution between Study and ABS Western Australian population in 2014.

Sample Bias

Study v PMH Data

Check for study sample bias by comparing study data against PMH data for Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```

##      Sample Bias Study v PMH
## Gender  Study PMH  Prop % by col Study  PMH
## Female    87   362     55.1%  45.0%
## Male     71   443     44.9%  55.0%
##

```

```

## By Gender                                Fishers Exact p-value=0.0232
## #
##           Sample Bias Study v PMH
## Cleft_Type Study PMH Prop % by col Study PMH
## Lip-only   25  162           15.8% 20.1%
## Lip & Palate 79  347           50.0% 43.1%
## Palate-only 54  296           34.2% 36.8%
##
## By Cleft_Type                            Fishers Exact p-value=0.2474
## #
##           Sample Bias Study v PMH
## Residence_Area Study PMH Prop % by col Study PMH
## Perth Metro 125  569           79.1% 70.7%
## WA Country  33  236           20.9% 29.3%
##
## By Residence_Area                       Fishers Exact p-value=0.0328
## #
##           Sample Bias Study v PMH
## ABS_Age_Group Study PMH Prop % by col Study PMH
## 20-24       29  135           18.4% 16.8%
## 25-34       81  483           51.3% 60.0%
## 35-44       48  187           30.4% 23.2%
##
## By ABS_Age_Group                       Fishers Exact p-value=0.0953
## #

```

There were two significant differences found for the sample bias tests: Gender and Residence_Area.

There were more female study participants than males and more Perth residents than WA Country compared to the PMH cleft patient population.

Study v PMH by Gender and Residence_Area

Calculate Odds Ratios and Risk Ratios for study v PMH by Gender and Residence_Area to given an indication of the scale of the significant differences found previously via the 95% Confidence Intervals. This was requested by the Journal paper reviewer.

```

##           Gender
## Group   Male Female Prop % by row Male Female
## PMH     443  362           55.0% 45.0%
## Study    71   87           44.9% 55.1%
##
## Odds Ratio=1.50 CI=(1.05,2.15) p.value=0.0232
## The Odds for Female of Gender is at least 5% higher for Study than PMH
##
## OR By Gender                                Odds-Ratio    p-value=0.0232
## #
## Risk Ratio=1.22 CI=(1.03,1.43) p.value=0.0232
## The Relative Risk for Female of Gender is at least 3% higher for Study than PMH
## of Group
##
## RR By Gender                                Relative Risk p-value=0.0232
## #
##           Residence_Area
## Group   WA Country Perth Metro Prop % by row WA Country Perth Metro
## PMH     236   569           29.3% 70.7%
## Study    33  125           20.9% 79.1%
##
## Odds Ratio=1.57 CI=(1.03,2.45) p.value=0.0328
## The Odds for Perth Metro of Residence_Area is at least 3% higher for Study than
## PMH
##
## OR By Residence_Area                       Odds-Ratio    p-value=0.0328
## #

```

```
##
## Risk Ratio=1.12 CI=(1.02,1.22) p.value=0.0328
## The Relative Risk for Perth Metro of Residence_Area is at least 2% higher for Study than PMH of Group
##
## RR By Residence_Area Relative Risk p-value=0.0328
## #
```

Study Responded v Not-Responded

Check for study sample bias by comparing study data (Responded = Y) against remaining PMH data (Responded = N) for Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```
## Study Responded v Not-Responded
## Gender Responded Not Responded Prop % by col Responded Not Responded
## Female 87 277 55.1% 42.8%
## Male 71 370 44.9% 57.2%
##
## By Gender Fishers Exact p-value=0.0058
## #
## Study Responded v Not-Responded
## Cleft_Type Responded Not Responded Prop % by col Responded Not Responded
## Lip-only 25 135 15.8% 20.9%
## Lip & Palate 79 270 50.0% 41.7%
## Palate-only 54 242 34.2% 37.4%
##
## By Cleft_Type Fishers Exact p-value=0.1394
## #
## Study Responded v Not-Responded
## Residence_Area Responded Not Responded Prop % by col Responded Not Responded
## Perth Metro 125 457 79.1% 70.6%
## WA Country 33 190 20.9% 29.4%
##
## By Residence_Area Fishers Exact p-value=0.0371
## #
## Study Responded v Not-Responded
## ABS_Age_Group Responded Not Responded Prop % by col Responded Not Responded
## 20-24 29 106 18.4% 16.4%
## 25-34 81 402 51.3% 62.1%
## 35-44 48 139 30.4% 21.5%
##
## By ABS_Age_Group Fishers Exact p-value=0.0295
## #
```

There were three significant differences found for the sample bias tests: Gender, Residence_Area, ABS_Age_Group.

There were more female study participants than males, more Perth residents than WA Country, more 35-44 year olds and less 25-34 year olds compared to the non-responders.

Participation Responded v Not Responded by Gender, Residence_Area and ABS_Age_Group

Calculate Odds Ratios and Risk Ratios for those from the PMH population who Responded (i.e. were in the study) versus those who did not respond by Gender, Residence_Area and ABS_Age_Group to given an indication of the scale of the significant differences found previously via the 95% Confidence Intervals. This was requested by the Journal paper reviewer.

```
## Gender
## Participation Male Female Prop % by row Male Female
## Not Responded 370 277 57.2% 42.8%
## Responded 71 87 44.9% 55.1%
##
## Odds Ratio=1.64 CI=(1.14,2.36) p.value=0.0058
## The Odds for Female of Gender is at least 14% higher for Responded than Not Responded
```



```

##
## OR By Gender                                Odds-Ratio    p-value=0.0058
## #
##
## Risk Ratio=1.29  CI=(1.08,1.51)  p.value=0.0058
## The Relative Risk for Female of Gender is at least 8% higher for Responded than
Not Responded of Participation
##
## RR By Gender                                Relative Risk p-value=0.0058
## #
##
## Participation      Residence_Area
## WA Country Perth Metro Prop % by row WA Country Perth Metro
## Not Responded    190      457                29.4%    70.6%
## Responded        33       125                20.9%    79.1%
##
## Odds Ratio=1.57  CI=(1.02,2.47)  p.value=0.0371
## The Odds for Perth Metro of Residence_Area is at least 2% higher for Responded t
han Not Responded
##
## OR By Residence_Area                        Odds-Ratio    p-value=0.0371
## #
##
## Risk Ratio=1.12  CI=(1.02,1.23)  p.value=0.0371
## The Relative Risk for Perth Metro of Residence_Area is at least 2% higher for Re
sponded than Not Responded of Participation
##
## RR By Residence_Area                        Relative Risk p-value=0.0371
## #
##
## Participation      ABS_Age_Group
## Remainder 20-24 Prop % by row Remainder 20-24
## Not Responded    541      106                83.6%    16.4%
## Responded        129      29                 81.6%    18.4%
##
## Odds Ratio=1.15  CI=(0.70,1.83)  p.value=0.5536
## Lower CI <=1 for 20-24 of ABS_Age_Group indicates no significant difference betw
een Responded and Not Responded
##
## OR By ABS_Age_Group 20-24                  Odds-Ratio    p-value=0.5536
## #
##
## Risk Ratio=1.12  CI=(0.73,1.60)  p.value=0.5536
## Lower CI <=1 for 20-24 of ABS_Age_Group indicates no significant difference betw
een Responded and Not Responded
##
## RR By ABS_Age_Group 20-24                  Relative Risk p-value=0.5536
## #
##
## Participation      ABS_Age_Group
## Remainder 25-34 Prop % by row Remainder 25-34
## Responded        77       81                 48.7%    51.3%
## Not Responded    245      402                37.9%    62.1%
##
## Odds Ratio=1.56  CI=(1.08,2.25)  p.value=0.0144
## The Odds for 25-34 of ABS_Age_Group is at least 8% higher for Not Responded than
Responded
##
## OR By ABS_Age_Group 25-34                  Odds-Ratio    p-value=0.0144
## #
##
## Risk Ratio=1.21  CI=(1.04,1.44)  p.value=0.0144
## The Relative Risk for 25-34 of ABS_Age_Group is at least 4% higher for Not Respo
nded than Responded of Participation
##
## RR By ABS_Age_Group 25-34                  Relative Risk p-value=0.0144
## #
##
## Participation      ABS_Age_Group
## Remainder 35-44 Prop % by row Remainder 35-44
## Not Responded    508      139                78.5%    21.5%
## Responded        110      48                 69.6%    30.4%

```

```
##
## Odds Ratio=1.59 CI=(1.06,2.38) p.value=0.0207
## The Odds for 35-44 of ABS_Age_Group is at least 6% higher for Responded than Not
Responded
##
## OR By ABS_Age_Group 35-44 Odds-Ratio p-value=0.0207
## #
##
## Risk Ratio=1.41 CI=(1.05,1.84) p.value=0.0207
## The Relative Risk for 35-44 of ABS_Age_Group is at least 5% higher for Responded
than Not Responded of Participation
##
## RR By ABS_Age_Group 35-44 Relative Risk p-value=0.0207
## #
```

There were significant differences in response rates for Gender, Residence_Area and age-group. There were more female study participants than males, more Perth residents than WA Country, more 35-44 year olds and less 25-34 year olds compared to the non-responders.

Occupation and Work Hours

Occupation Within Study

Within the Study - only look at those people who were Employed (otherwise they have no occupation). For employed participants, test Occupation_Cat by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```
## Occupation Cat Proportions
## Clerical & Admin 18 14.4%
## Community & Personal Svc 18 14.4%
## Labourers 9 7.2%
## Machinery Op & Drivers 6 4.8%
## Managers 9 7.2%
## Professionals 33 26.4%
## Sales 4 3.2%
## Technicians & Trades 28 22.4%
##
## Gender
## Occupation_Cat Female Male Prop % by col Female Male
## Clerical & Admin 11 7 16.9% 11.7%
## Community & Personal Svc 14 4 21.5% 6.7%
## Labourers 1 8 1.5% 13.3%
## Machinery Op & Drivers 1 5 1.5% 8.3%
## Managers 5 4 7.7% 6.7%
## Professionals 22 11 33.8% 18.3%
## Sales 3 1 4.6% 1.7%
## Technicians & Trades 8 20 12.3% 33.3%
##
## By Gender Fishers Exact p-value=0.0006
## #
## Cleft_Type
## Occupation_Cat Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-
only
## Clerical & Admin 4 8 6 16.0% 13.1% 15.4%
## Community & Personal Svc 3 7 8 12.0% 11.5% 20.5%
## Labourers 0 5 4 0.0% 8.2% 10.3%
## Machinery Op & Drivers 0 5 1 0.0% 8.2% 2.6%
## Managers 1 6 2 4.0% 9.8% 5.1%
## Professionals 8 15 10 32.0% 24.6% 25.6%
## Sales 1 2 1 4.0% 3.3% 2.6%
## Technicians & Trades 8 13 7 32.0% 21.3% 17.9%
##
## By Cleft_Type Fishers Exact p-value=0.8190
## #
## Residence_Area
## Occupation_Cat Perth Metro WA Country Prop % by col Perth Metro WA Country
## Clerical & Admin 12 6 6 11.9% 25.0%
## Community & Personal Svc 16 2 8.3%
## Labourers 9 0 8.9% 0.0%
## Machinery Op & Drivers 4 2 4.0% 8.3%
## Managers 6 3 5.9% 12.5%
## Professionals 28 5 27.7% 20.8%
## Sales 4 0 4.0% 0.0%
## Technicians & Trades 22 6 21.8% 25.0%
##
## By Residence_Area Fishers Exact p-value=0.2925
## #
```

```

##          ABS Age_Group
## Occupation_Cat  20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
## Clerical & Admin      4      8      6      19.0%  11.9%  16.2%
## Community & Personal Svc  7      8      3      33.3%  11.9%   8.1%
## Labourers              2      5      2       9.5%   7.5%   5.4%
## Machinery Op & Drivers  0      4      2       0.0%   6.0%   5.4%
## Managers               0      4      5       0.0%   6.0%  13.5%
## Professionals          1     23      9       4.8%  34.3%  24.3%
## Sales                  1      2      1       4.8%   3.0%   2.7%
## Technicians & Trades    6     13      9      28.6%  19.4%  24.3%
##
## By ABS Age Group                      Fishers Exact p-value=0.1375
## #

```

There was a significant difference for Occupation_Cat by Gender.

There is no significant difference for Occupation_Cat by Cleft_Type, Residence_Area or ABS_Age_Group.

Occupation Within Study by Gender

Pin-point where the significant difference is. Use Holm correction for p-values.

```

##          Gender
## Occupation_Cat  Female Male  Prop % by col Female Male
## Clerical & Admin    11      7      16.9%  11.7%
## Remainder           54     53      83.1%  88.3%
##
## By Clerical & Admin                      Fishers Exact p-value=0.4531
## #
##          Gender
## Occupation_Cat  Female Male  Prop % by col Female Male
## Community & Personal Svc  14      4      21.5%   6.7%
## Remainder              51     56      78.5%  93.3%
##
## By Community & Personal Svc              Fishers Exact p-value=0.0219
## #
##          Gender
## Occupation_Cat  Female Male  Prop % by col Female Male
## Labourers        1      8       1.5%  13.3%
## Remainder        64     52      98.5%  86.7%
##
## By Labourers                             Fishers Exact p-value=0.0139
## #
##          Gender
## Occupation_Cat  Female Male  Prop % by col Female Male
## Machinery Op & Drivers    1      5       1.5%   8.3%
## Remainder              64     55      98.5%  91.7%
##
## By Machinery Op & Drivers                Fishers Exact p-value=0.1040
## #
##          Gender
## Occupation_Cat  Female Male  Prop % by col Female Male
## Managers        5      4       7.7%   6.7%
## Remainder       60     56      92.3%  93.3%
##
## By Managers                             Fishers Exact p-value=1.0000
## #
##          Gender
## Occupation_Cat  Female Male  Prop % by col Female Male
## Professionals   22     11      33.8%  18.3%
## Remainder       43     49      66.2%  81.7%
##
## By Professionals                         Fishers Exact p-value=0.0673
## #
##          Gender
## Occupation_Cat  Female Male  Prop % by col Female Male
## Sales           3      1       4.6%   1.7%
## Remainder       62     59      95.4%  98.3%
##

```

```
## By Sales Fishers Exact p-value=0.6201
## #
## Gender
## Occupation_Cat Female Male Prop % by col Female Male
## Technicians & Trades 8 20 12.3% 33.3%
## Remainder 57 40 87.7% 66.7%
##
## By Technicians & Trades Fishers Exact p-value=0.0056
## #
```

There was a significant difference in Occupation of Technicians & Trades by Gender.
Significantly more males than females are in this occupation (which is an expected result).

Occupation for Technicians & Trades by Gender

Calculate Odds Ratios and Risk Ratios for Occupation for Technicians & Trades by Gender to given an indication of the scale of the significant differences found previously via the 95% Confidence Intervals.

```
## Occupation_Cat
## Gender Remainder Technicians & Trades Prop % by row Remainder Technicians & Trades
## Female 57 8 87.7% 12.3%
## Male 40 20 66.7% 33.3%
##
## Odds Ratio=3.53 CI=(1.33,10.23) p.value=0.0056
## The Odds for Technicians & Trades of Occupation_Cat is at least 33% higher for Male than Female
##
## OR By Technicians & Trades Odds-Ratio p-value=0.0056
## #
##
## Risk Ratio=2.71 CI=(1.38,6.86) p.value=0.0056
## The Relative Risk for Technicians & Trades of Occupation_Cat is at least 38% higher for Male than Female of Gender
##
## RR By Technicians & Trades Relative Risk p-value=0.0056
## #
```

Occupation 25-44 Study v ABS WA 2014

Calculate Odds Ratio and Risk Ratio for employed study participants for each occupation category in the 25-44 year age range compared to the ABS data for Western Australia in 2014 loaded from the WA Occupations 2014 tab in the master spreadsheet. Do not use the younger participants because the ABS data uses the age range 15-24 which is quite different to the 22-24 age ranges of the younger study participants.

```
## Group 25-44
## Occupation_Cat ABS 2014 Study Prop % by col ABS 2014 Study
## Remainder 547100 90 87.4% 86.5%
## Clerical & Admin 79100 14 12.6% 13.5%
##
## By Clerical & Admin Fishers Exact p-value=0.7678
## #
## Group 25-44
## Occupation_Cat ABS WA 2014 Study Prop % by col ABS WA 2014 Study
## Remainder 569400 93 90.9% 89.4%
## Community & Personal Svc 56800 11 9.1% 10.6%
##
## By Community & Personal Svc Fishers Exact p-value=0.6063
## #
## Group 25-44
## Occupation_Cat ABS WA 2014 Study Prop % by col ABS WA 2014 Study
## Remainder 572400 97 91.4% 93.3%
## Labourers 53800 7 8.6% 6.7%
##
```

```

## By Labourers Fishers Exact p-value=0.6017
## #
## Group 25-44
## Occupation_Cat ABS WA 2014 Study Prop % by col ABS WA 2014 Study
## Remainder 576100 98 92.0% 94.2%
## Machinery Op & Drivers 50100 6 8.0% 5.8%
##
## By Machinery Op & Drivers Fishers Exact p-value=0.5850
## #
## Group 25-44
## Occupation_Cat ABS WA 2014 Study Prop % by col ABS WA 2014 Study
## Remainder 555200 95 88.7% 91.3%
## Managers 71000 9 11.3% 8.7%
##
## By Managers 25-44 Study v ABS WA 2014 Fishers Exact p-value=0.5344
## #
## Group 25-44
## Occupation_Cat ABS WA 2014 Study Prop % by col ABS WA 2014 Study
## Remainder 468700 72 74.8% 69.2%
## Professionals 157500 32 25.2% 30.8%
##
## By Professionals Fishers Exact p-value=0.2130
## #
## Group 25-44
## Occupation_Cat ABS WA 2014 Study Prop % by col ABS WA 2014 Study
## Remainder 584500 101 93.3% 97.1%
## Sales 41700 3 6.7% 2.9%
##
## By Sales Fishers Exact p-value=0.1646
## #
## Group 25-44
## Occupation_Cat ABS WA 2014 Study Prop % by col ABS WA 2014 Study
## Remainder 510000 82 81.4% 78.8%
## Technicians & Trades 116200 22 18.6% 21.2%
##
## By Technicians & Trades Fishers Exact p-value=0.5276
## #

```

There was no significant difference for any of the Occupation categories for study participants in the age range 25-44 years compared to the WA general population in 2014.

Impact_Getting_Work Within Study

Impact of cleft on getting work by Gender, Cleft_Type, Residential_Area and ABS_Age_Group.

```

## Impact_Getting_Work Proportions
## N 131 82.9%
## Y 27 17.1%
##
## Gender
## Impact_Getting_Work Female Male Prop % by col Female Male
## N 72 59 82.8% 83.1%
## Y 15 12 17.2% 16.9%
##
## By Gender Fishers Exact p-value=1.0000
## #
## Cleft_Type
## Impact_Getting_Work Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## N 24 62 45 96.0% 78.5% 83.3%
## Y 1 17 9 4.0% 21.5% 16.7%
##
## By Cleft_Type Fishers Exact p-value=0.1163
## #
## Residence_Area
## Impact_Getting_Work Perth Metro WA Country Prop % by col Perth Metro WA Country
## N 104 27 83.2% 81.8%
## Y 21 6 16.8% 18.2%
##

```

```

## By Residence_Area                               Fishers Exact p-value=0.8002
## #
##          ABS_Age_Group
## Impact_Getting_Work 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##          N      24      63      44                82.8%  77.8%  91.7%
##          Y       5      18       4                17.2%  22.2%   8.3%
##
## By ABS_Age_Group                               Fishers Exact p-value=0.1317
## #

```

There was no significant difference for Impact_Getting_Work by Gender, Cleft_Type, Residence_Area or ABS_Age_Group.

Impact_Doing_Work Within Study

Impact of cleft on doing work by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```

##          Gender
## Impact_Doing_Work Female Male Prop % by col Female Male
##          N      73      63                83.9%  88.7%
##          Y      14       8                16.1%  11.3%
##
## By Gender                                       Fishers Exact p-value=0.4900
## #
##          Cleft_Type
## Impact_Doing_Work Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          N      24      69      43                96.0%  87.3%  79.6%
##          Y       1      10      11                4.0%  12.7%  20.4%
##
## By Cleft_Type                                   Fishers Exact p-value=0.1336
## #
##          Residence_Area
## Impact_Doing_Work Perth Metro WA Country Prop % by col Perth Metro WA Country
##          N      107                29                85.6%  87.9%
##          Y       18                 4                14.4%  12.1%
##
## By Residence_Area                               Fishers Exact p-value=1.0000
## #
##          ABS_Age_Group
## Impact_Doing_Work 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##          N      25      66      45                86.2%  81.5%  93.8%
##          Y       4      15       3                13.8%  18.5%   6.2%
##
## By ABS_Age_Group                               Fishers Exact p-value=0.1448
## #

```

There was no significant difference for Impact_Doing_Work by Gender, Cleft_Type, Residence_Area or ABS_Age_Group.

Work_Hours Within Study

Test Work_Hours (Full-time and Part-time) by Gender, Cleft_Type, Residence_Area and ABS_Age_Group. Exclude those who didn't work.

```

##          Gender
## Work_Hours Female Male Prop % by col Female Male
## Full-time  49      51                75.4%  85.0%
## Part-time  16       9                24.6%  15.0%
##
## By Gender                                       Fishers Exact p-value=0.2630
## #
##          Cleft_Type
## Work_Hours Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## Full-time  21      49      30                84.0%  80.3%  76.9%
## Part-time   4      12       9                16.0%  19.7%  23.1%
##
## By Cleft_Type                                   Fishers Exact p-value=0.8030
## #

```

```

## Residence_Area
## Work_Hours Perth Metro WA Country Prop % by col Perth Metro WA Country
## Full-time 81 19 80.2% 79.2%
## Part-time 20 5 19.8% 20.8%
##
## By Residence_Area Fishers Exact p-value=1.0000
## #
## ABS_Age_Group
## Work_Hours 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
## Full-time 14 53 33 66.7% 79.1% 89.2%
## Part-time 7 14 4 33.3% 20.9% 10.8%
##
## By ABS_Age_Group Fishers Exact p-value=0.1238
## #

```

There were no significant difference for Work_Hours by Gender, Cleft_Type, Residence_Area or ABS_Age_Group.

Work_Hours Study v ABS WA 2014 by Gender

Calculate Odds Ratio and Risk Ratio for study participants who work Full-time or Part-time and are in the 25-34 or 35-44 age groups to enable more accurate comparison. The ABS data is for WA in 2014 which has the youngest age group from 15-24 which was considered too different from the 20-24 age group in the study.

```

## Female Work_Hours
## Age_Group 25-44 Part-time Full-time Prop % by row Part-time Full-time
## ABS WA 2014 106000 159700 39.9% 60.1%
## Study 11 41 21.2% 78.8%
##
## Odds Ratio=2.47 CI=(1.25,5.34) p.value=0.0065
## The Odds for Full-time of Female Work_Hours is at least 25% higher for Study than ABS WA 2014
##
## OR By Females 25-44 Odds-Ratio p-value=0.0065
## #
##
## Risk Ratio=1.31 CI=(1.12,1.47) p.value=0.0065
## The Relative Risk for Full-time of Female Work_Hours is at least 12% higher for Study than ABS WA 2014 of Age_Group 25-44
##
## RR By Females 25-44 Relative Risk p-value=0.0065
## #
## Male Work_Hours
## Age_Group 25-44 Part-time Full-time Prop % by row Part-time Full-time
## Study 7 45 13.5% 86.5%
## ABS WA 2014 33100 327800 9.2% 90.8%
##
## Odds Ratio=1.54 CI=(0.59,3.44) p.value=0.3293
## Lower CI <=1 for Full-time of Male Work_Hours indicates no significant difference between ABS WA 2014 and Study
##
## OR By Males 25-44 Odds-Ratio p-value=0.3293
## #
##
## Risk Ratio=1.05 CI=(0.96,1.18) p.value=0.3293
## Lower CI <=1 for Full-time of Male Work_Hours indicates no significant difference between ABS WA 2014 and Study
##
## RR By Males 25-44 Relative Risk p-value=0.3293
## #

```

There was a significant difference for Work_Hours between Study and ABS for Females aged 25-44.

Female study participants were more likely to work Full-time than females in the WA general population in 2014.

Annual_Income

Annual_Income Full-time Within Study

Compare Annual_Income for Full-time employed study participants by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```
## Annual_Income Full-time Proportions
## <100K 35 35.0%
## <30K 6 6.0%
## <60K 42 42.0%
## 100K+ 17 17.0%
##
## Gender
## Annual_Income Full-time Female Male Prop % by col Female Male
## <100K 24 11 49.0% 21.6%
## <30K 2 4 4.1% 7.8%
## <60K 21 21 42.9% 41.2%
## 100K+ 2 15 4.1% 29.4%
##
## By Gender Fishers Exact p-value=0.0007
## #
## Cleft_Type
## Annual_Income Full-time Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-onl
y
## <100K 7 19 9 33.3% 38.8% 30.0%
## <30K 0 4 2 0.0% 8.2% 6.7%
## <60K 10 16 16 47.6% 32.7% 53.3%
## 100K+ 4 10 3 19.0% 20.4% 10.0%
##
## By Cleft_Type Fishers Exact p-value=0.5189
## #
## Residence_Area
## Annual_Income Full-time Perth Metro WA Country Prop % by col Perth Metro WA Country
## <100K 28 7 34.6% 36.8%
## <30K 5 1 6.2% 5.3%
## <60K 32 10 39.5% 52.6%
## 100K+ 16 1 19.8% 5.3%
##
## By Residence_Area Fishers Exact p-value=0.4581
## #
## ABS_Age_Group
## Annual_Income Full-time 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
## <100K 1 24 10 7.1% 45.3% 30.3%
## <30K 1 4 1 7.1% 7.5% 3.0%
## <60K 12 17 13 85.7% 32.1% 39.4%
## 100K+ 0 8 9 0.0% 15.1% 27.3%
##
## By ABS_Age_Group Fishers Exact p-value=0.0052
## #
```

There was a significant difference in Annual_Income for Full-time employed participants by Gender and ABS_Age_Group.

Male study participants were more likely to be in the 100K+ income category whilst females were more likely to be in the <100K category (i.e. earn between 60 and 100K per year). This is an expected result ... there is a well recognised gender gap in income, favouring males in Australia, and Western Australia.

Older study participants were more likely to be the higher income categories than the younger participants. This also is an expected result ... people in their late 30's and 40's earn more due to their experience, skills and time in the work place.

Annual Income Full-time Within Study by Gender

Calculate Odds Ratio and Risk Ratio for annual income for study participants who work Full-time in the \$100K+ and 60K categories to enable more accurate comparison between genders.

```
## Annual_Income Full-time
## Gender Remainder 100K+ Prop % by row Remainder 100K+
## Female 47 2 95.9% 4.1%
## Male 36 15 70.6% 29.4%
##
## Odds Ratio=9.59 CI=(2.03,91.85) p.value=0.0009
## The Odds for 100K+ of Annual_Income Full-time is at least 103% higher for Male than Female
##
## OR By Gender 100K+ Odds-Ratio p-value=0.0009
## #
##
## Risk Ratio=7.21 CI=(2.40,Inf) p.value=0.0009
## The Relative Risk for 100K+ of Annual_Income Full-time is at least 140% higher for Male than Female of Gender
##
## RR By Gender 100K+ Relative Risk p-value=0.0009
## #
## Annual_Income Full-time
## Gender Remainder <100K Prop % by row Remainder <100K
## Male 40 11 78.4% 21.6%
## Female 25 24 51.0% 49.0%
##
## Odds Ratio=3.45 CI=(1.35,9.26) p.value=0.0061
## The Odds for <100K of Annual_Income Full-time is at least 35% higher for Female than Male
##
## OR By Gender <100K Odds-Ratio p-value=0.0061
## #
##
## Risk Ratio=2.27 CI=(1.30,4.68) p.value=0.0061
## The Relative Risk for <100K of Annual_Income Full-time is at least 30% higher for Female than Male of Gender
##
## RR By Gender <100K Relative Risk p-value=0.0061
## #
```

Annual_Income Part-time Within Study

Compare Annual_Income for Part-time employed study participants by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```
## Annual_Income Part-time Proportions
## <100K 1 4.0%
## <30K 17 68.0%
## <60K 7 28.0%
##
## Gender
## Annual_Income Part-time Female Male Prop % by col Female Male
## <100K 1 0 6.2% 0.0%
## <30K 10 7 62.5% 77.8%
## <60K 5 2 31.2% 22.2%
##
## By Gender Fishers Exact p-value=0.7880
## #
## Cleft_Type
## Annual_Income Part-time Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## <100K 1 0 0 25.0% 0.0% 0.0%
## <30K 0 9 8 0.0% 75.0% 88.9%
## <60K 3 3 1 75.0% 25.0% 11.1%
##
## By Cleft_Type Fishers Exact p-value=0.0092
## #
## Residence_Area
## Annual_Income Part-time Perth Metro WA Country Prop % by col Perth Metro WA Country
```

```

##          <100K      1      0          5.0%      0.0%
##          <30K      13      4          65.0%      80.0%
##          <60K       6      1          30.0%      20.0%
##
## By Residence_Area          Fishers Exact p-value=1.0000
## #
##          ABS_Age_Group
## Annual_Income Part-time 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##          <100K      0      1      0          0.0%      7.1%      0.0%
##          <30K       7      9      1          100.0%     64.3%     25.0%
##          <60K       0      4      3          0.0%     28.6%     75.0%
##
## By ABS_Age_Group          Fishers Exact p-value=0.0668
## #

```

There was a significant difference in Annual_Income for Part-time employed participants by Cleft_Type.

Study participants with a cleft type of Lip-only were in the higher income categories whilst Palate-only were in the lower. However, the small numbers involved mean these results need to be treated with caution.

Annual_Income 25-44 years Study v ABS 2013

Calculate Odds Ratio and Relative Risk for each Annual_Income category for Full-time workers in 25-44 age-group compared to ABS Australian general population data for 2013. See Aust Income 2013 tab in the master spreadsheet for the ABS data source.

Note: Only use ages 25-44 as ABS data starts at 20 (rather than 22 for study), and these early years are skewed low for income. Also, only use Full-time Employed study participants as this is what ABS data contains.

```

##          Age-Group 25-44
## Annual_Income Full-time ABS 2013 Study Prop % by col ABS 2013 Study
##          Remainder 2450600      52          69.2%      60.5%
##          <100K      1092400      34          30.8%      39.5%
##
## By Age-Group 25-44 <100K          Fishers Exact p-value=0.1012
## #
##          Age-Group 25-44
## Annual_Income Full-time ABS 2013 Study Prop % by col ABS 2013 Study
##          Remainder 3427800      81          96.7%      94.2%
##          <30K       115200       5           3.3%       5.8%
##
## By Age-Group 25-44 <30K          Fishers Exact p-value=0.2069
## #
##          Age-Group 25-44
## Annual_Income Full-time ABS 2013 Study Prop % by col ABS 2013 Study
##          Remainder 1964400      56          55.4%      65.1%
##          <60K       1578600      30          44.6%      34.9%
##
## By Age-Group 25-44 <60K          Fishers Exact p-value=0.0822
## #
##          Age-Group 25-44
## Annual_Income Full-time ABS 2013 Study Prop % by col ABS 2013 Study
##          Remainder 2786200      69          78.6%      80.2%
##          100K+      756800       17          21.4%      19.8%
##
## By Age-Group 25-44 100K+          Fishers Exact p-value=0.7935
## #

```

There was no significant difference in any of the Annual_Income categories for Full-time employed study participants in the age range 25-44 years compared to the Australian general population in 2013.

Highest Education_Level Achieved

Education_Level Within Study

Test Highest Education_Level attained by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

Note: Education_Level of Other indicates Primary School level. Convert these into High School category as there are only 3 of them.

```
## Education_Level Proportions
## High School 47 29.7%
## TAFE Cert/Diploma 50 31.6%
## Uni Degree 43 27.2%
## Uni Post Grad 18 11.4%
##
## Gender
## Education_Level Female Male Prop % by col Female Male
## High School 18 29 20.7% 40.8%
## TAFE Cert/Diploma 27 23 31.0% 32.4%
## Uni Degree 29 14 33.3% 19.7%
## Uni Post Grad 13 5 14.9% 7.0%
##
## By Gender Fishers Exact p-value=0.0181
## #
## Cleft_Type
## Education_Level Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## High School 4 29 14 16.0% 36.7% 25.9%
## TAFE Cert/Diploma 11 23 16 44.0% 29.1% 29.6%
## Uni Degree 3 22 18 12.0% 27.8% 33.3%
## Uni Post Grad 7 5 6 28.0% 6.3% 11.1%
##
## By Cleft_Type Fishers Exact p-value=0.0253
## #
## Residence_Area
## Education_Level Perth Metro WA Country Prop % by col Perth Metro WA Country
## High School 34 13 27.2% 39.4%
## TAFE Cert/Diploma 43 7 34.4% 21.2%
## Uni Degree 32 11 25.6% 33.3%
## Uni Post Grad 16 2 12.8% 6.1%
##
## By Residence_Area Fishers Exact p-value=0.2358
## #
## ABS_Age_Group
## Education_Level 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
## High School 10 20 17 34.5% 24.7% 35.4%
## TAFE Cert/Diploma 7 26 17 24.1% 32.1% 35.4%
## Uni Degree 11 26 6 37.9% 32.1% 12.5%
## Uni Post Grad 1 9 8 3.4% 11.1% 16.7%
##
## By ABS_Age_Group Fishers Exact p-value=0.0776
## #
```

There were two significant difference for Education_Level: by Gender and by Cleft_Type.

Females study participants were more likely to have a higher Education_Level than males.

Lip-only Cleft_Type were more likely to have a Uni Post Grad or TAFE Cert/Diploma than the other cleft types.

Education_Level Within Study by Gender

Calculate Odds Ratio and Risk Ratio to look for specific difference in Education_Level by Gender. Also combine "Uni Degree" and "Uni Post Grad" into one "University" level and test that. This indicates study participants who have achieved a high level of education.

```
## Education_Level
## Gender Remainder High School Prop % by row Remainder High School
## Female 69 18 79.3% 20.7%
## Male 42 29 59.2% 40.8%
##
```

```

## Odds Ratio=2.63 CI=(1.24,5.70) p.value=0.0084
## The Odds for High School of Education_Level is at least 24% higher for Male than
Female
##
## OR By High School Odds-Ratio p-value=0.0084
## #
##
## Risk Ratio=1.97 CI=(1.23,3.47) p.value=0.0084
## The Relative Risk for High School of Education_Level is at least 23% higher for
Male than Female of Gender
##
## RR By High School Relative Risk p-value=0.0084
## #
## Education_Level
## Gender Remainder TAFE Cert/Diploma Prop % by row Remainder TAFE Cert/Diploma
## Female 60 27 69.0% 31.0%
## Male 48 23 67.6% 32.4%
##
## Odds Ratio=1.06 CI=(0.51,2.20) p.value=0.8652
## Lower CI <=1 for TAFE Cert/Diploma of Education_Level indicates no significant d
ifference between Male and Female
##
## OR By TAFE Cert/Diploma Odds-Ratio p-value=0.8652
## #
##
## Risk Ratio=1.04 CI=(0.65,1.65) p.value=0.8652
## Lower CI <=1 for TAFE Cert/Diploma of Education_Level indicates no significant d
ifference between Male and Female
##
## RR By TAFE Cert/Diploma Relative Risk p-value=0.8652
## #
## Education_Level
## Gender Remainder Uni Degree Prop % by row Remainder Uni Degree
## Male 57 14 80.3% 19.7%
## Female 58 29 66.7% 33.3%
##
## Odds Ratio=2.03 CI=(0.93,4.61) p.value=0.0722
## Lower CI <=1 for Uni Degree of Education_Level indicates no significant differen
ce between Female and Male
##
## OR By Uni Degree Odds-Ratio p-value=0.0722
## #
##
## Risk Ratio=1.69 CI=(1.00,3.26) p.value=0.0722
## The Relative Risk for Uni Degree of Education_Level is at least 0% higher for Fe
male than Male of Gender
##
## RR By Uni Degree Relative Risk p-value=0.0722
## #
## Education_Level
## Gender Remainder Uni Post Grad Prop % by row Remainder Uni Post Grad
## Male 66 5 93.0% 7.0%
## Female 74 13 85.1% 14.9%
##
## Odds Ratio=2.31 CI=(0.72,8.72) p.value=0.1380
## Lower CI <=1 for Uni Post Grad of Education_Level indicates no significant diffe
rence between Female and Male
##
## OR By Uni Post Grad Odds-Ratio p-value=0.1380
## #
##
## Risk Ratio=2.12 CI=(0.82,9.79) p.value=0.1380
## Lower CI <=1 for Uni Post Grad of Education_Level indicates no significant diffe
rence between Female and Male
##
## RR By Uni Post Grad Relative Risk p-value=0.1380
## #

```

```

##           Education_Level
## Gender      Remainder University Prop % by row Remainder University
##   Male         52          19                73.2%    26.8%
##   Female        45          42                51.7%    48.3%
##
## Odds Ratio=2.54  CI=(1.24,5.33)  p.value=0.0083
## The Odds for University of Education_Level is at least 24% higher for Female than Male
##
## OR By University                                Odds-Ratio    p-value=0.0083
## #
##
## Risk Ratio=1.80  CI=(1.21,2.99)  p.value=0.0083
## The Relative Risk for University of Education_Level is at least 21% higher for Female than Male of Gender
##
## RR By University                                Relative Risk p-value=0.0083
## #

```

There were two significant differences in Education_Level by Gender:

Male study participants were more likely to have High School as their highest education level than females.

Female study participants were more likely to have University as their highest education level than males.

Education_Level Within Study by Cleft_Type

Calculate Odds Ratio and Risk Ratio to look for specific difference in Education_Level by Cleft_Type. Also combine "Uni Degree" and "Uni Post Grad" into one "University" level and test that. This indicates study participants who have achieved a high level of education.

```

##           Education_Level
## Cleft_Type  Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Remainder    21      50          40                84.0%    63.3%    74.1%
##   High School    4      29          14                16.0%    36.7%    25.9%
##
## By High School                                Fishers Exact p-value=0.1211
## #
##           Education_Level
## Cleft_Type  Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Remainder    14      56          38                56.0%    70.9%    70.4%
##   TAFE Cert/Diploma  11      23          16                44.0%    29.1%    29.6%
##
## By TAFE Cert/Diploma                          Fishers Exact p-value=0.3668
## #
##           Education_Level
## Cleft_Type  Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Remainder    22      57          36                88.0%    72.2%    66.7%
##   Uni Degree     3      22          18                12.0%    27.8%    33.3%
##
## By Uni Degree                                Fishers Exact p-value=0.1406
## #
##           Education_Level
## Cleft_Type  Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Remainder    18      74          48                72.0%    93.7%    88.9%
##   Uni Post Grad  7      5           6                28.0%    6.3%    11.1%
##
## By Uni Post Grad                              Fishers Exact p-value=0.0171
## #
##           Education_Level
## Cleft_Type  Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Remainder    15      52          30                60.0%    65.8%    55.6%
##   University    10      27          24                40.0%    34.2%    44.4%
##
## By University                                Fishers Exact p-value=0.4657
## #

```

There was a significant difference by Cleft_Type for Uni Post Grad using unadjusted p-values.

However, the number of study participants involved are very small (18 participants). Combining Uni Degree + Uni Post Grad to give higher numbers produced no significant results. The Holm adjusted p

values are all not significant. Therefore don't report this in journal paper ... it is not "significant enough".

Education_Level 25-44 Study v ABS 2014

Compare Education_Level for study participants in 25-44 age range against ABS Australian general population in 2014. See Aust Education 2014 tab in the master spreadsheet for the ABS data source. Note: Only use ages 25-44 as ABS data starts at 20 (rather than 22 for study).

```
##           Age-Group 25-44
## Education_Level ABS 2014 Study Prop % by col ABS 2014 Study
##   Remainder 4488737 92 69.2% 71.3%
##   High School 1999033 37 30.8% 28.7%
##
## By High School Fishers Exact p-value=0.6347
## #
##           Age-Group 25-44
## Education_Level ABS 2014 Study Prop % by col ABS 2014 Study
##   Remainder 4296167 86 66.2% 66.7%
##   TAFE Cert/Diploma 2191603 43 33.8% 33.3%
##
## By TAFE Cert/Diploma Fishers Exact p-value=1.0000
## #
##           Age-Group 25-44
## Education_Level ABS 2014 Study Prop % by col ABS 2014 Study
##   Remainder 4696313 97 72.4% 75.2%
##   Uni Degree 1791457 32 27.6% 24.8%
##
## By Uni Degree Fishers Exact p-value=0.5546
## #
##           Age-Group 25-44
## Education_Level ABS 2014 Study Prop % by col ABS 2014 Study
##   Remainder 5982093 112 92.2% 86.8%
##   Uni Post Grad 505677 17 7.8% 13.2%
##
## By Uni Post Grad Fishers Exact p-value=0.0311
## #
##           Age-Group 25-44
## Education_Level ABS 2014 Study Prop % by col ABS 2014 Study
##   Remainder 4190636 80 64.6% 62.0%
##   University 2297134 49 35.4% 38.0%
##
## By University Fishers Exact p-value=0.5808
## #
```

There was a significant difference in Education_Level between Study and ABS for the 25-44 year age group using unadjusted p value.

Study participants were more likely to have a University Post Grad level of education than the Australian general population in 2014. However, the number of study participants involved are very small (17 participants). Combining Uni Degree + Uni Post Grad to give higher numbers produced no significant results. The Holm adjusted p values are all not significant. Therefore don't report this in journal paper ... it is not "significant enough".

Housing (Living Arrangemens)

Housing Within Study

Housing within study by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```
##           Housing Proportions
## Government 4 2.5%
## Own Home 58 36.7%
## Parents/Family 53 33.5%
```

```

## Rent                42    26.6%
## Work                 1     0.6%
##
##                      Gender
## Housing              Female Male  Prop % by col Female Male
##   Government         2       2      2.3%   2.8%
##   Own Home            32      26     36.8%  36.6%
##   Parents/Family     27      26     31.0%  36.6%
##   Rent                26      16     29.9%  22.5%
##   Work                 0       1      0.0%   1.4%
##
## By Gender                                Fishers Exact p-value=0.6879
## #
##                      Cleft_Type
## Housing              Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Government         0       3       1      0.0%   3.8%   1.9%
##   Own Home            9      32      17     36.0%  40.5%  31.5%
##   Parents/Family     7      23      23     28.0%  29.1%  42.6%
##   Rent                9      20      13     36.0%  25.3%  24.1%
##   Work                 0       1       0      0.0%   1.3%   0.0%
##
## By Cleft_Type                              Fishers Exact p-value=0.7090
## #
##                      Residence_Area
## Housing              Perth Metro WA  Country Prop % by col Perth Metro WA  Country
##   Government         1       3       0.8%   9.1%
##   Own Home            48      10     38.4%  30.3%
##   Parents/Family     41      12     32.8%  36.4%
##   Rent                34       8     27.2%  24.2%
##   Work                 1       0      0.8%   0.0%
##
## By Residence_Area                          Fishers Exact p-value=0.1227
## #
##                      ABS_Age_Group
## Housing              20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##   Government         0       3       1      0.0%   3.7%   2.1%
##   Own Home            1      29      28     3.4%  35.8%  58.3%
##   Parents/Family     21      25       7     72.4%  30.9%  14.6%
##   Rent                7      23      12     24.1%  28.4%  25.0%
##   Work                 0       1       0      0.0%   1.2%   0.0%
##
## By ABS_Age_Group                            Fishers Exact p-value=0.0000
## #

```

There was a significant difference for Housing by ABS_Age_Group.

This is as expected. Older participants tend to own their own home and not live with their Parents/Family.

Living At Home Study v ABS 2009

Calculate Odds Ratio and Risk Ratio for comparisons between study and ABS for people living with Parents/Family to ABS data for the age groups: 20-24, 25-29, 30-34 (no data was available for the 35-44 age group). See: ABS Australian Social Trends June 2009 Home and Away.pdf.

```

##                      Housing
## Age_Group 20-24 Remainder Living at home Prop % by row Remainder Living at home
##   ABS 2009 789518 705782 52.8% 47.2%
##   Study    8      21 27.6% 72.4%
##
## Odds Ratio=2.94 CI=(1.25,7.67) p.value=0.0083
## The Odds for Living at home of Housing is at least 25% higher for Study than ABS 2009
##
## OR By Age-Group 20-24 Odds-Ratio p-value=0.0083
## #
##
## Risk Ratio=1.53 CI=(1.17,1.83) p.value=0.0083
## The Relative Risk for Living at home of Housing is at least 17% higher for Study than ABS 2009 of Age_Group 20-24

```

```

##
## RR By Age-Group 20-24                               Relative Risk p-value=0.0083
## #
##           Housing
## Age_Group 25-29 Remainder Living at home Prop % by row Remainder Living at home
##           ABS 2009 1156147    233453                               83.2%    16.8%
##           Study    31         17                               64.6%    35.4%
##
## Odds Ratio=2.72  CI=(1.41,5.06)  p.value=0.0016
## The Odds for Living at home of Housing is at least 41% higher for Study than ABS
2009
##
## OR By Age-Group 25-29                               Odds-Ratio    p-value=0.0016
## #
##
## Risk Ratio=2.11  CI=(1.36,2.96)  p.value=0.0016
## The Relative Risk for Living at home of Housing is at least 36% higher for Study
than ABS 2009 of Age_Group 25-29
##
## RR By Age-Group 25-29                               Relative Risk p-value=0.0016
## #
##           Housing
## Age_Group 30-34 Remainder Living at home Prop % by row Remainder Living at home
##           ABS 2009 1315953    117547                               91.8%    8.2%
##           Study    25         8                               75.8%    24.2%
##
## Odds Ratio=3.58  CI=(1.40,8.19)  p.value=0.0044
## The Odds for Living at home of Housing is at least 40% higher for Study than ABS
2009
##
## OR By Age-Group 30-34                               Odds-Ratio    p-value=0.0044
## #
##
## Risk Ratio=2.96  CI=(1.11,4.81)  p.value=0.0044
## The Relative Risk for Living at home of Housing is at least 11% higher for Study
than ABS 2009 of Age_Group 30-34
##
## RR By Age-Group 30-34                               Relative Risk p-value=0.0044
## #

```

There were significant differences for living at home between Study and ABS 2009 for each age group.

In each case study participants were more likely to be living at home (i.e. with Parents/Family) than the Australian general population. A limitation of these results is that the ABS data used is from 2009 as more recent data could not be sourced.

Home Ownership study v ABS 2013-14

Calculate Odds Ratios and Risk Ratios for study participant home ownership against ABS for 25-34 and 35-44 age group data. See Aust Home Ownership 2013-14 tab of the master spreadsheet.

```

##           Housing
## Age_Group 25-34 Remainder Own Home Prop % by row Remainder Own Home
##           Study    52         29                               64.2%    35.8%
##           ABS 2013-14 894045    562055                               61.4%    38.6%
##
## Odds Ratio=1.13  CI=(0.70,1.84)  p.value=0.6492
## Lower CI <=1 for Own Home of Housing indicates no significant difference between
ABS 2013-14 and Study
##
## OR By Age-Group 25-34                               Odds-Ratio    p-value=0.6492
## #
##
## Risk Ratio=1.08  CI=(0.82,1.49)  p.value=0.6492
## Lower CI <=1 for Own Home of Housing indicates no significant difference between
ABS 2013-14 and Study

```



```

##
## RR By Age-Group 25-34                               Relative Risk p-value=0.6492
## #
##           Housing
## Age_Group 35-44 Remainder Own Home Prop % by row Remainder Own Home
##   Study      20      28
##   ABS 2013-14 633182 1059818 37.4% 62.6%
##
## Odds Ratio=1.20 CI=(0.64,2.20) p.value=0.5531
## Lower CI <=1 for Own Home of Housing indicates no significant difference between
## ABS 2013-14 and Study
##
## OR By Age-Group 35-44                               Odds-Ratio    p-value=0.5531
## #
##
## Risk Ratio=1.07 CI=(0.88,1.43) p.value=0.5531
## Lower CI <=1 for Own Home of Housing indicates no significant difference between
## ABS 2013-14 and Study
##
## RR By Age-Group 35-44                               Relative Risk p-value=0.5531
## #

```

There were no significant differences in home ownership for 25-34 or 35-44 year age group for study participants compared to the Australian general population as measured by the HILDA Wave 14 survey released in 2016.

Relationships

Close_To_Mother Within Study

Test study participants Close_To_Mother by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```

##   Close_To_Mother Proportions
## N    15          9.5%
## Y   143         90.5%
##
##           Gender
## Close_To_Mother Female Male Prop % by col Female Male
##           N      8      7          9.2%  9.9%
##           Y     79     64          90.8% 90.1%
##
## By Gender                               Fishers Exact p-value=1.0000
## #
##           Cleft_Type
## Close_To_Mother Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N      1      9      5          4.0%  11.4%  9.3%
##           Y     24     70     49          96.0%  88.6%  90.7%
##
## By Cleft_Type                           Fishers Exact p-value=0.6188
## #
##           Residence_Area
## Close_To_Mother Perth Metro WA Country Prop % by col Perth Metro WA Country
##           N      11      4          8.8%  12.1%
##           Y     114     29          91.2%  87.9%
##
## By Residence_Area                       Fishers Exact p-value=0.5187
## #
##           ABS_Age_Group
## Close_To_Mother 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##           N      1      8      6          3.4%  9.9%  12.5%
##           Y     28     73     42          96.6% 90.1%  87.5%
##
## By ABS_Age_Group                         Fishers Exact p-value=0.4436
## #

```

There were no significant difference in Close_To_Mother by Gender, Cleft_Type, Residence_Area or ABS_Age_Group.

Close_To_Father Within Study

Test study participants Close_To_Father by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```
## Close_To_Father Proportions
## N 43 27.2%
## Y 115 72.8%
## Gender
## Close_To_Father Female Male Prop % by col Female Male
## N 19 24 21.8% 33.8%
## Y 68 47 78.2% 66.2%
##
## By Gender Fishers Exact p-value=0.1076
## #
## Cleft_Type
## Close_To_Father Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## N 4 26 13 16.0% 32.9% 24.1%
## Y 21 53 41 84.0% 67.1% 75.9%
##
## By Cleft_Type Fishers Exact p-value=0.2214
## #
## Residence_Area
## Close_To_Father Perth Metro WA Country Prop % by col Perth Metro WA Country
## N 35 8 28.0% 24.2%
## Y 90 25 72.0% 75.8%
##
## By Residence_Area Fishers Exact p-value=0.8265
## #
## ABS_Age_Group
## Close_To_Father 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
## N 4 27 12 13.8% 33.3% 25.0%
## Y 25 54 36 86.2% 66.7% 75.0%
##
## By ABS_Age_Group Fishers Exact p-value=0.1189
## #
```

There were no significant difference in Close_To_Father by Gender, Cleft_Type, Residence_Area or ABS_Age_Group.

Relationships_Count Within Study

Test study participants for the number of significant relationships by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```
## Relationships_Count Proportions
## 0 48 30.4%
## 1 53 33.5%
## 2 35 22.2%
## 3 15 9.5%
## 4 6 3.8%
## 5 1 0.6%
## Gender
## Relationships_Count Female Male Prop % by col Female Male
## 0 27 21 31.0% 29.6%
## 1 29 24 33.3% 33.8%
## 2 20 15 23.0% 21.1%
## 3 7 8 8.0% 11.3%
## 4 3 3 3.4% 4.2%
## 5 1 0 1.1% 0.0%
##
## By Gender Fishers Exact p-value=0.9785
## #
```

```

## Cleft_Type
## Relationships_Count Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## 0 3 25 20 12.0% 31.6% 37.0%
## 1 6 31 16 24.0% 39.2% 29.6%
## 2 8 15 12 32.0% 19.0% 22.2%
## 3 6 5 4 24.0% 6.3% 7.4%
## 4 2 2 2 8.0% 2.5% 3.7%
## 5 0 1 0 0.0% 1.3% 0.0%
##
## By Cleft_Type Fishers Exact p-value=0.0795
## #
## Residence_Area
## Relationships_Count Perth Metro WA Country Prop % by col Perth Metro WA Country
## 0 36 12 28.8% 36.4%
## 1 43 10 34.4% 30.3%
## 2 27 8 21.6% 24.2%
## 3 14 1 11.2% 3.0%
## 4 5 1 4.0% 3.0%
## 5 0 1 0.0% 3.0%
##
## By Residence_Area Fishers Exact p-value=0.3424
## #
## ABS_Age_Group
## Relationships_Count 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
## 0 19 21 8 65.5% 25.9% 16.7%
## 1 6 37 10 20.7% 45.7% 20.8%
## 2 3 18 14 10.3% 22.2% 29.2%
## 3 1 3 11 3.4% 3.7% 22.9%
## 4 0 2 4 0.0% 2.5% 8.3%
## 5 0 0 1 0.0% 0.0% 2.1%
##
## By ABS_Age_Group Fishers Exact p-value=0.0000
## #

```

There was a significant difference in Relationships_Count by ABS_Age_Group.

As would be expected, older participants had more relationships than younger participants.

Married_Count Within Study

Test study participants for the number of marriages they have had by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```

## Married_Count Proportions
## 0 112 70.9%
## 1 43 27.2%
## 2 3 1.9%
##
## Gender
## Married_Count Female Male Prop % by col Female Male
## 0 56 56 64.4% 78.9%
## 1 28 15 32.2% 21.1%
## 2 3 0 3.4% 0.0%
##
## By Gender Fishers Exact p-value=0.0638
## #
## Cleft_Type
## Married_Count Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## 0 16 60 36 64.0% 75.9% 66.7%
## 1 8 18 17 32.0% 22.8% 31.5%
## 2 1 1 1 4.0% 1.3% 1.9%
##
## By Cleft_Type Fishers Exact p-value=0.4993
## #
## Residence_Area
## Married_Count Perth Metro WA Country Prop % by col Perth Metro WA Country
## 0 89 23 71.2% 69.7%
## 1 33 10 26.4% 30.3%
## 2 3 0 2.4% 0.0%
##

```

```
## By Residence_Area Fishers Exact p-value=0.9147
## #
## ABS Age Group
## Married_Count 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
## 0 29 64 19 100.0% 79.0% 39.6%
## 1 0 17 26 0.0% 21.0% 54.2%
## 2 0 0 3 0.0% 0.0% 6.2%
##
## By ABS_Age_Group Fishers Exact p-value=0.0000
## #
```

There was a significant difference in Married_Count by ABS_Age_Group.

Older participants were more likely to be married than younger ones as you would expect.

Marital_Status Within Study

Test study participants for their Marital_Status (Single, divorced etc.) by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```
## Marital_Status Proportions
## De facto 19 12.0%
## Married 39 24.7%
## Re-married 3 1.9%
## Separated/Divorced 4 2.5%
## Single 93 58.9%
##
## Gender
## Marital_Status Female Male Prop % by col Female Male
## De facto 9 10 10.3% 14.1%
## Married 27 12 31.0% 16.9%
## Re-married 3 0 3.4% 0.0%
## Separated/Divorced 1 3 1.1% 4.2%
## Single 47 46 54.0% 64.8%
##
## By Gender Fishers Exact p-value=0.0732
## #
## Cleft_Type
## Marital_Status Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
## De facto 4 12 3 16.0% 15.2% 5.6%
## Married 6 17 16 24.0% 21.5% 29.6%
## Re-married 1 1 1 4.0% 1.3% 1.9%
## Separated/Divorced 2 1 1 8.0% 1.3% 1.9%
## Single 12 48 33 48.0% 60.8% 61.1%
##
## By Cleft_Type Fishers Exact p-value=0.2788
## #
## Residence_Area
## Marital_Status Perth Metro WA Country Prop % by col Perth Metro WA Country
## De facto 16 3 12.8% 9.1%
## Married 29 10 23.2% 30.3%
## Re-married 3 0 2.4% 0.0%
## Separated/Divorced 4 0 3.2% 0.0%
## Single 73 20 58.4% 60.6%
##
## By Residence_Area Fishers Exact p-value=0.7965
## #
## ABS Age Group
## Marital_Status 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
## De facto 1 13 5 3.4% 16.0% 10.4%
## Married 0 16 23 0.0% 19.8% 47.9%
## Re-married 0 0 3 0.0% 0.0% 6.2%
## Separated/Divorced 0 1 3 0.0% 1.2% 6.2%
## Single 28 51 14 96.6% 63.0% 29.2%
##
## By ABS_Age_Group Fishers Exact p-value=0.0000
## #
```

There is a significant difference in Marital_Status by ABS_Age_Group.

Older participants were more likely to be married than younger ones as you would expect.

Single Study v ABS 2012-13

Calculate Odds Ratios and Risk Ratios to compare study participants who had no serious relationships (i.e are Single) with ABS data by age-group. Note the ABS data range of 18-24 is quite different to the youngest study participants (22 years) so do not include this data. See Table 11.1 Estimates worksheet in the ABS Family Characteristics and Transitions, Australia 2012-13 Couples Relationships By Age.xlsx spreadsheet.

```
##                               Marital_Status
## Age_Group 25-34 Remainder Single Prop % by row Remainder Single
##   ABS 2012-13 2772000    616000          81.8%    18.2%
##   Study      30         51          37.0%    63.0%
##
## Odds Ratio=7.65 CI=(4.78,12.44) p.value=0.0000
## The Odds for Single of Marital_Status is at least 378% higher for Study than ABS
2012-13
##
## OR By Age-Group 25-34                               Odds-Ratio    p-value=0.0000
## #
##
## Risk Ratio=3.46 CI=(2.91,4.01) p.value=0.0000
## The Relative Risk for Single of Marital_Status is at least 191% higher for Study
than ABS 2012-13 of Age_Group 25-34
##
## RR By Age-Group 25-34                               Relative Risk p-value=0.0000
## #
##                               Marital_Status
## Age_Group 35-44 Remainder Single Prop % by row Remainder Single
##   ABS 2012-13 2980000    229000          92.9%     7.1%
##   Study      34         14          70.8%    29.2%
##
## Odds Ratio=5.36 CI=(2.66,10.25) p.value=0.0000
## The Odds for Single of Marital_Status is at least 166% higher for Study than ABS
2012-13
##
## OR By Age-Group 35-44                               Odds-Ratio    p-value=0.0000
## #
##
## Risk Ratio=4.09 CI=(2.33,5.85) p.value=0.0000
## The Relative Risk for Single of Marital_Status is at least 133% higher for Study
than ABS 2012-13 of Age_Group 35-44
##
## RR By Age-Group 35-44                               Relative Risk p-value=0.0000
## #
```

There were two significant differences for study participants not having a relationship (i.e. Single).

In each case study participants were significantly more likely to be Single than the Australian general population as measured by the ABS Family Characteristics and Transitions, Australia 2012-13 Couples Relationships By Age survey.

Marital_Status Study v HILDA 2011

Calculate Odds Ratios and Risk Ratios to compare Marital_Status for study participants with HILDA 2011 survey results. Only use age groups 25-34 and 35-44 as the youngest age category in HILDA data is 15-24 which is quite different to the youngest study participants (22).

HILDA = The Household, Income and Labour Dynamics in Australia Survey, Wave 11, 2011
See HILDA Relationships 2011 tab in master database spreadsheet.

Note: HILDA uses Single, Divorced, De facto and Married. The study uses Single, Separated/Divorced, De facto, Married, Re-married. Combine the study Married and Re-married data to compare against the HILDA Married data.

```

##           Marital_Status
## Age_Group 25-34 Remainder Single Prop % by row Remainder Single
##   HILDA 2011    64      36      64.0%    36.0%
##   Study      30      51      37.0%    63.0%
##
## Odds Ratio=3.00 CI=(1.58,5.82) p.value=0.0003
## The Odds for Single of Marital_Status is at least 58% higher for Study than HILDA
A 2011
##
## OR By 25-34 Single                      Odds-Ratio    p-value=0.0003
## #
##
## Risk Ratio=1.75 CI=(1.30,2.47) p.value=0.0003
## The Relative Risk for Single of Marital_Status is at least 30% higher for Study
than HILDA 2011 of Age_Group 25-34
##
## RR By 25-34 Single                      Relative Risk p-value=0.0003
## #
##           Marital_Status
## Age_Group 25-34 Remainder Separated/Divorced Prop % by row Remainder Separated/D
ivorced
##   Study      80      1      98.8%    1.2%
##   HILDA 2011  97      3      97.0%    3.0%
##
## Odds Ratio=2.46 CI=(0.19,131.40) p.value=0.6292
## Lower CI <=1 for Separated/Divorced of Marital_Status indicates no significant d
ifference between HILDA 2011 and Study
##
## OR By 25-34 Separated/Divorced          Odds-Ratio    p-value=0.6292
## #
##
## Risk Ratio=2.43 CI=(0.26,22.92) p.value=0.6292
## Lower CI <=1 for Separated/Divorced of Marital_Status indicates no significant d
ifference between HILDA 2011 and Study
##
## RR By 25-34 Separated/Divorced          Relative Risk p-value=0.6292
## #
##           Marital_Status
## Age_Group 25-34 Remainder De facto Prop % by row Remainder De facto
##   Study      68      13      84.0%    16.0%
##   HILDA 2011  79      21      79.0%    21.0%
##
## Odds Ratio=1.39 CI=(0.61,3.26) p.value=0.4475
## Lower CI <=1 for De facto of Marital_Status indicates no significant difference
between HILDA 2011 and Study
##
## OR By 25-34 De facto                    Odds-Ratio    p-value=0.4475
## #
##
## Risk Ratio=1.31 CI=(0.71,2.66) p.value=0.4475
## Lower CI <=1 for De facto of Marital_Status indicates no significant difference
between HILDA 2011 and Study
##
## RR By 25-34 De facto                    Relative Risk p-value=0.4475
## #
##           Marital_Status
## Age_Group 25-34 Remainder Married Prop % by row Remainder Married
##   Study      65      16      80.2%    19.8%
##   HILDA 2011  59      41      59.0%    41.0%
##
## Odds Ratio=2.81 CI=(1.37,5.96) p.value=0.0023
## The Odds for Married of Marital_Status is at least 37% higher for HILDA 2011 tha

```

```

n Study
##
## OR By 25-34 Married                      Odds-Ratio    p-value=0.0023
## #
##
## Risk Ratio=2.08  CI=(1.30,3.69)  p.value=0.0023
## The Relative Risk for Married of Marital_Status is at least 30% higher for HILDA
2011 than Study of Age_Group 25-34
##
## RR By 25-34 Married                      Relative Risk p-value=0.0023
## #
##           Marital_Status
## Age_Group 35-44 Remainder Single Prop % by row Remainder Single
##   HILDA 2011      84      16      84.0%      16.0%
##   Study           34      14      70.8%      29.2%
##
## Odds Ratio=2.15  CI=(0.87,5.30)  p.value=0.0805
## Lower CI <=1 for Single of Marital_Status indicates no significant difference be
tween Study and HILDA 2011
##
## OR By 35-44 Single                      Odds-Ratio    p-value=0.0805
## #
##
## Risk Ratio=1.82  CI=(0.94,3.54)  p.value=0.0805
## Lower CI <=1 for Single of Marital_Status indicates no significant difference be
tween Study and HILDA 2011
##
## RR By 35-44 Single                      Relative Risk p-value=0.0805
## #
##           Marital_Status
## Age_Group 35-44 Remainder Separated/Divorced Prop % by row Remainder Separated/D
ivorced
##   Study           45      3      93.8%      6.2%
##   HILDA 2011     92      8      92.0%      8.0%
##
## Odds Ratio=1.30  CI=(0.29,7.98)  p.value=1.0000
## Lower CI <=1 for Separated/Divorced of Marital_Status indicates no significant d
ifference between HILDA 2011 and Study
##
## OR By 35-44 Separated/Divorced          Odds-Ratio    p-value=1.0000
## #
##
## Risk Ratio=1.28  CI=(0.38,Inf)  p.value=1.0000
## Lower CI <=1 for Separated/Divorced of Marital_Status indicates no significant d
ifference between HILDA 2011 and Study
##
## RR By 35-44 Separated/Divorced          Relative Risk p-value=1.0000
## #
##           Marital_Status
## Age_Group 35-44 Remainder De facto Prop % by row Remainder De facto
##   Study           43      5      89.6%      10.4%
##   HILDA 2011     86      14     86.0%      14.0%
##
## Odds Ratio=1.40  CI=(0.44,5.29)  p.value=0.6104
## Lower CI <=1 for De facto of Marital_Status indicates no significant difference
between HILDA 2011 and Study
##
## OR By 35-44 De facto                    Odds-Ratio    p-value=0.6104
## #
##
## Risk Ratio=1.34  CI=(0.55,5.76)  p.value=0.6104
## Lower CI <=1 for De facto of Marital_Status indicates no significant difference
between HILDA 2011 and Study
##
## RR By 35-44 De facto                    Relative Risk p-value=0.6104
## #
##           Marital_Status
## Age_Group 35-44 Remainder Married Prop % by row Remainder Married

```

```

##      Study      22      26      45.8%    54.2%
##      HILDA 2011  37      63      37.0%    63.0%
##
## Odds Ratio=1.44 CI=(0.67,3.06) p.value=0.3704
## Lower CI <=1 for Married of Marital_Status indicates no significant difference b
etween HILDA 2011 and Study
##
## OR By 35-44 Married                      Odds-Ratio    p-value=0.3704
## #
##
## Risk Ratio=1.16 CI=(0.88,1.63) p.value=0.3704
## Lower CI <=1 for Married of Marital_Status indicates no significant difference b
etween HILDA 2011 and Study
##
## RR By 35-44 Married                      Relative Risk p-value=0.3704
## #

```

There were two significant differences between study and HILDA data for Marital_Status.

Study participants in the 25-34 age group were more likely to be single and less likely to be married than the Australian general population as reported in the HILDA 2011 survey.

Registered Marital Status 25-44 Study v ABS WA 2011

Compare Registered Marital Status for study participants in the age range 25-44 years with ABS 2011 Census results for Western Australia. See WA Marital Status 2011 tab in master database spreadsheet which uses: Married, Never Married, Separated/Divorced, Widowed. Use the same categories from the study as follows: Married = Married + Re-married, Never Married = Single + De facto, Separated/Divorced = Separated/Divorced. There were no Widows in the study so do not report this category.

```

##      Registered Marital Status
## Group 25-44 Remainder Married Prop % by row Remainder Married
##      Study      87      42      67.4%    32.6%
##      ABS 2011 323748  332239  49.4%    50.6%
##
## Odds Ratio=2.13 CI=(1.45,3.15) p.value=0.0000
## The Odds for Married of Registered Marital Status is at least 45% higher for ABS
2011 than Study
##
## OR By 25-44 Married                      Odds-Ratio    p-value=0.0000
## #
##
## Risk Ratio=1.56 CI=(1.23,2.04) p.value=0.0000
## The Relative Risk for Married of Registered Marital Status is at least 23% highe
r for ABS 2011 than Study of Group 25-44
##
## RR By 25-44 Married                      Relative Risk p-value=0.0000
## #
##      Registered Marital Status
## Group 25-44 Remainder Never Married Prop % by row Remainder Never Married
##      ABS 2011 387495  268492  59.1%    40.9%
##      Study      46      83      35.7%    64.3%
##
## Odds Ratio=2.60 CI=(1.80,3.82) p.value=0.0000
## The Odds for Never Married of Registered Marital Status is at least 80% higher f
or Study than ABS 2011
##
## OR By 25-44 Never Married                Odds-Ratio    p-value=0.0000
## #
##
## Risk Ratio=1.57 CI=(1.36,1.78) p.value=0.0000
## The Relative Risk for Never Married of Registered Marital Status is at least 36%
higher for Study than ABS 2011 of Group 25-44
##

```



```

## RR By 25-44 Never Married                               Relative Risk p-value=0.0000
## #
## Registered Marital Status
## Group 25-44 Remainder Separated/Divorced Prop % by row Remainder Separated/Divorced
## Study          125          4          96.9%          3.1%
## ABS 2011 602804    53183          91.9%          8.1%
##
## Odds Ratio=2.76 CI=(1.05,10.28) p.value=0.0346
## The Odds for Separated/Divorced of Registered Marital Status is at least 5% higher for ABS 2011 than Study
##
## OR By 25-44 Separated/Divorced                         Odds-Ratio    p-value=0.0346
## #
## Risk Ratio=2.61 CI=(1.30,10.52) p.value=0.0346
## The Relative Risk for Separated/Divorced of Registered Marital Status is at least 30% higher for ABS 2011 than Study of Group 25-44
##
## RR By 25-44 Separated/Divorced                         Relative Risk p-value=0.0346
## #

```

Age_1st_Relationship Study v Mu=15

Compare the median age of first serious relationship for study participants with the population median of 15 from Price M, et al, Young Love: Romantic Concerns and associated mental health issues among adolescent help seekers. Behaviour Science, May 2016. Only include those who have had at least 1 relationship in the study.

```

## Age_1st_Relationship Proportions
## 15      1      0.9%
## 16     10     9.1%
## 17     15    13.6%
## 18     17    15.5%
## 19     19    17.3%
## 20     10     9.1%
## 21     11    10.0%
## 22      6     5.5%
## 23      7     6.4%
## 24      9     8.2%
## 26      1     0.9%
## 27      1     0.9%
## 28      1     0.9%
## 31      1     0.9%
## 33      1     0.9%
## Study median age 1st relationship = 19 v Price et al = 15 years
##
## At Least 1 Relationship                               Wilcoxon      p-value=0.0000
## #

```

There was a significant difference in Age_1st_Relationship for study participants compared to population median.

Study participants were significantly older (median=19) compared to the population (median=15).

Age_1st_Married Study v AIFS 2013

Compare the median age of first marriage for study participants with the population median of 30.8 for males and 28.1 for females from Australian Institute of Family Studies (AIFS Marriage in Australia source data 2013.pdf). Only include those who have had at least 1 marriage in the study.

```

## Age_1st_Married Proportions
## 20      1      6.7%
## 21      1      6.7%
## 26      4     26.7%
## 27      1      6.7%
## 28      2     13.3%

```

```

## 29      1      6.7%
## 31      1      6.7%
## 33      1      6.7%
## 34      1      6.7%
## 35      2     13.3%
## Study median age 1st married for Males = 28 v AIFS Males = 29.9 years
##
## Married Males                               Wilcoxon      p-value=0.3623
## #
##   Age_1st_Married Proportions
## 18      1      3.2%
## 20      1      3.2%
## 21      2      6.5%
## 22      2      6.5%
## 23      5     16.1%
## 24      1      3.2%
## 25      2      6.5%
## 26      3      9.7%
## 27      3      9.7%
## 28      3      9.7%
## 29      1      3.2%
## 30      5     16.1%
## 31      2      6.5%
## Study median age 1st married for Females = 26 v AIFS Females = 28.3 years
##
## Married Females                             Wilcoxon      p-value=0.0016
## #

```

There is a significant difference in female median Age_1st_Married compared to AIF population median.

Female study participants married earlier than the general population. However, only 46 out of 158 (29%) married at all.

Counselling_Before Children Within Study

Test if study participants thought Genetic Counselling was important before having children by Gender, Cleft_Type, Residence_Area and ABS_Age_Group. Quite a number of study participants did not answer this question (N/A). Only include if responses was Y or N.

```

## Counselling_Before Proportions
## N      51      39.8%
## Y      77      60.2%
##
##           Gender
## Counselling_Before Female Male Prop % by col Female Male
##           N      25      26      35.2%  45.6%
##           Y      46      31      64.8%  54.4%
##
## By Gender                               Fishers Exact p-value=0.2771
## #
##           Cleft_Type
## Counselling_Before Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N      12      22      17      57.1%  31.9%  44.7%
##           Y      9      47      21      42.9%  68.1%  55.3%
##
## By Cleft_Type                             Fishers Exact p-value=0.0920
## #
##           Residence_Area
## Counselling_Before Perth Metro WA Country Prop % by col Perth Metro WA Country
##           N      39      12      38.6%  44.4%
##           Y      62      15      61.4%  55.6%
##
## By Residence_Area                         Fishers Exact p-value=0.6599
## #
##           ABS_Age_Group
## Counselling_Before 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##           N      8      24      19      40.0%  34.8%  48.7%
##           Y      12     45      20      60.0%  65.2%  51.3%
##

```

```
## By ABS_Age_Group Fishers Exact p-value=0.3840
## #
```

There were no significant differences for Counselling_Before by Gender, Cleft_Type, Residence_Area or ABS_Age_Group.

Psychosocial Issues

Psychosocial Issues by Gender

Determine significant differences in the following psychosocial issues variables by Gender: Anxiety, Depression, Lack_Motivation, Panic_Attacks, Impact_Self_Esteem, Self_Harm, Suicidal_Thoughts, Unworthy.

```
## Gender
## Anxiety Female Male Prop % by col Female Male
## N 37 46 42.5% 64.8%
## Y 50 25 57.5% 35.2%
##
## By Anxiety Fishers Exact p-value=0.0065
## #
## Gender
## Depression Female Male Prop % by col Female Male
## N 45 45 51.7% 63.4%
## Y 42 26 48.3% 36.6%
##
## By Depression Fishers Exact p-value=0.1500
## #
## Gender
## Lack_Motivation Female Male Prop % by col Female Male
## N 43 35 49.4% 49.3%
## Y 44 36 50.6% 50.7%
##
## By Lack_Motivation Fishers Exact p-value=1.0000
## #
## Gender
## Panic_Attacks Female Male Prop % by col Female Male
## N 61 63 70.1% 88.7%
## Y 26 8 29.9% 11.3%
##
## By Panic_Attacks Fishers Exact p-value=0.0060
## #
## Gender
## Impact_Self_Esteem Female Male Prop % by col Female Male
## N 29 29 33.3% 40.8%
## Y 58 42 66.7% 59.2%
##
## By Impact_Self_Esteem Fishers Exact p-value=0.4070
## #
## Gender
## Self_Harm Female Male Prop % by col Female Male
## N 68 62 78.2% 87.3%
## Y 19 9 21.8% 12.7%
##
## By Self_Harm Fishers Exact p-value=0.1482
## #
## Gender
## Suicidal_Thoughts Female Male Prop % by col Female Male
## N 67 53 77.0% 74.6%
## Y 20 18 23.0% 25.4%
##
## By Suicidal_Thoughts Fishers Exact p-value=0.8518
## #
## Gender
## Unworthy Female Male Prop % by col Female Male
## N 47 40 54.0% 56.3%
```

```
##           Y      40      31              46.0%  43.7%
##
## By Unworthy                               Fishers Exact p-value=0.8724
## #
```

There were two significant differences for Psychosocial Issues by Gender:

Female study participants were more likely to report Anxiety and Panic_Attacks than males.

Anxiety and Panic_Attacks by Gender

Calculate Odds Ratios and Risk Ratios for study participants with Anxiety and Panic_Attacks by gender to get 95%CI.

```
##           Psychosocial_Issue
## Gender   No Anxiety Has Anxiety Prop % by row No Anxiety Has Anxiety
##   Male      46        25          64.8%      35.2%
##   Female    37        50          42.5%      57.5%
##
## Odds Ratio=2.47 CI=(1.24,5.00) p.value=0.0065
## The Odds for Has Anxiety of Psychosocial_Issue is at least 24% higher for Female
than Male
##
## OR By Anxiety                               Odds-Ratio    p-value=0.0065
## #
##
## Risk Ratio=1.63 CI=(1.15,2.45) p.value=0.0065
## The Relative Risk for Has Anxiety of Psychosocial_Issue is at least 15% higher f
or Female than Male of Gender
##
## RR By Anxiety                               Relative Risk p-value=0.0065
## #
##           Psychosocial_Issue
## Gender   No Panic Attacks Has Panic Attacks Prop % by row No Panic Attacks Has P
anic Attacks
##   Male      63            8          88.7%          11.3
%
##   Female    61            26          70.1%          29.9
%
##
## Odds Ratio=3.33 CI=(1.34,9.20) p.value=0.0060
## The Odds for Has Panic Attacks of Psychosocial_Issue is at least 34% higher for
Female than Male
##
## OR By Panic_Attacks                       Odds-Ratio    p-value=0.0060
## #
##
## Risk Ratio=2.65 CI=(1.39,6.80) p.value=0.0060
## The Relative Risk for Has Panic Attacks of Psychosocial_Issue is at least 39% hi
gher for Female than Male of Gender
##
## RR By Panic_Attacks                       Relative Risk p-value=0.0060
## #
```

Psychosocial Issues by Cleft_Type

Determine significant differences in the following psychosocial issues variables by Cleft_Type:

Anxiety, Depression, Lack_Motivation, Panic_Attacks, Impact_Self_Esteem, Self_Harm, Suicidal_Thoughts, Unworthy.

```
##           Cleft_Type
## Anxiety Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   N      14      44      25          56.0%   55.7%   46.3%
##   Y      11      35      29          44.0%   44.3%   53.7%
##
## By Anxiety                               Fishers Exact p-value=0.5323
## #
##           Cleft_Type
## Depression Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   N      15      45      30          60.0%   57.0%   55.6%
```

```

##           Y      10      34      24      40.0%  43.0%  44.4%
##
## By Depression                               Fishers Exact p-value=0.9523
## #
##           Cleft_Type
## Lack_Motivation Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N      11      38      29      44.0%  48.1%  53.7%
##           Y      14      41      25      56.0%  51.9%  46.3%
##
## By Lack Motivation                           Fishers Exact p-value=0.6955
## #
##           Cleft_Type
## Panic_Attacks Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N      22      64      38      88.0%  81.0%  70.4%
##           Y       3      15      16      12.0%  19.0%  29.6%
##
## By Panic_Attacks                             Fishers Exact p-value=0.1785
## #
##           Cleft_Type
## Impact_Self_Esteem Lip-Only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N       8      21      29      32.0%  26.6%  53.7%
##           Y      17      58      25      68.0%  73.4%  46.3%
##
## By Impact Self Esteem                       Fishers Exact p-value=0.0056
## #
##           Cleft_Type
## Self_Harm Lip-Only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N      24      65      41      96.0%  82.3%  75.9%
##           Y       1      14      13       4.0%  17.7%  24.1%
##
## By Self_Harm                                 Fishers Exact p-value=0.0759
## #
##           Cleft_Type
## Suicidal_Thoughts Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N      21      59      40      84.0%  74.7%  74.1%
##           Y       4      20      14      16.0%  25.3%  25.9%
##
## By Suicidal Thoughts                         Fishers Exact p-value=0.6505
## #
##           Cleft_Type
## Unworthy Lip-Only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N      14      39      34      56.0%  49.4%  63.0%
##           Y      11      40      20      44.0%  50.6%  37.0%
##
## By Unworthy                                  Fishers Exact p-value=0.3006
## #

```

There was one significant difference for Psychosocial Issues by Cleft_Type: Self Esteem.

Impact_Self_Esteem by Cleft_Type

Calculate Odds Ratios and Risk Ratios for study participant Impact_Self_Esteem by Cleft_Type to get 95%CI.

```

##           Impact_Self_Esteem
## Cleft_Type   Has Impact No Impact Prop % by row Has Impact No Impact
## Remainder    75         29         72.1%  27.9%
## Palate-only  25         29         46.3%  53.7%
##
## Odds Ratio=2.98 CI=(1.43,6.30) p.value=0.0018
## The Odds for No Impact of Impact_Self_Esteem is at least 43% higher for Palate-only than Remainder
##
## OR By Palate-only                            Odds-Ratio    p-value=0.0018
## #
##
## Risk Ratio=1.93 CI=(1.30,2.89) p.value=0.0018
## The Relative Risk for No Impact of Impact_Self_Esteem is at least 30% higher for Palate-only than Remainder of Cleft_Type
##
## RR By Palate-only                            Relative Risk p-value=0.0018
## #
##           Impact_Self_Esteem
## Cleft_Type   No Impact Has Impact Prop % by row No Impact Has Impact
## Remainder    37         42         46.8%  53.2%
## Lip & Palate  21         58         26.6%  73.4%
##

```

```

## Odds Ratio=2.42 CI=(1.19,5.02) p.value=0.0130
## The Odds for Has Impact of Impact_Self_Esteem is at least 19% higher for Lip & P
alate than Remainder
##
## OR By Lip & Palate Odds-Ratio p-value=0.0130
## #
##
## Risk Ratio=1.38 CI=(1.09,1.79) p.value=0.0130
## The Relative Risk for Has Impact of Impact_Self_Esteem is at least 9% higher for
Lip & Palate than Remainder of Cleft_Type
##
## RR By Lip & Palate Relative Risk p-value=0.0130
## #
## Impact_Self_Esteem
## Cleft_Type No Impact Has Impact Prop % by row No Impact Has Impact
## Remainder 50 83 37.6% 62.4%
## Lip-only 8 17 32.0% 68.0%
##
## Odds Ratio=1.28 CI=(0.48,3.68) p.value=0.6570
## Lower CI <=1 for Has Impact of Impact_Self_Esteem indicates no significant diffe
rence between Lip-only and Remainder
##
## OR By Lip-only Odds-Ratio p-value=0.6570
## #
##
## Risk Ratio=1.09 CI=(0.77,1.43) p.value=0.6570
## Lower CI <=1 for Has Impact of Impact_Self_Esteem indicates no significant diffe
rence between Lip-only and Remainder
##
## RR By Lip-only Relative Risk p-value=0.6570
## #

```

Cleft_Type of Palate-only is less likely and Lip & Palate is more likely to have self esteem impacted.

Psychosocial Issues by Residence_Area

Determine significant differences in the following psychosocial issues variables by Residence_Area: Anxiety, Depression, Lack_Motivation, Panic_Attacks, Impact_Self_Esteem, Self_Harm, Suicidal_Thoughts, Unworthy.

```

## Residence_Area
## Anxiety Perth Metro WA Country Prop % by col Perth Metro WA Country
## N 65 18 52.0% 54.5%
## Y 60 15 48.0% 45.5%
##
## By Anxiety Fishers Exact p-value=0.8463
## #
## Residence_Area
## Depression Perth Metro WA Country Prop % by col Perth Metro WA Country
## N 70 20 56.0% 60.6%
## Y 55 13 44.0% 39.4%
##
## By Depression Fishers Exact p-value=0.6956
## #
## Residence_Area
## Lack_Motivation Perth Metro WA Country Prop % by col Perth Metro WA Country
## N 62 16 49.6% 48.5%
## Y 63 17 50.4% 51.5%
##
## By Lack_Motivation Fishers Exact p-value=1.0000
## #
## Residence_Area
## Panic_Attacks Perth Metro WA Country Prop % by col Perth Metro WA Country
## N 98 26 78.4% 78.8%
## Y 27 7 21.6% 21.2%
##

```

```

## By Panic_Attacks                      Fishers Exact p-value=1.0000
## #
##           Residence_Area
## Impact_Self_Esteem Perth Metro WA Country Prop % by col Perth Metro WA Country
##           N      42          16          33.6%          48.5%
##           Y      83          17          66.4%          51.5%
##
## By Impact_Self_Esteem                  Fishers Exact p-value=0.1546
## #
##           Residence_Area
## Self_Harm Perth Metro WA Country Prop % by col Perth Metro WA Country
##           N     103          27          82.4%          81.8%
##           Y      22           6          17.6%          18.2%
##
## By Self_Harm                           Fishers Exact p-value=1.0000
## #
##           Residence_Area
## Suicidal_Thoughts Perth Metro WA Country Prop % by col Perth Metro WA Country
##           N      92          28          73.6%          84.8%
##           Y      33           5          26.4%          15.2%
##
## By Suicidal_Thoughts                   Fishers Exact p-value=0.2522
## #
##           Residence_Area
## Unworthy Perth Metro WA Country Prop % by col Perth Metro WA Country
##           N      66          21          52.8%          63.6%
##           Y      59          12          47.2%          36.4%
##
## By Unworthy                            Fishers Exact p-value=0.3267
## #

```

There were no significant differences in Psychosocial Issues by Residence_Area.

Psychosocial Issues by ABS_Age_Group

Determine significant differences in the following psychosocial issues variables by ABS_Age_Group: Anxiety, Depression, Lack_Motivation, Panic_Attacks, Impact_Self_Esteem, Self_Harm, Suicidal_Thoughts, Unworthy.

```

##           ABS_Age_Group
## Anxiety 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##           N     17     39     27          58.6%  48.1%  56.2%
##           Y     12     42     21          41.4%  51.9%  43.8%
##
## By Anxiety                             Fishers Exact p-value=0.5423
## #
##           ABS_Age_Group
## Depression 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##           N      18     46     26          62.1%  56.8%  54.2%
##           Y      11     35     22          37.9%  43.2%  45.8%
##
## By Depression                          Fishers Exact p-value=0.8069
## #
##           ABS_Age_Group
## Lack_Motivation 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##           N      14     39     25          48.3%  48.1%  52.1%
##           Y      15     42     23          51.7%  51.9%  47.9%
##
## By Lack_Motivation                     Fishers Exact p-value=0.9100
## #
##           ABS_Age_Group
## Panic_Attacks 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##           N      23     58     43          79.3%  71.6%  89.6%
##           Y       6     23     5          20.7%  28.4%  10.4%
##
## By Panic_Attacks                       Fishers Exact p-value=0.0486
## #

```

```

##          ABS_Age_Group
## Impact_Self_Esteem 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##          N      13      27      18          44.8% 33.3% 37.5%
##          Y      16      54      30          55.2% 66.7% 62.5%
##
## By Impact_Self_Esteem          Fishers Exact p-value=0.5316
## #
##          ABS_Age_Group
## Self_Harm 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##          N      25      66      39          86.2% 81.5% 81.2%
##          Y       4      15       9          13.8% 18.5% 18.8%
##
## By Self_Harm          Fishers Exact p-value=0.8878
## #
##          ABS_Age_Group
## Suicidal_Thoughts 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##          N      24      59      37          82.8% 72.8% 77.1%
##          Y       5      22      11          17.2% 27.2% 22.9%
##
## By Suicidal_Thoughts          Fishers Exact p-value=0.6011
## #
##          ABS_Age_Group
## Unworthy 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##          N      18      40      29          62.1% 49.4% 60.4%
##          Y      11      41      19          37.9% 50.6% 39.6%
##
## By Unworthy          Fishers Exact p-value=0.3495
## #

```

There were no significant differences in Psychosocial Issues by ABS_Age_Group.

At least 1 Psychosocial Issue

Special case: Determine At least 1 of the psychosocial issues (OR them all together). Determine significant differences by Gender, Cleft_Type, Residence_Area and ABS_Age_Group: Anxiety, Depression, Lack_Motivation, Panic_Attacks, Impact_Self_Esteem, Self_Harm, Suicidal_Thoughts, Unworthy.

```

##          Gender
## Psychosocial Issues Female Male Prop % by col Female Male
##          At Least 1      72      51          82.8% 71.8%
##          No Issues      15      20          17.2% 28.2%
##
## By Gender          Fishers Exact p-value=0.1240
## #
##          Cleft_Type
## Psychosocial Issues Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          At Least 1      20      67      36          80.0% 84.8% 66.7%
##          No Issues       5      12      18          20.0% 15.2% 33.3%
##
## By Cleft_Type          Fishers Exact p-value=0.0493
## #
##          Residence_Area
## Psychosocial Issues Perth Metro WA Country Prop % by col Perth Metro WA Country
##          At Least 1      100      23          80.0% 69.7%
##          No Issues       25      10          20.0% 30.3%
##
## By Residence_Area          Fishers Exact p-value=0.2397
## #
##          ABS_Age_Group
## Psychosocial Issues 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##          At Least 1      21      67      35          72.4% 82.7% 72.9%
##          No Issues       8      14      13          27.6% 17.3% 27.1%
##
## By ABS_Age_Group          Fishers Exact p-value=0.3125
## #

```


Although there was one significant difference reported (by Cleft_Type) it's p-value (0.0493) is so close to 0.05 that it can be disregarded. The remainder were all non-significant.

Anxiety and Depression Study v ABS WA 2014

Compare Study Psychosocial Issues of Anxiety and Depression with ABS National Health Survey (2014-15) in Western Australia over the age range 25-44 years. See WA Health Survey 2014 tab in the Master data spreadsheet.

```
##          Psychosocial_Issue
## Age_Group 25-34 No Anxiety Has Anxiety Prop % by row No Anxiety Has Anxiety
## ABS 2014-15 667900      67900      90.8%      9.2%
## Study      66          63      51.2%      48.8%
##
## Odds Ratio=9.39 CI=(6.54,13.47) p.value=0.0000
## The Odds for Has Anxiety of Psychosocial_Issue is at least 554% higher for Study
than ABS 2014-15
##
## OR By Anxiety 25-44      Odds-Ratio      p-value=0.0000
## #
##
## Risk Ratio=5.29 CI=(4.36,6.23) p.value=0.0000
## The Relative Risk for Has Anxiety of Psychosocial_Issue is at least 336% higher
for Study than ABS 2014-15 of Age_Group 25-34
##
## RR By Anxiety 25-44      Relative Risk p-value=0.0000
## #
##          Psychosocial_Issue
## Age_Group 25-34 No Depression Has Depression Prop % by row No Depression Has Dep
ression
## ABS 2014-15 678200      57600      92.2%      7.8%
## Study      72          57      55.8%      44.2%
##
## Odds Ratio=9.32 CI=(6.47,13.39) p.value=0.0000
## The Odds for Has Depression of Psychosocial_Issue is at least 547% higher for St
udy than ABS 2014-15
##
## OR By Depression 25-44      Odds-Ratio      p-value=0.0000
## #
##
## Risk Ratio=5.64 CI=(4.55,6.74) p.value=0.0000
## The Relative Risk for Has Depression of Psychosocial_Issue is at least 355% high
er for Study than ABS 2014-15 of Age_Group 25-34
##
## RR By Depression 25-44      Relative Risk p-value=0.0000
## #
```

There were significant difference for both Anxiety and Depression between Study and ABS WA 2014-15.

Study participatns in the age range 25-44 are significantly more likely to experience Anxiety and Depression than the WA general population as reported in the ABS National Health Survey First Results 2014-15.

Anxiety Within Study

Test Anxiety by Education_Level, Marital_Status, Housing, Annual_Income, Imp_Face_Appearance and Body_Weight.

```
##          Education_Level
## Anxiety High School TAFE Cert/Diploma Uni Degree Uni Post Grad Prop % by col High School TAFE Cert/Diploma Uni Degree
## N 25 23 26 9 53.2% 46.0% 60.5%
## Y 22 27 17 9 46.8% 54.0% 39.5%
##          Education_Level
## Anxiety Uni Post Grad
## N 50.0%
## Y 50.0%
```

```

##
## By Education_Level Fishers Exact p-value=0.5584
## #
## Marital_Status
## Anxiety De facto Married Re-married Separated/Divorced Single Prop % by col De facto Married Re-married Separated/Divorced Single
## N 10 23 1 3 46 52.6% 59.0% 33.3% 75.0% 49.5%
## Y 9 16 2 1 47 47.4% 41.0% 66.7% 25.0% 50.5%
##
## By Marital_Status Fishers Exact p-value=0.7170
## #
## Housing
## Anxiety Government Own Home Parents/Family Rent Work Prop % by col Government Own Home Parents/Family Rent Work
## N 0 34 30 18 1 0.0% 58.6% 56.6% 42.9% 100.0%
## Y 4 24 23 24 0 100.0% 41.4% 43.4% 57.1% 0.0%
##
## By Housing Fishers Exact p-value=0.0682
## #
## Annual_Income
## Anxiety <100K <30K <60K 100K+ Prop % by col <100K <30K <60K 100K+
## N 22 25 24 12 61.1% 45.5% 48.0% 70.6%
## Y 14 30 26 5 38.9% 54.5% 52.0% 29.4%
##
## By Annual_Income Fishers Exact p-value=0.1904
## #
## Imp_Face_Appearance
## Anxiety Extremely Not At All Not Very Somewhat Very Prop % by col Extremely Not At All Not Very Somewhat Very
## N 15 2 8 25 33 38.5% 40.0% 72.7% 53.2% 58.9%
## Y 24 3 3 22 23 61.5% 60.0% 27.3% 46.8% 41.1%
##
## By Imp_Face_Appearance Fishers Exact p-value=0.1913
## #
## Body_Weight
## Anxiety Little Over Normal Quite Over Under Prop % by col Little Over Normal Quite Over Under
## N 28 45 3 7 50.0% 58.4% 20.0% 70.0%
## Y 28 32 12 3 50.0% 41.6% 80.0% 30.0%
##
## By Body_Weight Fishers Exact p-value=0.0305
## #

```

There were no significant differences in Anxiety by Education_Level, Marital_Status, Housing, Annual_Income, Imp_Face_Appearance or Body_Weight.

Depression

Test Depression by Education_Level, Marital_Status, Housing, Annual_Income, Imp_Face_Appearance and Body_Weight.

```

##
## Education_Level
## Depression High School TAFE CeRT/Diploma Uni Degree Uni Post Grad Prop % by col High School TAFE CeRT/Diploma Uni Degree
## N 26 25 28 11 55.3% 50.0% 65.1%
## Y 21 25 15 7 44.7% 50.0% 34.9%
##
## Education_Level
## Depression Uni Post Grad
## N 61.1%
## Y 38.9%
##
## By Education_Level Fishers Exact p-value=0.5123
## #
## Marital_Status
## Depression De facto Married Re-married Separated/Divorced Single Prop % by col De facto Married Re-married Separated/Divorced
## N 11 24 2 2 51 57.9% 61.5% 66.7% 50.0%
## Y 8 15 1 2 42 42.1% 38.5% 33.3% 50.0%
##
## Marital_Status
## Depression Single
## N 54.8%
## Y 45.2%
##
## By Marital_Status Fishers Exact p-value=0.9596
## #
## Housing
## Depression Government Own Home Parents/Family Rent Work Prop % by col Government Own Home Parents/Family Rent Work
## N 2 37 32 18 1 50.0% 63.8% 60.4% 42.9% 100.0%
## Y 2 21 21 24 0 50.0% 36.2% 39.6% 57.1% 0.0%

```

```

##
## By Housing                               Fishers Exact p-value=0.1936
## #
##           Annual_Income
## Depression <100K <30K <60K 100K+ Prop % by col <100K <30K <60K 100K+
##           N      24    28    25    13          66.7%  50.9%  50.0%  76.5%
##           Y      12    27    25     4          33.3%  49.1%  50.0%  23.5%
##
## By Annual_Income                         Fishers Exact p-value=0.1240
## #
##           Imp_Face_Appearance
## Depression Extremely Not At All Not Very Somewhat Very Prop % by col Extremely Not At All Not Very Somewhat Very
##           N      20     3     7     27    33          51.3%  60.0%  63.6%  57.4%  58.9%
##           Y      19     2     4     20    23          48.7%  40.0%  36.4%  42.6%  41.1%
##
## By Imp_Face_Appearance                   Fishers Exact p-value=0.9465
## #
##           Body_Weight
## Depression Little Over Normal Quite Over Under Prop % by col Little Over Normal Quite Over Under
##           N      32     47     3     8          57.1%  61.0%  20.0%  80.0%
##           Y      24     30    12     2          42.9%  39.0%  80.0%  20.0%
##
## By Body_Weight                           Fishers Exact p-value=0.0118
## #

```

There were no significant differences in Depression by Education_Level, Marital_Status, Housing, Annual_Income, Imp_Face_Appearance or Body_Weight.

General Health

Long_Term_Cond

Test Long-term medical condition by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```

## Long_Term_Cond Proportions
## N      110          69.6%
## Y       48          30.4%
##
##           Gender
## Long_Term_Cond Female Male Prop % by col Female Male
##           N      58     52          66.7%  73.2%
##           Y      29     19          33.3%  26.8%
##
## By Gender                               Fishers Exact p-value=0.3904
## #
##           Cleft_Type
## Long_Term_Cond Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##           N      18     59     33          72.0%  74.7%  61.1%
##           Y       7     20     21          28.0%  25.3%  38.9%
##
## By Cleft_Type                           Fishers Exact p-value=0.2533
## #
##           Residence_Area
## Long_Term_Cond Perth Metro WA Country Prop % by col Perth Metro WA Country
##           N      88     22          70.4%  66.7%
##           Y      37     11          29.6%  33.3%
##
## By Residence_Area                       Fishers Exact p-value=0.6755
## #
##           ABS_Age_Group
## Long_Term_Cond 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##           N      21     54     35          72.4%  66.7%  72.9%
##           Y       8     27     13          27.6%  33.3%  27.1%
##
## By ABS_Age_Group                         Fishers Exact p-value=0.7369
## #

```

There were no significant differences for Long_Term_Cond by Gender, Cleft_Type, Residence_Area or ABS_Age_Group.

Drink_Alcohol Within Study

Test frequency of drinking alcohol by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```
##          Drink_Alcohol Proportions
## Daily          13          8.2%
## Monthly         27         17.1%
## Never           25         15.8%
## Seldom          29         18.4%
## Weekly          64         40.5%
##
##          Gender
## Drink_Alcohol Female Male Prop % by col Female Male
##      Daily      3      10      3.4% 14.1%
##     Monthly     14     13     16.1% 18.3%
##      Never      18      7     20.7%  9.9%
##     Seldom     19     10     21.8% 14.1%
##     Weekly     33     31     37.9% 43.7%
##
## By Gender                               Fishers Exact p-value=0.0419
## #
##          Cleft_Type
## Drink Alcohol Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##      Daily      4      5      4     16.0%  6.3%  7.4%
##     Monthly     0     19      8     0.0% 24.1% 14.8%
##      Never      3     13      9     12.0% 16.5% 16.7%
##     Seldom     4     14     11     16.0% 17.7% 20.4%
##     Weekly     14     28     22     56.0% 35.4% 40.7%
##
## By Cleft_Type                             Fishers Exact p-value=0.1236
## #
##          Residence_Area
## Drink_Alcohol Perth Metro WA Country Prop % by col Perth Metro WA Country
##      Daily      10      3      8.0%  9.1%
##     Monthly     18      9     14.4% 27.3%
##      Never      18      7     14.4% 21.2%
##     Seldom     26      3     20.8%  9.1%
##     Weekly     53     11     42.4% 33.3%
##
## By Residence_Area                         Fishers Exact p-value=0.2020
## #
##          ABS_Age_Group
## Drink_Alcohol 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##      Daily      3      4      6     10.3%  4.9% 12.5%
##     Monthly     5     14      8     17.2% 17.3% 16.7%
##      Never      3     15      7     10.3% 18.5% 14.6%
##     Seldom     8     12      9     27.6% 14.8% 18.8%
##     Weekly     10     36     18     34.5% 44.4% 37.5%
##
## By ABS_Age_Group                           Fishers Exact p-value=0.6589
## #
```

There is a significant difference for Drink_Alcohol by Gender.

Female study participants were significantly less likely to drink alcohol as frequently as the male study participants.

Drink_Alcohol Within Study by Gender

Calculate Odds Ratios and Risk Ratios for study participant Drink_Alcohol for daily consumption and abstaining by Gender to get 95%CI.

```
##          Drink_Alcohol
## Gender  Remainder Daily Prop % by row Remainder Daily
##   Female      84      3     96.6%  3.4%
##   Male       61     10     85.9% 14.1%
##
## Odds Ratio=4.55 CI=(1.11,26.79) p.value=0.0198
## The Odds for Daily of Drink_Alcohol is at least 11% higher for Male than Female
```

```

##
## OR By Drink Daily                               Odds-Ratio    p-value=0.0198
## #
##
## Risk Ratio=4.08  CI=(1.38,Inf)  p.value=0.0198
## The Relative Risk for Daily of Drink_Alcohol is at least 38% higher for Male than Female of Gender
##
## RR By Drink Daily                               Relative Risk p-value=0.0198
## #
##           Drink_Alcohol
## Gender  Remainder Never Prop % by row Remainder Never
##   Male      64          7          90.1%    9.9%
##   Female    69         18          79.3%   20.7%
##
## Odds Ratio=2.37  CI=(0.87,7.18)  p.value=0.0802
## Lower CI <=1 for Never of Drink_Alcohol indicates no significant difference between Female and Male
##
## OR By Drink Never                               Odds-Ratio    p-value=0.0802
## #
##
## Risk Ratio=2.10  CI=(0.98,5.98)  p.value=0.0802
## Lower CI <=1 for Never of Drink_Alcohol indicates no significant difference between Female and Male
##
## RR By Drink Never                               Relative Risk p-value=0.0802
## #

```

Drink_Alcohol Study v ABS 2014-15

Compare Study against ABS data by Gender (as Study has signif diff by Gender). Only compare age ranges 25-44 as the ABS data range of 18-24 is quite different to the youngest study participants (22 years). The ABS report alcohol consumption in the last week (i.e not daily as per smoking). For the Study combine Daily and Weekly levels into one level (Daily_Weekly). Also compare those who have Never consmed alcohol. See Table_10_1 in the ABS National Health Survey First Results 2014-15 Western Australia.xlsx spreadsheet.

```

##           Female_Drink_Alcohol
## Age_Group 25-44 Remainder Daily_Weekly Prop % by row Remainder Daily_Weekly
##   Study           40          28          58.8%    41.2%
##   ABS 2014-15 181700    190100          48.9%    51.1%
##
## Odds Ratio=1.49  CI=(0.90,2.52)  p.value=0.1147
## Lower CI <=1 for Daily_Weekly of Female_Drink_Alcohol indicates no significant difference between ABS 2014-15 and Study
##
## OR Female Daily_Weekly 25-44                   Odds-Ratio    p-value=0.1147
## #
##
## Risk Ratio=1.24  CI=(0.96,1.74)  p.value=0.1147
## Lower CI <=1 for Daily_Weekly of Female_Drink_Alcohol indicates no significant difference between ABS 2014-15 and Study
##
## RR Female Daily_Weekly 25-44                   Relative Risk p-value=0.1147
## #
##           Male_Drink_Alcohol
## Age_Group 25-44 Remainder Daily_Weekly Prop % by row Remainder Daily_Weekly
##   Study           25          36          41.0%    59.0%
##   ABS 2014-15 115000    254500          31.1%    68.9%
##
## Odds Ratio=1.54  CI=(0.88,2.63)  p.value=0.0986
## Lower CI <=1 for Daily_Weekly of Male_Drink_Alcohol indicates no significant difference between ABS 2014-15 and Study
##
## OR Male Daily_Weekly 25-44                     Odds-Ratio    p-value=0.0986
## #

```

```

##
## Risk Ratio=1.17 CI=(0.98,1.50) p.value=0.0986
## Lower CI <=1 for Daily Weekly of Male_Drink_Alcohol indicates no significant dif
## ference between ABS 2014-15 and Study
##
## RR Male Daily_Weekly 25-44 Relative Risk p-value=0.0986
## #
## Female_Drink_Alcohol
## Age_Group 25-44 Remainder Never Prop % by row Remainder Never
## ABS 2014-15 331000 40800 89.0% 11.0%
## Study 52 16 76.5% 23.5%
##
## Odds Ratio=2.50 CI=(1.33,4.44) p.value=0.0028
## The Odds for Never of Female_Drink_Alcohol is at least 33% higher for Study than
## ABS 2014-15
##
## OR Female Never 25-44 Odds-Ratio p-value=0.0028
## #
##
## Risk Ratio=2.14 CI=(1.22,3.08) p.value=0.0028
## The Relative Risk for Never of Female_Drink_Alcohol is at least 22% higher for S
## tudy than ABS 2014-15 of Age_Group 25-44
##
## RR Female Never 25-44 Relative Risk p-value=0.0028
## #
## Male_Drink_Alcohol
## Age_Group 25-44 Remainder Never Prop % by row Remainder Never
## ABS 2014-15 348600 20900 94.3% 5.7%
## Study 55 6 90.2% 9.8%
##
## Odds Ratio=1.82 CI=(0.64,4.22) p.value=0.1587
## Lower CI <=1 for Never of Male_Drink_Alcohol indicates no significant difference
## between Study and ABS 2014-15
##
## OR Male Never 25-44 Odds-Ratio p-value=0.1587
## #
##
## Risk Ratio=1.74 CI=(0.58,3.19) p.value=0.1587
## Lower CI <=1 for Never of Male_Drink_Alcohol indicates no significant difference
## between Study and ABS 2014-15
##
## RR Male Never 25-44 Relative Risk p-value=0.1587
## #

```

There was a significant difference for Drink_Alcohol=Never between Study and ABS for Females.
 Female study participants were more likely to Never drink than the WA general population 2014-15.

Smoke_Cigarettes Within Study

Test frequency of smoking by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```

## Smoke_Cigarettes Proportions
## Daily 16 10.1%
## Monthly 3 1.9%
## Never 126 79.7%
## Seldom 11 7.0%
## Weekly 2 1.3%
##
## Gender
## Smoke_Cigarettes Female Male Prop % by col Female Male
## Daily 8 8 9.2% 11.3%
## Monthly 1 2 1.1% 2.8%
## Never 73 53 83.9% 74.6%
## Seldom 4 7 4.6% 9.9%
## Weekly 1 1 1.1% 1.4%
##
## By Gender Fishers Exact p-value=0.5883
## #

```

```

##                               Cleft_Type
## Smoke_Cigarettes Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Daily           2         7           7           8.0%      8.9%      13.0%
##   Monthly          0         1           2           0.0%      1.3%      3.7%
##   Never            16        65          45          64.0%     82.3%     83.3%
##   Seldom           6         5           0           24.0%     6.3%      0.0%
##   Weekly           1         1           0           4.0%      1.3%      0.0%
##
## By Cleft_Type                               Fishers Exact p-value=0.0085
## #
##                               Residence_Area
## Smoke_Cigarettes Perth Metro WA Country Prop % by col Perth Metro WA Country
##   Daily           14         2           11.2%      6.1%
##   Monthly          3         0           2.4%      0.0%
##   Never            97        29          77.6%     87.9%
##   Seldom           9         2           7.2%      6.1%
##   Weekly           2         0           1.6%      0.0%
##
## By Residence_Area                           Fishers Exact p-value=0.8855
## #
##                               ABS_Age_Group
## Smoke_Cigarettes 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##   Daily           2         10          4           6.9%     12.3%    8.3%
##   Monthly          2         1           0           6.9%     1.2%     0.0%
##   Never            24        63          39          82.8%    77.8%    81.2%
##   Seldom           1         6           4           3.4%     7.4%     8.3%
##   Weekly           0         1           1           0.0%     1.2%     2.1%
##
## By ABS_Age_Group                             Fishers Exact p-value=0.6727
## #

```

There was a significant differences for Smoke_Cigarettes by Cleft_Type.

Palate-only were more likely to smoke daily, but also more likely to have Never smoked.

Smoke_Cigarettes Study V ABS 2014-15

Compare Study against ABS data for Daily and Never categories of smoking for age ranges 25-44.

Note the ABS data range of 18-24 is quite different to the youngest study participants (22 years) so do not include this data. See Table_9_1 in the ABS National Health Survey First Results 2014-15 Western Australia.xlsx spreadsheet.

```

##                               Smoke_Cigarettes
## Age_Group 25-44 Remainder Daily Prop % by row Remainder Daily
##   Study           115         14           89.1%     10.9%
##   ABS 2014-15 610800 120700           83.5%     16.5%
##
## Odds Ratio=1.62 CI=(0.93,3.06) p.value=0.0959
## Lower CI <=1 for Daily of Smoke_Cigarettes indicates no significant difference b
etween ABS 2014-15 and Study
##
## OR By Smoke Daily 25-44                               Odds-Ratio    p-value=0.0959
## #
##
## Risk Ratio=1.52 CI=(1.01,3.03) p.value=0.0959
## The Relative Risk for Daily of Smoke_Cigarettes is at least 1% higher for ABS 20
14-15 than Study of Age_Group 25-44
##
## RR By Smoke Daily 25-44                               Relative Risk p-value=0.0959
## #
##                               Smoke_Cigarettes
## Age_Group 25-44 Remainder Never Prop % by row Remainder Never
##   ABS 2014-15 343300 388200           46.9%     53.1%
##   Study           27         102           20.9%     79.1%
##
## Odds Ratio=3.34 CI=(2.17,5.31) p.value=0.0000
## The Odds for Never of Smoke_Cigarettes is at least 117% higher for Study than AB
S 2014-15

```

```

##
## OR By Smoke Never 25-44                      Odds-Ratio    p-value=0.0000
## #
##
## Risk Ratio=1.49  CI=(1.36,1.62)  p.value=0.0000
## The Relative Risk for Never of Smoke_Cigarettes is at least 36% higher for Study
than ABS 2014-15 of Age_Group 25-44
##
## RR By Smoke Never 25-44                      Relative Risk  p-value=0.0000
## #

```

There was a significant difference for Smoke Never between Study and ABS.

Study participants were significantly more likely Never to have smoked than the WA general population in 2014-15.

Use_Social_Drugs Within Study

Test Frequency of using social (illicit) drugs by Gender, Cleft_Type, Residence_Area and ABS_Age_Group. Combine Monthly and Seldom into Infrequently as these two categories are sparsely populated.

```

##          Use_Social_Drugs Proportions
## Daily          1          0.6%
## Monthly        4          2.5%
## Never         121         76.6%
## Seldom        27         17.1%
## Weekly         5          3.2%
##
##          Gender
## Use_Social_Drugs Female Male Prop % by col Female Male
##          Daily      0      1          0.0%   1.4%
##          Monthly    0      4          0.0%   5.6%
##          Never     73     48          83.9%  67.6%
##          Seldom    13     14          14.9%  19.7%
##          Weekly     1      4          1.1%   5.6%
##
## By Gender                      Fishers Exact p-value=0.0169
## #
##          Cleft_Type
## Use Social Drugs Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##          Daily      0      1      0          0.0%   1.3%   0.0%
##          Monthly    3      0      1          12.0%   0.0%   1.9%
##          Never     13     62     46          52.0%  78.5%  85.2%
##          Seldom     9     13     5          36.0%  16.5%   9.3%
##          Weekly     0      3      2          0.0%   3.8%   3.7%
##
## By Cleft_Type                  Fishers Exact p-value=0.0035
## #
##          Residence_Area
## Use_Social_Drugs Perth Metro WA Country Prop % by col Perth Metro WA Country
##          Daily      1      0          0.8%   0.0%
##          Monthly    4      0          3.2%   0.0%
##          Never     93     28          74.4%  84.8%
##          Seldom    22     5          17.6%  15.2%
##          Weekly     5      0          4.0%   0.0%
##
## By Residence_Area              Fishers Exact p-value=0.7402
## #
##          ABS_Age_Group
## Use_Social_Drugs 20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##          Daily      0      1      0          0.0%   1.2%   0.0%
##          Monthly    1      1      2          3.4%   1.2%   4.2%
##          Never     21     62     38          72.4%  76.5%  79.2%
##          Seldom     6     14     7          20.7%  17.3%  14.6%
##          Weekly     1      3      1          3.4%   3.7%   2.1%
##
## By ABS_Age_Group              Fishers Exact p-value=0.9396
## #

```


There were significant differences for Use_Social_Drugs by Gender and by Cleft_Type.

Female study participants overall used social drugs significantly less frequently than male study participants.

Palate-only were more likely to Never have used social drugs.

Use_Social_Drugs Within Study by Gender

Calculate Odds Ratios and Risk Ratios for study participant Use_Social_Drugs for daily/weekly consumption, infrequently (Monthly + Seldom) and Never by Gender to get 95%CI.

```
##          Use_Social_Drugs
## Gender  Daily Monthly Never Seldom Weekly Prop % by col Daily Monthly Never Seldom Weekly
## Female    0     0    73   13     1      0.0%   0.0%  60.3%  48.1%  20.0%
## Male      1     4    48   14     4     100.0% 100.0%  39.7%  51.9%  80.0%
##          Use_Social_Drugs
## Gender  Remainder Daily or Weekly Prop % by row Remainder Daily or Weekly
## Female    86         1          98.9%         1.1%
## Male      66         5          93.0%         7.0%
##
## Odds Ratio=6.45 CI=(0.70,311.16) p.value=0.0907
## Lower CI <=1 for Daily or Weekly of Use_Social_Drugs indicates no significant di
## fference between Male and Female
##
## OR By Use Daily or Weekly                      Odds-Ratio      p-value=0.0907
## #
##
## Risk Ratio=6.13 CI=(0.73,51.25) p.value=0.0907
## Lower CI <=1 for Daily or Weekly of Use_Social_Drugs indicates no significant di
## fference between Male and Female
##
## RR By Use Daily or Weekly                      Relative Risk p-value=0.0907
## #
##          Use_Social_Drugs
## Gender  Remainder Monthly or Seldom Prop % by row Remainder Monthly or Seldom
## Female    74         13          85.1%         14.9%
## Male      53         18          74.6%         25.4%
##
## Odds Ratio=1.93 CI=(0.81,4.68) p.value=0.1114
## Lower CI <=1 for Monthly or Seldom of Use_Social_Drugs indicates no significant
## difference between Male and Female
##
## OR By Use Monthly or Seldom                    Odds-Ratio      p-value=0.1114
## #
##
## Risk Ratio=1.70 CI=(0.90,3.52) p.value=0.1114
## Lower CI <=1 for Monthly or Seldom of Use_Social_Drugs indicates no significant
## difference between Male and Female
##
## RR By Use Monthly or Seldom                    Relative Risk p-value=0.1114
## #
##          Use_Social_Drugs
## Gender  Remainder Never Prop % by row Remainder Never
## Male    23         48          32.4%         67.6%
## Female  14         73          16.1%         83.9%
##
## Odds Ratio=2.48 CI=(1.10,5.78) p.value=0.0229
## The Odds for Never of Use_Social_Drugs is at least 10% higher for Female than Ma
## le
##
## OR By Use Never                                Odds-Ratio      p-value=0.0229
## #
##
## Risk Ratio=1.24 CI=(1.04,1.51) p.value=0.0229
## The Relative Risk for Never of Use_Social_Drugs is at least 4% higher for Female
## than Male of Gender
##
```

```
## RR By Use Never Relative Risk p-value=0.0229
## #
```

There was a significant difference for Use_Social_Drugs = Never by Gender

Females were more likely to not have ever used social drugs.

Use_Social_Drugs Within Study by Cleft_Type

Calculate Odds Ratios and Risk Ratios for study participant Use_Social_Drugs infrequently (Monthly + Seldom) and Never by Cleft_Type to get 95%CI.

```
## Use_Social_Drugs
## Cleft_Type Daily Monthly Never Seldom Weekly Prop % by col Daily Monthly Never Seldom Weekly
## Lip-only 0 3 13 9 0 0.0% 75.0% 10.7% 33.3% 0.0%
## Lip & Palate 1 0 62 13 3 100.0% 0.0% 51.2% 48.1% 60.0%
## Palate-only 0 1 46 5 2 0.0% 25.0% 38.0% 18.5% 40.0%
## Use_Social_Drugs
## Cleft_Type Remainder Monthly or Seldom Prop % by row Remainder Monthly or Seldom
## Remainder 114 19 85.7% 14.3%
## Lip-only 13 12 52.0% 48.0%
##
## Odds Ratio=5.46 CI=(1.96,15.29) p.value=0.0004
## The Odds for Monthly or Seldom of Use_Social_Drugs is at least 96% higher for Lip-only than Remainder
##
## OR By Use Monthly or Seldom Odds-Ratio p-value=0.0004
## #
##
## Risk Ratio=3.36 CI=(1.77,6.14) p.value=0.0004
## The Relative Risk for Monthly or Seldom of Use_Social_Drugs is at least 77% higher for Lip-only than Remainder of Cleft_Type
##
## RR By Use Monthly or Seldom Relative Risk p-value=0.0004
## #
## Use_Social_Drugs
## Cleft_Type Remainder Never Prop % by row Remainder Never
## Lip-only 12 13 48.0% 52.0%
## Remainder 25 108 18.8% 81.2%
##
## Odds Ratio=3.94 CI=(1.46,10.70) p.value=0.0036
## The Odds for Never of Use_Social_Drugs is at least 46% higher for Remainder than Lip-only
##
## OR By Use Never Odds-Ratio p-value=0.0036
## #
##
## Risk Ratio=1.56 CI=(1.13,2.54) p.value=0.0036
## The Relative Risk for Never of Use_Social_Drugs is at least 13% higher for Remainder than Lip-only of Cleft_Type
##
## RR By Use Never Relative Risk p-value=0.0036
## #
```

There was a significant difference for Use_Social_Drugs = Monthly or Seldom and for Never by Gender = Lip-only.

Use_Social_Drugs Study v AIHW 2013

Compare social drug use by study participants against AIHW data by Gender (as Study has significant difference by Gender).

Note: AIHW = Australian Institute of Health and Welfare. They report on weekly use so combine Daily and Weekly together for the comparisons. See Table 5.5 in the AIHW National National Drug Strategy Survey 2013 Online illicit drug tables.xlsx spreadsheet.

```

##           Males_Use_Social_Drugs
## Group      Remainder Daily_Weekly Prop % by row Remainder Daily_Weekly
##   AIHW 2013   935         65          93.5%    6.5%
##   Study       66          5          93.0%    7.0%
##
## Odds Ratio=1.09 CI=(0.33,2.81) p.value=0.8035
## Lower CI <=1 for Daily_Weekly of Males_Use_Social_Drugs indicates no significant
difference between Study and AIHW 2013
##
## OR By Males Use Daily or Weekly          Odds-Ratio    p-value=0.8035
## #
##
## Risk Ratio=1.08 CI=(0.23,2.19) p.value=0.8035
## Lower CI <=1 for Daily_Weekly of Males_Use_Social_Drugs indicates no significant
difference between Study and AIHW 2013
##
## RR By Males Use Daily or Weekly          Relative Risk p-value=0.8035
## #
##           Males_Use_Social_Drugs
## Group      Remainder Never Prop % by row Remainder Never
##   AIHW 2013   455         545          45.5%    54.5%
##   Study       23          48          32.4%    67.6%
##
## Odds Ratio=1.74 CI=(1.02,3.05) p.value=0.0355
## The Odds for Never of Males_Use_Social_Drugs is at least 2% higher for Study than
AIHW 2013
##
## OR By Males Use Never                    Odds-Ratio    p-value=0.0355
## #
##
## Risk Ratio=1.24 CI=(1.02,1.45) p.value=0.0355
## The Relative Risk for Never of Males_Use_Social_Drugs is at least 2% higher for
Study than AIHW 2013 of Group
##
## RR By Males Use Never                    Relative Risk p-value=0.0355
## #
##           Females_Use_Social_Drugs
## Group      Remainder Daily_Weekly Prop % by row Remainder Daily_Weekly
##   Study       86          1          98.9%    1.1%
##   AIHW 2013   960         40          96.0%    4.0%
##
## Odds Ratio=3.58 CI=(0.59,146.62) p.value=0.2463
## Lower CI <=1 for Daily_Weekly of Females_Use_Social_Drugs indicates no significant
difference between AIHW 2013 and Study
##
## OR By Females Use Daily or Weekly        Odds-Ratio    p-value=0.2463
## #
##
## Risk Ratio=3.48 CI=(0.99,Inf) p.value=0.2463
## Lower CI <=1 for Daily_Weekly of Females_Use_Social_Drugs indicates no significant
difference between AIHW 2013 and Study
##
## RR By Females Use Daily or Weekly        Relative Risk p-value=0.2463
## #
##           Females_Use_Social_Drugs
## Group      Remainder Never Prop % by row Remainder Never
##   AIHW 2013   381         619          38.1%    61.9%
##   Study       14          73          16.1%    83.9%
##
## Odds Ratio=3.21 CI=(1.76,6.24) p.value=0.0000
## The Odds for Never of Females_Use_Social_Drugs is at least 76% higher for Study
than AIHW 2013
##
## OR By Females Use Never                  Odds-Ratio    p-value=0.0000
## #
##
## Risk Ratio=1.36 CI=(1.21,1.49) p.value=0.0000
## The Relative Risk for Never of Females_Use_Social_Drugs is at least 21% higher f

```

```

or Study than AIHW 2013 of Group
##
## RR By Females Use Never          Relative Risk p-value=0.0000
## #

```

There were two significant differences for Use_Social_Drugs between Study and AIHW.
Male study participants were more likely to have Never used social drugs than the AIHW survey males. Similarly female study participants were more likely to have Never used social drugs.

Exercise Within Study

Test frequency of Exercise by Gender, Cleft_Type, Residence_Area and ABS_Age_Group.

```

##           Exercise Proportions
## Daily      42      26.6%
## Monthly    15       9.5%
## Never       8       5.1%
## Seldom     30     19.0%
## Weekly     63     39.9%
##           Gender
## Exercise  Female Male  Prop % by col Female Male
##   Daily      19   23      21.8%  32.4%
##   Monthly     8    7       9.2%   9.9%
##   Never       7    1       8.0%   1.4%
##   Seldom     16   14      18.4%  19.7%
##   Weekly     37   26      42.5%  36.6%
##
## By Gender          Fishers Exact p-value=0.2502
## #
##           Cleft_Type
## Exercise  Lip-only Lip & Palate Palate-only Prop % by col Lip-only Lip & Palate Palate-only
##   Daily     10     18      14      40.0%  22.8%  25.9%
##   Monthly    3      8       4      12.0%  10.1%  7.4%
##   Never      0      2       6       0.0%   2.5%  11.1%
##   Seldom    6     15      9      24.0%  19.0%  16.7%
##   Weekly    6     36     21     24.0%  45.6%  38.9%
##
## By Cleft_Type     Fishers Exact p-value=0.2224
## #
##           Residence_Area
## Exercise  Perth Metro WA Country Prop % by col Perth Metro WA Country
##   Daily     34      8       27.2%  24.2%
##   Monthly   11      4       8.8%  12.1%
##   Never      5      3       4.0%   9.1%
##   Seldom    21      9      16.8%  27.3%
##   Weekly    54      9      43.2%  27.3%
##
## By Residence_Area Fishers Exact p-value=0.2442
## #
##           ABS_Age_Group
## Exercise  20-24 25-34 35-44 Prop % by col 20-24 25-34 35-44
##   Daily    11    21    10     37.9%  25.9%  20.8%
##   Monthly   4     7     4     13.8%   8.6%   8.3%
##   Never     1     3     4      3.4%   3.7%   8.3%
##   Seldom    3    17    10    10.3%  21.0%  20.8%
##   Weekly   10    33    20    34.5%  40.7%  41.7%
##
## By ABS_Age_Group  Fishers Exact p-value=0.6790
## #

```

There were no significant differences for Exercise by Gender, Cleft_Type, Residence_Area or ABS_Age_Group.

Exercise Study v ABS 2014-15

Compare exercise by study participatns against ABS. Only compare age ranges 25-44 as the ABS data range of 18-24 is quite different to the youngest study participants (22 years). See Table_13_1 in the ABS National Health Survey First Results 2014-15 Western Australia.xlsx spreadsheet.

```
##
## Exercise
## Group      Remainder Daily Prop % by row Remainder Daily
##   ABS 2014-15 614800    125700          83.0%    17.0%
##   Study      116        42           73.4%    26.6%
##
## Odds Ratio=1.77 CI=(1.21,2.54) p.value=0.0028
## The Odds for Daily of Exercise is at least 21% higher for Study than ABS 2014-15
##
## OR By Exercise Daily                      Odds-Ratio    p-value=0.0028
## #
##
## Risk Ratio=1.57 CI=(1.19,1.97) p.value=0.0028
## The Relative Risk for Daily of Exercise is at least 19% higher for Study than ABS
## 2014-15 of Group
##
## RR By Exercise Daily                      Relative Risk p-value=0.0028
## #
## Exercise
## Group      Remainder Infrequently Prop % by row Remainder Infrequently
##   Study      113        45           71.5%    28.5%
##   ABS 2014-15 498200    242300          67.3%    32.7%
##
## Odds Ratio=1.22 CI=(0.86,1.77) p.value=0.2713
## Lower CI <=1 for Infrequently of Exercise indicates no significant difference be
## tween ABS 2014-15 and Study
##
## OR By Exercise Infrequently              Odds-Ratio    p-value=0.2713
## #
##
## Risk Ratio=1.15 CI=(0.92,1.52) p.value=0.2713
## Lower CI <=1 for Infrequently of Exercise indicates no significant difference be
## tween ABS 2014-15 and Study
##
## RR By Exercise Infrequently              Relative Risk p-value=0.2713
## #
## Exercise
## Group      Remainder Never Prop % by row Remainder Never
##   Study      150        8           94.9%    5.1%
##   ABS 2014-15 533100    207400          72.0%    28.0%
##
## Odds Ratio=7.29 CI=(3.61,17.20) p.value=0.0000
## The Odds for Never of Exercise is at least 261% higher for ABS 2014-15 than Stud
## y
##
## OR By Exercise Never                      Odds-Ratio    p-value=0.0000
## #
##
## Risk Ratio=5.53 CI=(3.16,14.75) p.value=0.0000
## The Relative Risk for Never of Exercise is at least 216% higher for ABS 2014-15
## than Study of Group
##
## RR By Exercise Never                      Relative Risk p-value=0.0000
## #
## Exercise
## Group      Remainder Weekly Prop % by row Remainder Weekly
##   ABS 2014-15 575400    165100          77.7%    22.3%
##   Study      95        63           60.1%    39.9%
##
## Odds Ratio=2.31 CI=(1.65,3.21) p.value=0.0000
## The Odds for Weekly of Exercise is at least 65% higher for Study than ABS 2014-1
## 5
##
```

```

## OR By Exercise Weekly                      Odds-Ratio    p-value=0.0000
## #
##
## Risk Ratio=1.79  CI=(1.45,2.13)  p.value=0.0000
## The Relative Risk for Weekly of Exercise is at least 45% higher for Study than A
BS 2014-15 of Group
##
## RR By Exercise Weekly                      Relative Risk p-value=0.0000
## #

```

There were significant differences in Exercise frequency between Study participants and the ABS general population.

Study participants exercised more frequently than the general population.

Bully-Victim Psychosocial Issues

Compare the participants who were Bully-Victims (i.e. were bullied themselves and then they bullied others) against the other participants for a range of psychosocial issues variables.

```

##
## Anxiety
## Bully_Victim      No_Anxiety Had_Anxiety Prop % by row No_Anxiety Had_Anxiety
##   Not_Bully_Victim    74      65                53.2%    46.8%
##   Was_Bully_Victim     9      10                47.4%    52.6%
##
## Odds Ratio=1.26  CI=(0.43,3.75)  p.value=0.8072
## Lower CI <=1 for Had_Anxiety of Anxiety indicates no significant difference betw
een Was_Bully_Victim and Not_Bully_Victim
##
## OR By Anxiety                      Odds-Ratio    p-value=0.8072
## #
##
## Risk Ratio=1.13  CI=(0.63,1.70)  p.value=0.8072
## Lower CI <=1 for Had_Anxiety of Anxiety indicates no significant difference betw
een Was_Bully_Victim and Not_Bully_Victim
##
## RR By Anxiety                      Relative Risk p-value=0.8072
## #
##
## Depression
## Bully_Victim      No_Depression Had_Depression Prop % by row No_Depression Had_Depression
##   Not_Bully_Victim    82      57                59.0%    41.0%
##   Was_Bully_Victim     8      11                42.1%    57.9%
##
## Odds Ratio=1.97  CI=(0.67,6.02)  p.value=0.2172
## Lower CI <=1 for Had_Depression of Depression indicates no significant differenc
e between Was_Bully_Victim and Not_Bully_Victim
##
## OR By Depression                      Odds-Ratio    p-value=0.2172
## #
##
## Risk Ratio=1.41  CI=(0.84,2.11)  p.value=0.2172
## Lower CI <=1 for Had_Depression of Depression indicates no significant differenc
e between Was_Bully_Victim and Not_Bully_Victim
##
## RR By Depression                      Relative Risk p-value=0.2172
## #
##
## Impact_Friends_Age
## Bully_Victim      No_Impact Had_Impact Prop % by row No_Impact Had_Impact
##   Not_Bully_Victim    115     24                82.7%    17.3%
##   Was_Bully_Victim     14      5                73.7%    26.3%
##
## Odds Ratio=1.70  CI=(0.44,5.64)  p.value=0.3485
## Lower CI <=1 for Had_Impact of Impact_Friends_Age indicates no significant diffe
rence between Was_Bully_Victim and Not_Bully_Victim
##
## OR By Impact_Friends_Age                      Odds-Ratio    p-value=0.3485
## #

```

```

##
## Risk Ratio=1.52 CI=(0.41,3.18) p.value=0.3485
## Lower CI <=1 for Had_Impact of Impact_Friends_Age indicates no significant difference between Was_Bully_Victim and Not_Bully_Victim
##
## RR By Impact_Friends_Age Relative Risk p-value=0.3485
## #
## Impact_Friends_Opp_Sex
## Bully_Victim No_Impact Had_Impact Prop % by row No_Impact Had_Impact
## Not_Bully_Victim 95 44 68.3% 31.7%
## Was_Bully_Victim 12 7 63.2% 36.8%
##
## Odds Ratio=1.26 CI=(0.39,3.75) p.value=0.7941
## Lower CI <=1 for Had_Impact of Impact_Friends_Opp_Sex indicates no significant difference between Was_Bully_Victim and Not_Bully_Victim
##
## OR By Impact_Friends_Opp_Sex Odds-Ratio p-value=0.7941
## #
##
## Risk Ratio=1.16 CI=(0.50,2.03) p.value=0.7941
## Lower CI <=1 for Had_Impact of Impact_Friends_Opp_Sex indicates no significant difference between Was_Bully_Victim and Not_Bully_Victim
##
## RR By Impact_Friends_Opp_Sex Relative Risk p-value=0.7941
## #
## Impact_Self_Esteem
## Bully_Victim No_Impact Had_Impact Prop % by row No_Impact Had_Impact
## Not_Bully_Victim 54 85 38.8% 61.2%
## Was_Bully_Victim 4 15 21.1% 78.9%
##
## Odds Ratio=2.37 CI=(0.71,10.33) p.value=0.2035
## Lower CI <=1 for Had_Impact of Impact_Self_Esteem indicates no significant difference between Was_Bully_Victim and Not_Bully_Victim
##
## OR By Impact_Self_Esteem Odds-Ratio p-value=0.2035
## #
##
## Risk Ratio=1.29 CI=(0.95,1.65) p.value=0.2035
## Lower CI <=1 for Had_Impact of Impact_Self_Esteem indicates no significant difference between Was_Bully_Victim and Not_Bully_Victim
##
## RR By Impact_Self_Esteem Relative Risk p-value=0.2035
## #

```

Analysis Summary

The following table summarises all of the statistical tests conducted in this analysis.

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Age Distribution Study v ABS WA 2014	By Gender Females	Fishers Exact	0.4738		
Age Distribution Study v ABS WA 2014	By Gender Males	Fishers Exact	0.7191		
Age Distribution Study v ABS WA 2014	By Gender All	Fishers Exact	0.3808		
Sample Bias Study v PMH	By Gender	Fishers Exact	0.0232		Significant
Sample Bias Study v PMH	By Cleft_Type	Fishers Exact	0.2474		
Sample Bias Study v PMH	By Residence_Area	Fishers Exact	0.0328		Significant
Sample Bias Study v PMH	By ABS_Age_Group	Fishers Exact	0.0953		
Sample Bias Study v PMH	OR By Gender	Odds-Ratio	0.0232		Significant
Sample Bias Study v PMH	RR By Gender	Relative Risk	0.0232		Significant
Sample Bias Study v PMH	OR By Residence_Area	Odds-Ratio	0.0328		Significant
Sample Bias Study v PMH	RR By Residence_Area	Relative Risk	0.0328		Significant
Study Responded v Not-Responded	By Gender	Fishers Exact	0.0058		Significant
Study Responded v Not-Responded	By Cleft_Type	Fishers Exact	0.1394		
Study Responded v Not-Responded	By Residence_Area	Fishers Exact	0.0371		Significant

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Study Responded v Not-Responded	By ABS_Age_Group	Fishers Exact	0.0295		Significant
Responded v Not Responded	OR By Gender	Odds-Ratio	0.0058		Significant
Responded v Not Responded	RR By Gender	Relative Risk	0.0058		Significant
Responded v Not Responded	OR By Residence_Area	Odds-Ratio	0.0371		Significant
Responded v Not Responded	RR By Residence_Area	Relative Risk	0.0371		Significant
Responded v Not Responded	OR By ABS_Age_Group 20-24	Odds-Ratio	0.5536		
Responded v Not Responded	RR By ABS_Age_Group 20-24	Relative Risk	0.5536		
Responded v Not Responded	OR By ABS_Age_Group 25-34	Odds-Ratio	0.0144		Significant
Responded v Not Responded	RR By ABS_Age_Group 25-34	Relative Risk	0.0144		Significant
Responded v Not Responded	OR By ABS_Age_Group 35-44	Odds-Ratio	0.0207		Significant
Responded v Not Responded	RR By ABS_Age_Group 35-44	Relative Risk	0.0207		Significant
Occupation_Cat Within Study	By Gender	Fishers Exact	0.0006		Significant
Occupation_Cat Within Study	By Cleft_Type	Fishers Exact	0.8190		
Occupation_Cat Within Study	By Residence_Area	Fishers Exact	0.2925		
Occupation_Cat Within Study	By ABS_Age_Group	Fishers Exact	0.1375		
Individual Occupation_Cat by Gender	By Clerical & Admin	Fishers Exact	0.4531	1.0000	
Individual Occupation_Cat by Gender	By Community & Personal Svc	Fishers Exact	0.0219	0.1314	
Individual Occupation_Cat by Gender	By Labourers	Fishers Exact	0.0139	0.0975	
Individual Occupation_Cat by Gender	By Machinery Op & Drivers	Fishers Exact	0.1040	0.4159	
Individual Occupation_Cat by Gender	By Managers	Fishers Exact	1.0000	1.0000	
Individual Occupation_Cat by Gender	By Professionals	Fishers Exact	0.0673	0.3363	
Individual Occupation_Cat by Gender	By Sales	Fishers Exact	0.6201	1.0000	
Individual Occupation_Cat by Gender	By Technicians & Trades	Fishers Exact	0.0056	0.0444	Significant
Occupation By Gender	OR By Technicians & Trades	Odds-Ratio	0.0056		Significant
Occupation By Gender	RR By Technicians & Trades	Relative Risk	0.0056		Significant
Occupation_Cat Study v ABS WA 2014 25-44	By Clerical & Admin	Fishers Exact	0.7678	1.0000	
Occupation_Cat Study v ABS WA 2014 25-44	By Community & Personal Svc	Fishers Exact	0.6063	1.0000	
Occupation_Cat Study v ABS WA 2014 25-44	By Labourers	Fishers Exact	0.6017	1.0000	
Occupation_Cat Study v ABS WA 2014 25-44	By Machinery Op & Drivers	Fishers Exact	0.5850	1.0000	
Occupation_Cat Study v ABS WA 2014 25-44	By Managers 25-44 Study v ABS WA 2014	Fishers Exact	0.5344	1.0000	
Occupation_Cat Study v ABS WA 2014 25-44	By Professionals	Fishers Exact	0.2130	1.0000	
Occupation_Cat Study v ABS WA 2014 25-44	By Sales	Fishers Exact	0.1646	1.0000	
Occupation_Cat Study v ABS WA 2014 25-44	By Technicians & Trades	Fishers Exact	0.5276	1.0000	
Impact_Getting_Work Within Study	By Gender	Fishers Exact	1.0000		
Impact_Getting_Work Within Study	By Cleft_Type	Fishers Exact	0.1163		
Impact_Getting_Work Within Study	By Residence_Area	Fishers Exact	0.8002		
Impact_Getting_Work Within Study	By ABS_Age_Group	Fishers Exact	0.1317		
Impact_Doing_Work Within Study	By Gender	Fishers Exact	0.4900		
Impact_Doing_Work Within Study	By Cleft_Type	Fishers Exact	0.1336		
Impact_Doing_Work Within Study	By Residence_Area	Fishers Exact	1.0000		
Impact_Doing_Work Within Study	By ABS_Age_Group	Fishers Exact	0.1448		
Work_Hours Within Study	By Gender	Fishers Exact	0.2630		
Work_Hours Within Study	By Cleft_Type	Fishers Exact	0.8030		
Work_Hours Within Study	By Residence_Area	Fishers Exact	1.0000		
Work_Hours Within Study	By ABS_Age_Group	Fishers Exact	0.1238		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Work_Hours Study v ABS WA 2014	OR By Females 25-44	Odds-Ratio	0.0065		Significant
Work_Hours Study v ABS WA 2014	RR By Females 25-44	Relative Risk	0.0065		Significant
Work_Hours Study v ABS WA 2014	OR By Males 25-44	Odds-Ratio	0.3293		
Work_Hours Study v ABS WA 2014	RR By Males 25-44	Relative Risk	0.3293		
Annual_Income Full-time Within Study	By Gender	Fishers Exact	0.0007		Significant
Annual_Income Full-time Within Study	By Cleft_Type	Fishers Exact	0.5189		
Annual_Income Full-time Within Study	By Residence_Area	Fishers Exact	0.4581		
Annual_Income Full-time Within Study	By ABS_Age_Group	Fishers Exact	0.0052		Significant
Annual_Income Full-time Within Study	OR By Gender <100K	Odds-Ratio	0.0061		Significant
Annual_Income Full-time Within Study	RR By Gender <100K	Relative Risk	0.0061		Significant
Annual_Income Part-time Within Study	By Gender	Fishers Exact	0.7880		
Annual_Income Part-time Within Study	By Cleft_Type	Fishers Exact	0.0092		Significant
Annual_Income Part-time Within Study	By Residence_Area	Fishers Exact	1.0000		
Annual_Income Part-time Within Study	By ABS_Age_Group	Fishers Exact	0.0668		
Annual_Income Full-time Study v ABS 2013	By Age-Group 25-44 <100K	Fishers Exact	0.1012	0.3290	
Annual_Income Full-time Study v ABS 2013	By Age-Group 25-44 <30K	Fishers Exact	0.2069	0.4138	
Annual_Income Full-time Study v ABS 2013	By Age-Group 25-44 <60K	Fishers Exact	0.0822	0.3290	
Annual_Income Full-time Study v ABS 2013	By Age-Group 25-44 100K+	Fishers Exact	0.7935	0.7935	
Education_Level Within Study	By Gender	Fishers Exact	0.0181		Significant
Education_Level Within Study	By Cleft_Type	Fishers Exact	0.0253		Significant
Education_Level Within Study	By Residence_Area	Fishers Exact	0.2358		
Education_Level Within Study	By ABS_Age_Group	Fishers Exact	0.0776		
Education_Level Within Study By Gender	OR By High School	Odds-Ratio	0.0084		Significant
Education_Level Within Study By Gender	RR By High School	Relative Risk	0.0084		Significant
Education_Level Within Study By Gender	OR By TAFE Cert/Diploma	Odds-Ratio	0.8652		
Education_Level Within Study By Gender	RR By TAFE Cert/Diploma	Relative Risk	0.8652		
Education_Level Within Study By Gender	OR By Uni Degree	Odds-Ratio	0.0722		
Education_Level Within Study By Gender	RR By Uni Degree	Relative Risk	0.0722		
Education_Level Within Study By Gender	OR By Uni Post Grad	Odds-Ratio	0.1380		
Education_Level Within Study By Gender	RR By Uni Post Grad	Relative Risk	0.1380		
Education_Level Within Study By Gender	OR By University	Odds-Ratio	0.0083		Significant
Education_Level Within Study By Gender	RR By University	Relative Risk	0.0083		Significant
Education_Level Within Study By Cleft_Type	By High School	Fishers Exact	0.1211	0.4845	
Education_Level Within Study By Cleft_Type	By TAFE Cert/Diploma	Fishers Exact	0.3668	0.7336	
Education_Level Within Study By Cleft_Type	By Uni Degree	Fishers Exact	0.1406	0.4845	
Education_Level Within Study By Cleft_Type	By Uni Post Grad	Fishers Exact	0.0171	0.0853	
Education_Level Within Study By Cleft_Type	By University	Fishers Exact	0.4657	0.7336	
Education_Level Study v ABS 2014 25-44	By High School	Fishers Exact	0.6347	1.0000	
Education_Level Study v ABS 2014 25-44	By TAFE Cert/Diploma	Fishers Exact	1.0000	1.0000	
Education_Level Study v ABS 2014 25-44	By Uni Degree	Fishers Exact	0.5546	1.0000	
Education_Level Study v ABS 2014 25-44	By Uni Post Grad	Fishers Exact	0.0311	0.1555	
Education_Level Study v ABS 2014 25-44	By University	Fishers Exact	0.5808	1.0000	
Housing Within Study	By Gender	Fishers Exact	0.6879		
Housing Within Study	By Cleft_Type	Fishers Exact	0.7090		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Housing Within Study	By Residence_Area	Fishers Exact	0.1227		
Housing Within Study	By ABS_Age_Group	Fishers Exact	0.0000		Significant
Living At Home Study v ABS 2009	OR By Age-Group 20-24	Odds-Ratio	0.0083		Significant
Living At Home Study v ABS 2009	RR By Age-Group 20-24	Relative Risk	0.0083		Significant
Living At Home Study v ABS 2009	OR By Age-Group 25-29	Odds-Ratio	0.0016		Significant
Living At Home Study v ABS 2009	RR By Age-Group 25-29	Relative Risk	0.0016		Significant
Living At Home Study v ABS 2009	OR By Age-Group 30-34	Odds-Ratio	0.0044		Significant
Living At Home Study v ABS 2009	RR By Age-Group 30-34	Relative Risk	0.0044		Significant
Home Ownership Study v ABS 2013-14	OR By Age-Group 25-34	Odds-Ratio	0.6492		
Home Ownership Study v ABS 2013-14	RR By Age-Group 25-34	Relative Risk	0.6492		
Close_To_Mother Within Study	By Gender	Fishers Exact	1.0000		
Close_To_Mother Within Study	By Cleft_Type	Fishers Exact	0.6188		
Close_To_Mother Within Study	By Residence_Area	Fishers Exact	0.5187		
Close_To_Mother Within Study	By ABS_Age_Group	Fishers Exact	0.4436		
Close_To_Father Within Study	By Gender	Fishers Exact	0.1076		
Close_To_Father Within Study	By Cleft_Type	Fishers Exact	0.2214		
Close_To_Father Within Study	By Residence_Area	Fishers Exact	0.8265		
Close_To_Father Within Study	By ABS_Age_Group	Fishers Exact	0.1189		
Relationships_Count Within Study	By Gender	Fishers Exact	0.9785		
Relationships_Count Within Study	By Cleft_Type	Fishers Exact	0.0795		
Relationships_Count Within Study	By Residence_Area	Fishers Exact	0.3424		
Relationships_Count Within Study	By ABS_Age_Group	Fishers Exact	0.0000		Significant
Married_Count Within Study	By Gender	Fishers Exact	0.0638		
Married_Count Within Study	By Cleft_Type	Fishers Exact	0.4993		
Married_Count Within Study	By Residence_Area	Fishers Exact	0.9147		
Married_Count Within Study	By ABS_Age_Group	Fishers Exact	0.0000		Significant
Marital_Status Within Study	By Gender	Fishers Exact	0.0732		
Marital_Status Within Study	By Cleft_Type	Fishers Exact	0.2788		
Marital_Status Within Study	By Residence_Area	Fishers Exact	0.7965		
Marital_Status Within Study	By ABS_Age_Group	Fishers Exact	0.0000		Significant
Single Study v ABS 2012-13	OR By Age-Group 25-34	Odds-Ratio	0.0000		Significant
Single Study v ABS 2012-13	RR By Age-Group 25-34	Relative Risk	0.0000		Significant
Single Study v ABS 2012-13	OR By Age-Group 35-44	Odds-Ratio	0.0000		Significant
Single Study v ABS 2012-13	RR By Age-Group 35-44	Relative Risk	0.0000		Significant
Marital_Status Study v HILDA 2011	OR By 25-34 Single	Odds-Ratio	0.0003		Significant
Marital_Status Study v HILDA 2011	RR By 25-34 Single	Relative Risk	0.0003		Significant
Marital_Status Study v HILDA 2011	OR By 25-34 Separated/Divorced	Odds-Ratio	0.6292		
Marital_Status Study v HILDA 2011	RR By 25-34 Separated/Divorced	Relative Risk	0.6292		
Marital_Status Study v HILDA 2011	OR By 25-34 De facto	Odds-Ratio	0.4475		
Marital_Status Study v HILDA 2011	RR By 25-34 De facto	Relative Risk	0.4475		
Marital_Status Study v HILDA 2011	OR By 25-34 Married	Odds-Ratio	0.0023		Significant
Marital_Status Study v HILDA 2011	RR By 25-34 Married	Relative Risk	0.0023		Significant
Marital_Status Study v HILDA 2011	OR By 35-44 Single	Odds-Ratio	0.0805		
Marital_Status Study v HILDA 2011	RR By 35-44 Single	Relative Risk	0.0805		
Marital_Status Study v HILDA 2011	OR By 35-44 Separated/Divorced	Odds-Ratio	1.0000		
Marital_Status Study v HILDA 2011	RR By 35-44 Separated/Divorced	Relative Risk	1.0000		
Marital_Status Study v HILDA 2011	OR By 35-44 De facto	Odds-Ratio	0.6104		
Marital_Status Study v HILDA 2011	RR By 35-44 De facto	Relative Risk	0.6104		
Marital_Status Study v HILDA 2011	OR By 35-44 Married	Odds-Ratio	0.3704		
Marital_Status Study v HILDA 2011	RR By 35-44 Married	Relative Risk	0.3704		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Registered Marital Status Study v ABS WA 2011	OR By 25-44 Separated/Divorced	Odds-Ratio	0.0346		Significant
Registered Marital Status Study v ABS WA 2011	RR By 25-44 Separated/Divorced	Relative Risk	0.0346		Significant
Median Age_1st_Relationship Study v Price	At Least 1 Relationship	Wilcoxon	0.0000		Significant
Median Age_1st_Married Study v AIFS 2013	Married Males	Wilcoxon	0.3623		
Median Age_1st_Married Study v AIFS 2013	Married Females	Wilcoxon	0.0016		Significant
Counselling_Before Children Within Study	By Gender	Fishers Exact	0.2771		
Counselling_Before Children Within Study	By Cleft_Type	Fishers Exact	0.0920		
Counselling_Before Children Within Study	By Residence_Area	Fishers Exact	0.6599		
Counselling_Before Children Within Study	By ABS_Age_Group	Fishers Exact	0.3840		
Psychosocial Issues by Gender	By Anxiety	Fishers Exact	0.0065	0.0482	Significant
Psychosocial Issues by Gender	By Depression	Fishers Exact	0.1500	0.8890	
Psychosocial Issues by Gender	By Lack_Motivation	Fishers Exact	1.0000	1.0000	
Psychosocial Issues by Gender	By Panic_Attacks	Fishers Exact	0.0060	0.0482	Significant
Psychosocial Issues by Gender	By Impact_Self_Esteem	Fishers Exact	0.4070	1.0000	
Psychosocial Issues by Gender	By Self_Harm	Fishers Exact	0.1482	0.8890	
Psychosocial Issues by Gender	By Suicidal_Thoughts	Fishers Exact	0.8518	1.0000	
Psychosocial Issues by Gender	By Unworthy	Fishers Exact	0.8724	1.0000	
Psychosocial Issues by Gender	OR By Anxiety	Odds-Ratio	0.0065		Significant
Psychosocial Issues by Gender	RR By Anxiety	Relative Risk	0.0065		Significant
Psychosocial Issues by Gender	OR By Panic_Attacks	Odds-Ratio	0.0060		Significant
Psychosocial Issues by Gender	RR By Panic_Attacks	Relative Risk	0.0060		Significant
Psychosocial Issues by Cleft_Type	By Anxiety	Fishers Exact	0.5323	1.0000	
Psychosocial Issues by Cleft_Type	By Depression	Fishers Exact	0.9523	1.0000	
Psychosocial Issues by Cleft_Type	By Lack_Motivation	Fishers Exact	0.6955	1.0000	
Psychosocial Issues by Cleft_Type	By Panic_Attacks	Fishers Exact	0.1785	1.0000	
Psychosocial Issues by Cleft_Type	By Impact_Self_Esteem	Fishers Exact	0.0056	0.0444	Significant
Psychosocial Issues by Cleft_Type	By Self_Harm	Fishers Exact	0.0759	0.5314	
Psychosocial Issues by Cleft_Type	By Suicidal_Thoughts	Fishers Exact	0.6505	1.0000	
Psychosocial Issues by Cleft_Type	By Unworthy	Fishers Exact	0.3006	1.0000	
Psychosocial Issues by Cleft_Type	OR By Palate-only	Odds-Ratio	0.0018		Significant
Psychosocial Issues by Cleft_Type	RR By Palate-only	Relative Risk	0.0018		Significant
Psychosocial Issues by Cleft_Type	OR By Lip & Palate	Odds-Ratio	0.0130		Significant
Psychosocial Issues by Cleft_Type	RR By Lip & Palate	Relative Risk	0.0130		Significant
Psychosocial Issues by Cleft_Type	OR By Lip-only	Odds-Ratio	0.6570		
Psychosocial Issues by Cleft_Type	RR By Lip-only	Relative Risk	0.6570		
Psychosocial Issues by Residence_Area	By Anxiety	Fishers Exact	0.8463	1.0000	
Psychosocial Issues by Residence_Area	By Depression	Fishers Exact	0.6956	1.0000	
Psychosocial Issues by Residence_Area	By Lack_Motivation	Fishers Exact	1.0000	1.0000	
Psychosocial Issues by Residence_Area	By Panic_Attacks	Fishers Exact	1.0000	1.0000	
Psychosocial Issues by Residence_Area	By Impact_Self_Esteem	Fishers Exact	0.1546	1.0000	
Psychosocial Issues by Residence_Area	By Self_Harm	Fishers Exact	1.0000	1.0000	
Psychosocial Issues by Residence_Area	By Suicidal_Thoughts	Fishers Exact	0.2522	1.0000	
Psychosocial Issues by Residence_Area	By Unworthy	Fishers Exact	0.3267	1.0000	
Psychosocial Issues by ABS_Age_Group	By Anxiety	Fishers Exact	0.5423	1.0000	

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Psychosocial Issues by ABS_Age_Group	By Depression	Fishers Exact	0.8069	1.0000	
Psychosocial Issues by ABS_Age_Group	By Lack_Motivation	Fishers Exact	0.9100	1.0000	
Psychosocial Issues by ABS_Age_Group	By Panic_Attacks	Fishers Exact	0.0486	0.3891	
Psychosocial Issues by ABS_Age_Group	By Impact_Self_Esteem	Fishers Exact	0.5316	1.0000	
Psychosocial Issues by ABS_Age_Group	By Self_Harm	Fishers Exact	0.8878	1.0000	
Psychosocial Issues by ABS_Age_Group	By Suicidal_Thoughts	Fishers Exact	0.6011	1.0000	
Psychosocial Issues by ABS_Age_Group	By Unworthy	Fishers Exact	0.3495	1.0000	
At least 1 Psychosocial Issue	By Gender	Fishers Exact	0.1240		
At least 1 Psychosocial Issue	By Cleft_Type	Fishers Exact	0.0493		Significant
At least 1 Psychosocial Issue	By Residence_Area	Fishers Exact	0.2397		
At least 1 Psychosocial Issue	By ABS_Age_Group	Fishers Exact	0.3125		
Anxiety Depression Study v ABS WA 2014	OR By Anxiety 25-44	Odds-Ratio	0.0000		Significant
Anxiety Depression Study v ABS WA 2014	RR By Anxiety 25-44	Relative Risk	0.0000		Significant
Anxiety Depression Study v ABS WA 2014	OR By Depression 25-44	Odds-Ratio	0.0000		Significant
Anxiety Depression Study v ABS WA 2014	RR By Depression 25-44	Relative Risk	0.0000		Significant
Psychosocial Issue Anxiety	By Education_Level	Fishers Exact	0.5584	1.0000	
Psychosocial Issue Anxiety	By Marital_Status	Fishers Exact	0.7170	1.0000	
Psychosocial Issue Anxiety	By Housing	Fishers Exact	0.0682	0.3410	
Psychosocial Issue Anxiety	By Annual_Income	Fishers Exact	0.1904	0.7614	
Psychosocial Issue Anxiety	By Imp_Face_Appearance	Fishers Exact	0.1913	0.7614	
Psychosocial Issue Anxiety	By Body_Weight	Fishers Exact	0.0305	0.1833	
Psychosocial Issue Depression	By Education_Level	Fishers Exact	0.5123	1.0000	
Psychosocial Issue Depression	By Marital_Status	Fishers Exact	0.9596	1.0000	
Psychosocial Issue Depression	By Housing	Fishers Exact	0.1936	0.7744	
Psychosocial Issue Depression	By Annual_Income	Fishers Exact	0.1240	0.6198	
Psychosocial Issue Depression	By Imp_Face_Appearance	Fishers Exact	0.9465	1.0000	
Psychosocial Issue Depression	By Body_Weight	Fishers Exact	0.0118	0.0708	
Long_Term_Cond Within Study	By Gender	Fishers Exact	0.3904		
Long_Term_Cond Within Study	By Cleft_Type	Fishers Exact	0.2533		
Long_Term_Cond Within Study	By Residence_Area	Fishers Exact	0.6755		
Long_Term_Cond Within Study	By ABS_Age_Group	Fishers Exact	0.7369		
Drink_Alcohol Within Study	By Gender	Fishers Exact	0.0419		Significant
Drink_Alcohol Within Study	By Cleft_Type	Fishers Exact	0.1236		
Drink_Alcohol Within Study	By Residence_Area	Fishers Exact	0.2020		
Drink_Alcohol Within Study	By ABS_Age_Group	Fishers Exact	0.6589		
Drink_Alcohol By Gender	OR By Drink Daily	Odds-Ratio	0.0198		Significant
Drink_Alcohol By Gender	RR By Drink Daily	Relative Risk	0.0198		Significant
Drink_Alcohol By Gender	OR By Drink Never	Odds-Ratio	0.0802		
Drink_Alcohol By Gender	RR By Drink Never	Relative Risk	0.0802		
Drink_Alcohol Study v ABS 2014-15	OR Female Daily_Weekly 25-44	Odds-Ratio	0.1147		
Drink_Alcohol Study v ABS 2014-15	RR Female Daily_Weekly 25-44	Relative Risk	0.1147		
Drink_Alcohol Study v ABS 2014-15	OR Male Daily_Weekly 25-44	Odds-Ratio	0.0986		
Drink_Alcohol Study v ABS 2014-15	RR Male Daily_Weekly 25-44	Relative Risk	0.0986		
Drink_Alcohol Study v ABS 2014-15	OR Female Never 25-44	Odds-Ratio	0.0028		Significant
Drink_Alcohol Study v ABS 2014-15	RR Female Never 25-44	Relative Risk	0.0028		Significant
Drink_Alcohol Study v ABS 2014-15	OR Male Never 25-44	Odds-Ratio	0.1587		
Drink_Alcohol Study v ABS 2014-15	RR Male Never 25-44	Relative Risk	0.1587		
Smoke_Cigarettes Within Study	By Gender	Fishers Exact	0.5883		
Smoke_Cigarettes Within Study	By Cleft_Type	Fishers Exact	0.0085		Significant
Smoke_Cigarettes Within Study	By Residence_Area	Fishers Exact	0.8855		
Smoke_Cigarettes Within Study	By ABS_Age_Group	Fishers Exact	0.6727		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Smoke_Cigarettes Study V ABS 2014-15	OR By Smoke Daily 25-44	Odds-Ratio	0.0959		
Smoke_Cigarettes Study V ABS 2014-15	RR By Smoke Daily 25-44	Relative Risk	0.0959		
Smoke_Cigarettes Study V ABS 2014-15	OR By Smoke Never 25-44	Odds-Ratio	0.0000		Significant
Smoke_Cigarettes Study V ABS 2014-15	RR By Smoke Never 25-44	Relative Risk	0.0000		Significant
Use_Social_Drugs Within Study	By Gender	Fishers Exact	0.0169		Significant
Use_Social_Drugs Within Study	By Cleft_Type	Fishers Exact	0.0035		Significant
Use_Social_Drugs Within Study	By Residence_Area	Fishers Exact	0.7402		
Use_Social_Drugs Within Study	By ABS_Age_Group	Fishers Exact	0.9396		
Use_Social_Drugs Within Study By Gender	OR By Use Daily or Weekly	Odds-Ratio	0.0907		
Use_Social_Drugs Within Study By Gender	RR By Use Daily or Weekly	Relative Risk	0.0907		
Use_Social_Drugs Within Study By Gender	OR By Use Monthly or Seldom	Odds-Ratio	0.1114		
Use_Social_Drugs Within Study By Gender	RR By Use Monthly or Seldom	Relative Risk	0.1114		
Use_Social_Drugs Within Study By Gender	OR By Use Never	Odds-Ratio	0.0229		Significant
Use_Social_Drugs Within Study By Gender	RR By Use Never	Relative Risk	0.0229		Significant
Use_Social_Drugs Within Study By Cleft_Type	OR By Use Monthly or Seldom	Odds-Ratio	0.0004		Significant
Use_Social_Drugs Within Study By Cleft_Type	RR By Use Monthly or Seldom	Relative Risk	0.0004		Significant
Use_Social_Drugs Within Study By Cleft_Type	OR By Use Never	Odds-Ratio	0.0036		Significant
Use_Social_Drugs Within Study By Cleft_Type	RR By Use Never	Relative Risk	0.0036		Significant
Use_Social_Drugs Study v AIHW 2013	OR By Males Use Daily or Weekly	Odds-Ratio	0.8035		
Use_Social_Drugs Study v AIHW 2013	RR By Males Use Daily or Weekly	Relative Risk	0.8035		
Use_Social_Drugs Study v AIHW 2013	OR By Males Use Never	Odds-Ratio	0.0355		Significant
Use_Social_Drugs Study v AIHW 2013	RR By Males Use Never	Relative Risk	0.0355		Significant
Use_Social_Drugs Study v AIHW 2013	OR By Females Use Daily or Weekly	Odds-Ratio	0.2463		
Use_Social_Drugs Study v AIHW 2013	RR By Females Use Daily or Weekly	Relative Risk	0.2463		
Use_Social_Drugs Study v AIHW 2013	OR By Females Use Never	Odds-Ratio	0.0000		Significant
Use_Social_Drugs Study v AIHW 2013	RR By Females Use Never	Relative Risk	0.0000		Significant
Exercise Within Study	By Gender	Fishers Exact	0.2502		
Exercise Within Study	By Cleft_Type	Fishers Exact	0.2224		
Exercise Within Study	By Residence_Area	Fishers Exact	0.2442		
Exercise Within Study	By ABS_Age_Group	Fishers Exact	0.6790		
Exercise Study v ABS 2014-15	OR By Exercise Daily	Odds-Ratio	0.0028		Significant
Exercise Study v ABS 2014-15	RR By Exercise Daily	Relative Risk	0.0028		Significant
Exercise Study v ABS 2014-15	OR By Exercise Infrequently	Odds-Ratio	0.2713		
Exercise Study v ABS 2014-15	RR By Exercise Infrequently	Relative Risk	0.2713		
Exercise Study v ABS 2014-15	OR By Exercise Never	Odds-Ratio	0.0000		Significant
Exercise Study v ABS 2014-15	RR By Exercise Never	Relative Risk	0.0000		Significant
Exercise Study v ABS 2014-15	OR By Exercise Weekly	Odds-Ratio	0.0000		Significant
Exercise Study v ABS 2014-15	RR By Exercise Weekly	Relative Risk	0.0000		Significant
Bully-Victim Psychosocial Issues	OR By Impact_Self_Esteem	Odds-Ratio	0.2035		
Bully-Victim Psychosocial Issues	RR By Impact_Self_Esteem	Relative Risk	0.2035		

Data Analysis for Chapter 8: An international comparison of psychosocial support provision for patients with a cleft or other visible difference.

Background

The Health Care Professionals Questionnaire (HCPQ) was designed to examine societal appearance perceptions and training requirements of Health Care Professionals (HCPs) from Australia and four European countries (Bulgaria, Serbia, Latvia and Turkey) who have worked with individuals with a visible difference. For the thesis chapter the aim was to identify the perceptions of HCPs on the following themes:

- The level of confidence HCPs had in supporting patients with visible differences;
- The psychosocial training received by HCPs;
- Extra psychosocial training requirements of HCPs.

This analysis was conducted using R version: 3.4.1 and RStudio version: 1.0.143 using RMarkdown version:1.6.

Confident in addressing patient psychosocial needs

Participants were asked: To what extent do you feel confident in addressing the psychosocial needs of patients and their families?

```
##          Confident_Addressing_Needs
## Gender  No      Sometimes Yes  Prop % by row No      Sometimes Yes
## Female  36      9          21    54.5%  13.6%   31.8%
## Male    21      3          20    47.7%   6.8%   45.5%
##
## By Gender                                Fishers Exact p-value=0.2805
## #

##          Confident_Addressing_Needs
## Age_Group No      Sometimes Yes  Prop % by row No      Sometimes Yes
## 20-29     7        3            4    50.0%  21.4%   28.6%
## 30-39    17        3           10    56.7%  10.0%   33.3%
## 40-49    16        3           13    50.0%   9.4%   40.6%
## 50-59    12        2           11    48.0%   8.0%   44.0%
## 60+       5        1            3    55.6%  11.1%   33.3%
##
## By Age_Group                            Fishers Exact p-value=0.9534
## #

##          Confident_Addressing_Needs
## Service_Yrs_Group No      Sometimes Yes  Prop % by row No      Sometimes Yes
## 0-4        7        4            6    41.2%  23.5%   35.3%
## 5-9       12        1            8    57.1%   4.8%   38.1%
## 10-14      8        1            3    66.7%   8.3%   25.0%
## 15-19      5        2           10    29.4%  11.8%   58.8%
## 20-24      9        1            5    60.0%   6.7%   33.3%
## 25+       16        3            9    57.1%  10.7%   32.1%
##
## By Service_Yrs_Group                    Fishers Exact p-value=0.5454## #
```

```

##          Confident_Addressing_Needs
## Country      No      Sometimes Yes      Prop % by row No      Sometimes Yes
## Australia    37      6          7          74.0% 12.0%   14.0%
## Bulgaria     2      0          13         13.3%  0.0%   86.7%
## Latvia       15      0          0          100.0% 0.0%   0.0%
## Serbia        0      0          15          0.0%  0.0%  100.0%
## Turkey        3      6          6          20.0% 40.0%   40.0%
##
## By Country                                Fishers Exact p-value=0.0000
## #

##          Confident_Addressing_Needs
## Profession_Group No      Sometimes Yes      Prop % by row No      Sometimes Yes
## Administration  3      1          0          75.0% 25.0%   0.0%
## Dental & Ortho  13     2          7          59.1%  9.1%  31.8%
## Nurse           9      2          9          45.0% 10.0%  45.0%
## Surgeon         19     1          20         47.5%  2.5%  50.0%
## Therapist       13     6          5          54.2% 25.0%  20.8%
##
## By Profession_Group                        Fishers Exact p-value=0.0544
## #

##          Confident_Addressing_Needs
## Received_Training No      Sometimes Yes      Prop % by row No      Sometimes Yes
## No                50     6          28         59.5%  7.1%  33.3%
## Yes                7      6          13         26.9% 23.1%  50.0%
##
## By Received_Training                      Fishers Exact p-value=0.0050
## #

```

Psychosocial Training History

Participants were asked:

Have you received any training about the psychological impacts of disfigurement and how to meet the needs of patients?

```

##          Received_Training
## Gender      No      Yes      Prop % by row No      Yes
## Female      51     15          77.3% 22.7%
## Male        33     11          75.0% 25.0%
##
## By Gender                                Fishers Exact p-value=0.8214
## #

##          Received_Training
## Age_Group No      Yes      Prop % by row No      Yes
## 20-29      9      5          64.3% 35.7%
## 30-39      24     6          80.0% 20.0%
## 40-49      26     6          81.2% 18.8%
## 50-59      19     6          76.0% 24.0%
## 60+        6      3          66.7% 33.3%
##
## By Age_Group                            Fishers Exact p-value=0.6617
## #

##          Received_Training
## Service_Yrs_Group No      Yes      Prop % by row No      Yes
## 0-4          14     3          82.4% 17.6%
## 5-9          15     6          71.4% 28.6%
## 10-14        9      3          75.0% 25.0%
## 15-19       15     2          88.2% 11.8%
## 20-24       12     3          80.0% 20.0%
## 25+         19     9          67.9% 32.1%

```

```

##
## By Service_Yrs_Group                      Fishers Exact p-value=0.6930
## #
##          Received_Training
## Country  No    Yes  Prop % by row No    Yes
## Australia 40   10   80.0% 20.0%
## Bulgaria  12   3    80.0% 20.0%
## Latvia    13   2    86.7% 13.3%
## Serbia    13   2    86.7% 13.3%
## Turkey     6   9    40.0% 60.0%
##
## By Country                                Fishers Exact p-value=0.0204
## #
##          Received_Training
## Profession_Group No    Yes  Prop % by row No    Yes
## Administration  3    1    75.0% 25.0%
## Dental & Ortho  15   7    68.2% 31.8%
## Nurse           14   6    70.0% 30.0%
## Surgeon         34   6    85.0% 15.0%
## Therapist       18   6    75.0% 25.0%
##
## By Profession_Group                        Fishers Exact p-value=0.4832
## #

```

Psychosocial training requirements

Participants were asked:

"What would help you address the needs of patients and their families more effectively? (e.g. training - what sort; how should it be delivered; who needs training - you? Other members of the team?)".

From the responses (multiple were allowed), FOUR themes emerged: On-the-job training, Formal training (lectures, seminars, workshops etc), Written materials, and Community education.

```

##          Response
## Extra_Training  No    Yes  Prop % by row No    Yes
## Formal_Training 14   96   12.7% 87.3%
## On_The_Job_Support 99   11   90.0% 10.0%
## Written_Materials 100  10   90.9%  9.1%
## Community_Education 102  8    92.7%  7.3%

```

Analysis Summary

The following table summarises all of the statistical tests conducted in this analysis.

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Confident_Addressing_Needs	By Gender	Fishers Exact	0.2805		
Confident_Addressing_Needs	By Age_Group	Fishers Exact	0.9534		
Confident_Addressing_Needs	By Service_Yrs_Group	Fishers Exact	0.5454		

Group_Name	Test_Name	Test_Type	PValue	AdjPValue	Significant
Confident_Addressing_Needs	By Country	Fishers Exact	0.0000		Significant
Confident_Addressing_Needs	By Profession_Group	Fishers Exact	0.0544		
Confident_Addressing_Needs	By Received_Training	Fishers Exact	0.0050		Significant
Received_Training	By Gender	Fishers Exact	0.8214		
Received_Training	By Age_Group	Fishers Exact	0.6617		
Received_Training	By Service_Yrs_Group	Fishers Exact	0.6930		
Received_Training	By Country	Fishers Exact	0.0204		Significant
Received_Training	By Profession_Group	Fishers Exact	0.4832		

Appendix 6. Contributions by co-author declarations.

Declaration of Authorship


Publication	Role
<p>Paper 1: Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups.</p> <p>Nicholls W, Harper C, Selvey L, Robinson S, Hartig G, Persson M.</p> <p>Accepted for publication Cleft Palate Craniofacial Journal, May 2017</p>	<ul style="list-style-type: none"> • Identified and developed the topic • Conducted a literature search • Designed this study with supervision • Collected the data • Conducted basic quantitative analysis • Collaboratively conducted advanced quantitative analysis • Drew conclusions and corresponding implications • Wrote and edited the paper with supervision • Dissemination of the findings
<p>Paper 2: Adult specific life outcomes of cleft lip and palate in a Western Australian cohort.</p> <p>Nicholls W, Harper C, Robinson S, Persson M Selvey L.</p> <p>Accepted for publication Cleft Palate Craniofacial Journal, June 2017</p>	<ul style="list-style-type: none"> • Identified and developed the topic • Conducted a literature search • Designed this study with supervision • Collected the data • Conducted basic quantitative analysis • Collaboratively conducted advanced quantitative analysis • Drew conclusions and corresponding implications • Wrote and edited the paper with supervision • Dissemination of the findings
<p>Paper 3: The psychosocial impact of cleft in a Western Australian cohort across three age-groups.</p> <p>Nicholls W, Selvey L, Harper C, Robinson S, Persson M.</p> <p>Accepted for publication Cleft Palate Craniofacial Journal, June 2017</p>	<ul style="list-style-type: none"> • Identified and developed the topic • Conducted a literature search • Designed this study with supervision • Collected the data • Conducted basic quantitative analysis • Collaboratively conducted advanced quantitative analysis • Drew conclusions and corresponding implications • Wrote and edited the paper with supervision • Dissemination of the findings
<p>Paper 4: Adult narratives of the psychosocial impact of cleft in a Western Australian cohort.</p> <p>Nicholls W, Robinson S, Persson M, Selvey L.</p> <p>Accepted for publication Cleft Palate Craniofacial Journal, May 2017</p>	<ul style="list-style-type: none"> • Identified and developed the topic • Conducted a literature search • Designed this study with supervision • Collected the data • Conducted qualitative analysis with supervision • Drew conclusions and corresponding implications • Wrote and edited the paper with supervision • Dissemination of the findings

Co-author declarations.

Contribution by co-author.

1. Title *Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups.*
2. Title *Adult specific life outcomes of cleft lip and palate in a Western Australian cohort.*
3. Title *The psychosocial impact of cleft in a Western Australian cohort across three age-groups.*
4. Title *Adult narratives of the psychosocial impact of cleft in a Western Australian cohort.*

I advise the contribution made to the above papers was supervision for study design, data analysis, proof-reading and editing.



Signed: _____ Suzanne Robinson (Supervisor).

Contribution by co-author.

1. Title *Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups.*
2. Title *Adult specific life outcomes of cleft lip and palate in a Western Australian cohort.*
3. Title *The psychosocial impact of cleft in a Western Australian cohort across three age-groups.*
4. Title *Adult narratives of the psychosocial impact of cleft in a Western Australian cohort.*

I advise the contribution made to the above papers was supervision for study design, data analysis, proof-reading and editing.



Signed: _____ Linda Selvey (Supervisor).

Contribution by co-author.

1. Title *Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups.*

2. Title *Adult specific life outcomes of cleft lip and palate in a Western Australian cohort.*

3. Title *The psychosocial impact of cleft in a Western Australian cohort across three age-groups.*

4. Title *Adult narratives of the psychosocial impact of cleft in a Western Australian cohort.*

I advise the contribution made to the above papers was supervision for study design, data analysis, proof-reading and editing.

Signed:  Martin Persson (Supervisor).

Contribution by co-author.

Paper: *Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups.*

Paper: *Adult specific life outcomes of cleft lip and palate in a Western Australian cohort.*

Paper: *The psychosocial impact of cleft in a Western Australian cohort across three age-groups.*

I advise the contribution made to the above papers was advice for data analysis, proof-reading and editing.

Signed:  Craig Harper Data Analyst.

Contribution by co-author.

Paper: *Body-esteem in a Western Australian cleft lip and/or palate cohort across three age-groups.*

We advise the contribution made to the above paper was advice for data analysis, proof-reading and editing.

Signed:  Gerald Hartig Data Scientist.


Appendix 7. Permission to use Body-Esteem Scale instrument

PERMISSION TO USE COPYRIGHT MATERIAL AS SPECIFIED BELOW:

Body Esteem Scale Questionnaires

I hereby give permission for **Wendy Nicholls** to include the abovementioned material(s) in his/her higher degree thesis for Curtin University, and to communicate this material via the espace institutional repository. This permission is granted on a non-exclusive basis and for an indefinite period.

I confirm that I am the copyright owner of the specified material.

Signed: 
Name: BEYERLEY K. MENDELSON
Position: TEACHER AT VANIER COLLEGE (RETIRED)
Date: SEPTEMBER 26, 2017.

Appendix 8. Additional publications by the candidate

School performance for children with cleft lip and palate: a population-based study. 2016.
Child: Care, Health & Development. (in press).

Dental anomalies in children with cleft lip and palate in Western Australia. [Eur J Dent](#). 2016
Apr-Jun;10(2):254-8. doi: 10.4103/1305-7456.178317.

Antenatal Ultrasound Detection of Cleft in Western Australia from 2003 to 2012: A Follow-Up
Study. *Cleft Palate Craniofac J*. 2015 Oct 27.

The Assessment of Digital Study Models Using the GOSLON Yardstick Index. *Cleft Palate
Craniofac J*. 2014 May;51(3):264-9.

Additional conference presentations

Research and Advances CAHS Perth Western Australia.

Oral presentation: Adult specific life outcomes of cleft lip and palate in a Western
Australian cohort.

VCFS/22q Deletion Meeting Perth, Western Australia, 2017.

Oral presentation: Adult specific life outcomes of cleft lip and palate in a Western
Australian cohort.

13th INTERNATIONAL CONGRESS on Cleft Palate and Related Craniofacial Anomalies,
Chennai, India. 2017.

Poster: Adult narratives of the psychosocial impact of cleft in a Western
Australian cohort.

Oral presentation: Adult specific life outcomes of cleft lip and palate in a Western
Australian cohort.

Oral presentation (co-author): Healthcare Providers' awareness and ability to provide
psychosocial support for patients with a cleft or other visible
difference: Europe and Australia.

Oral presentation: The impact of cleft lip and palate across the lifespan: as part of the
Global Taskforce presentation.

Australian and New Zealand Paediatric Dentistry Association Western Australian Branch
Winter Meeting, Bunker Bay, Western Australia. 2015

Oral presentation: Cleft lip and palate: a comparative psychosocial perspective.

12th INTERNATIONAL CONGRESS on Cleft Palate and Related Craniofacial Anomalies,
Orlando, United States. 2012.

Poster: AUSTCLEFT -a proposed pilot for participative multicenter cleft
studies in Australia, New Zealand and Asia Pacific.

Australasian Cleft Lip and Palate Association and 7th Asian Pacific Cleft Lip and Palate /
Craniofacial Congress Perth, Western Australia. 2010.

Posters: Cleft Lip and Palate: a father's perspective
Cleft Lip and Palate in WA: a team approach
Dental anomalies in children with cleft lip and palate in Western
Australia
Timetable of Intervention: The Management of Cleft Lip and Palate in
Western Australia

11TH INTERNATIONAL CONGRESS on Cleft Palate and Related Craniofacial Anomalies,
Fortaleza, Brazil. 2009.

Posters: GOSLON Yardstick Index and psycho-social outcomes
Ectodermal Dysplasia: a patient perspective

10th INTERNATIONAL CONGRESS on Cleft Palate and Related Craniofacial Anomalies.
Durban, South Africa. 2005.

Oral presentation: Cleft lip and palate: a patient perspective.