

**School of Information Systems
Curtin Business School**

**A Framework for
Assistive Communications Technology in
Cross-Cultural Healthcare**

Volume One

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Doctor of Philosophy
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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.

Signature:

A handwritten signature in black ink, appearing to be 'D. C.', written on a light blue grid background.

Date: 13 November 2013

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Glossary of Acronyms

ABS	Australian Bureau of Statistics
ACT	Assistive Communications Technology
AE	Aboriginal English
AEHT	Aboriginal English Home Talk/Health Talk
AHMAC	Australian Health Ministers' Advisory Council
AHPs	Allied Health Professionals
AHW	Aboriginal Health Worker
AI	Artificial Intelligence
AIHW	Australian Institute of Health and Welfare
AT	Assistive Technology
ATSI	Aboriginal and Torres Strait Islander
COAG	Council of Australian Governments
CPGs	Clinical Practice Guidelines
GLs	Guidelines
GPs	General Practitioners
ICT	Information and Communications Technology
IMGs	International Medical Graduates
IS	Information Systems
MokCa	Mobile Knowledge Capturing Application
NACCHO	National Aboriginal Community Controlled Health Organisation
OTDs	Overseas trained doctors
OWL	Web Ontology Language
PoCT	Point of Care Tests/Testing
PPAC	Patient-Practitioner Assistive Communications
PPIE	Patient-Practitioner Interview Encounter
QGA	Qualitative Gap Analysis
RACGP	The Royal Australian College of General Practitioners
RDF	Resource Description Framework
SAE	Standard Australian English
SDM	Shared Decision Making

SE	Standard English
SPARQL	Simple Protocol and RDF Query Language
T2D	Type 2 Diabetes
T2DM	Type 2 Diabetes Mellitus
W3C	World Wide Web Consortium
WA	Western Australia
WHO	World Health Organisation

Summary of the Thesis

Socio-culturally disadvantaged people globally endure significant health and health care disparities compared with the mainstream population, in great part due to communications barriers arising from the lack of equitable acculturation within patient-practitioner consultations. Rural and remote Australian Aboriginal communities suffer seriously adverse life expectancy rates, lifestyle disease complications and hospital treatment needs due to type 2 diabetes. Identifying Aboriginal English dialectal engagement practice as an asset for acculturative contributions to healthcare communications, this research work presents a framework foundation for computerised delivery of a patient-practitioner lingua franca. It has combined behavioural and design science methods through computer ontology ICT development to devise the first known framework for an Australian intercultural patient-practitioner type 2 diabetes assistive communications system, known as P-PAC. The ontology maps and merges Aboriginal English dialectal and cultural communications pragmatics with Australia's type 2 diabetes clinical guidelines. This will ultimately avail Australia's rural and remote living Aboriginal patients and their healthcare providers of a user-friendly communications, health education and knowledge exchange application. The framework model will support variant applications to benefit communications and cognition for other disadvantaged ethnic minorities and to address different forms of chronic disease care.

Chapter 1: Introduction and Background

The research described in this thesis is intended to establish an assistive communications technology (ACT) system framework to help overcome communications barriers which are depriving many of Australia's Aboriginal people of optimum healthcare. The framework addresses and counters barriers using a system of acculturation support for participants in primary care consultations.

Specifically the framework is designed as a response to exceptional and significant health and health care disparities of Aboriginal Type 2 diabetes mellitus (T2DM) patients when compared with the majority non-Indigenous population.

The possible cause of these disparities, which extend to other ethnic minority groups, is the perceived Australian 'one-size-fits-all' institutionalized western medicine approach to healthcare service delivery. The shortcoming within this approach is the absence of equitable and shared cross-cultural cognition. Efficacious knowledge exchange is seemingly too often diminished or defeated through the impact of communications barriers, which go unrecognized and/or unresolved.

Much of the analysis for the framework building process is focused on Western Australia's Aboriginal English speaking communities and the related regional (rural and remote) patient demographic profile. Accordingly the Aboriginal English dialect is central to design work for the assistive communications concept.

This thesis investigates previous work across several related and detailed dimensions, including pragmatic intercultural conversation and world perspective influences, clinical practice guidelines and ICT/ACT factoring. Data is assimilated and analysed from wide ranging schema sources more substantive solutions than previously offered or proposed.

In this and subsequent chapters acronyms are commonly used as found in the glossary at the front of this thesis. From time to time however I use the complete words to aid memory and ease the need for repetitious checking.

1.1 Problem focus

The problems tackled in this research are multi faceted, i.e. several contributory components in unsatisfactory health care each requires attention in order to fuse a single communications solutions formula; and barriers to the required research process further compound the problem profile.

These facets comprise:

- Complexity of type 2 diabetes clinical terminology in a PPIE conversational context
- Limited availability of documented Aboriginal English pragmatic dialectal data and taxonomic schema
- Dissonance in present day cross-cultural communication for PPIEs
- Cultural barriers to research in Aboriginal communities
- Design challenges for ICT adoption aimed at equitable intercultural knowledge sharing

1.2 The problem of Type 2 Diabetes Mellitus (T2DM) Management for Aboriginal patients in Western Australia

Taylor in the introduction for her 2010 doctoral thesis on intercultural communication in Central Australian healthcare recorded two statements from an Aboriginal community member. These succinctly encapsulate the dire state of health care communications affecting rural and remote Aboriginal communities:

Our people are dying...because they don't understand what doctors and nurses are saying to them.

Yuwa (yes) they feel shame and they just walk away and finish up (die) [1]

The demographic profile, accompanying infrastructure and socio-economic strains impacting health care services covering such a large and diverse geographical region, was readily identified as requiring systems of care that inter alia can overcome distance. The exceptional vulnerability in terms of wellbeing, chronic disease management and incidence of age related premature mortality affecting the

Aboriginal population was identified by Taylor as a stark example of service inadequacies in Central Australia.

In the course of this subsequent Western Australia-based information systems technology (ACT) thesis research it has become apparent that Australia stands to benefit from the communications focus in a hitherto unexpected way. The communications problems, lessons and proposed solutions for Aboriginal healthcare have parallels within, and in turn, opportunities to learn from the experiences of Australia's diverse immigrant population. In basic form, any ICT system that depends upon human-machine interaction for competent and effective healthcare communications must aim to achieve a consistent high level of shared cognition between patients and providers.

When demographics, economic disadvantage and critical state healthcare trends are factored together, WA's remote area Indigenous T2DM patients are disproportionately at risk of developing chronic diseases compared with non-Indigenous people living in or close to urban areas [2]. Western Australia has the largest land area (2,532,400sq km) of any Australian State or Territory. Its coastline of 12,500km amounts to 34% of Australia's total coastline. Over 72% of Western Australia's population is located in Perth, where principal health care support facilities, medical treatment and pathology testing services are located[3].

Rural and remote communities rely upon thinly-spread, mobility-dependent, over-stretched, ill-equipped and sometimes inaccessible, primary care resources; and on a relatively small cohort of Aboriginal Health Workers of Indigenous ethnicity. These adverse factors are compounded by comparably weak communications infrastructure, and sporadic development of telehealth services [4, 5].

In 2008 the **Council of Australian Governments** (COAG) agreed to six ambitious targets to address social disadvantages faced by Indigenous Australians[6]. The 'Close the Gap' initiative focused on securing improvements in life expectancy, child mortality, education and employment. Two of the six stated goals were then:

- To close the gap in life expectancy within a generation (by 2031)

- To halve the gap in mortality rates for Indigenous children under five by 2018

Other goals with target dates relate to improvements in early childhood education; to halve the gap in reading, writing and numeracy achievements; to halve the gap for Indigenous students in Year 12 (or equivalent) attainment rates; and to halve the gap in employment outcomes between Indigenous and other Australians. Whereas just two of these goals are directed toward health wellbeing improvement, there is an implicit connection between all six targets that will unfold in this thesis, centred on communications. Collectively these goals all contribute to improving the prospects for wellbeing of Aboriginal people. One key likelihood is that improved standards of literacy in the community will translate to improved quality of PPIE communications.

1.3 Type 2 Diabetes

Chronic diseases include heart disease, stroke, cancer, chronic respiratory diseases and diabetes. Chronic diseases represent an increasingly dominant public healthcare demand factor globally [7, 8]. Type 2 diabetes management for culturally disadvantaged patients justifies a concentrated effort to counter exceptionally adverse mortality rates and unsatisfactory wellbeing outcomes. Type 2 diabetes mellitus (T2DM) is chosen as the ACT supported management target, based upon research findings as described below.

Diabetes is one of the most serious chronic diseases prevalent in the world today. The World Health Organization (WHO) describes chronic diseases as ‘diseases of long duration and generally slow progression’. Type 2 Diabetes Mellitus (T2DM) comprises 80% to 90% of all diabetes cases [8]. The first accurate diabetes prevalence study commissioned in Australia led to a 2001 report by the International Diabetes Institute suggesting that almost one in four Australians aged 25 years and older had either diabetes or a condition of impaired glucose metabolism [9].

Diabetes WA reports that in the 2007/08 financial year, 12.37% of all hospitalisations in Western Australia, i.e. 95,775 admissions, involved patients with diabetes, whether as a direct or associated condition [10].

In the case of the impact of disadvantage relevant to Aboriginal type 2 diabetes treatment and care, the health and mortality risk management goal for the T2DM patient is to routinely achieve a consistent and safe level of glycemic or ‘metabolic’ control. The reality for socio-economically and culturally disadvantaged groups, notably rural and remote region living Aboriginal Australians is that lifestyle circumstances are not conducive to achieving a good quality of self-management and wellbeing outcomes.

1.3.1 Overview of Type 2 Diabetes Mellitus (T2DM) in Context

From a November 2007 Federal Election article [11] in the Australian Medical Journal six further observations apply:

- Around 900,000 Australians have Type 2 diabetes (T2DM); half are undiagnosed.
- Each year sees about 3 million consultations with doctors and 65,000 hospital admissions for diabetes.
- Diabetes cost to the nation is estimated at \$3 billion annually.
- Average annual cost for each individual with diabetes is (2007) estimated at \$7566, of which \$5,325 is health care costs. Annual health care costs can rise to \$9610 due to complications.
- Significant evidence shows that self-management programs can help to reduce hospitalizations and improve patient quality of life; and that a broader systemic approach applying patient-centric principles is needed.

1.3.2 Existing management models

The principal diabetes management document underpinning this work is titled ‘The Diabetes Management in General Practice - Guidelines for Type 2 Diabetes’ and is jointly published by Diabetes Australia and The Royal Australian College of General Practitioners[12]. Hereafter it will be referred to as the ‘RACGP GLs’ for T2DM. These guidelines are designed for use by medical practitioners and are updated/republished annually. The term Patient-Practitioner Interview Encounter (PPIE) is applied throughout this thesis to denote an emphasis on the role of the patient and the two-way nature of the primary care consultation process. This runs

counter to established dominant western medical practice in which the clinician (Practitioner) culture inclines toward unidirectional, and commonly described as paternal, control over the primary care consultation.

‘Practitioner’ is equivalent to ‘Clinician’, and to ‘Provider’ as well as to ‘Physician’ all of which may appear in this treatise. ‘Practitioner’ in the context of PPIE is chosen as the preferred description of the medical professional who works directly with patients as a provider of healthcare. It includes, among an extensive listing, Allied Health Professionals (AHPs) such as Aboriginal Health Workers (AHWs), Dieticians, Exercise Physiologists, Occupational Therapists, Osteopaths, Podiatrists, and Psychologists.

The specific environment of interest within PPIE parameters is Primary (Health) Care. In Australia this predominantly but not exclusively involves consultation with General Practitioners (GPs). Wiese et.al describe Australia’s primary healthcare as ‘largely delivered through two parallel systems: Medicare supported primary care delivered by fee-for-service general practitioners, and state funded and managed community health services’ [13]. Investigating current links between GPs and local primary healthcare providers these authors found barriers to links including ‘communication and information, access and availability of services, GP lack of awareness and understanding of services provided in the state funded sector, and lack of time to gain information’.

Qualified nurses are major contributors to PPIE, and given the demographic profile of Australia, are commonly in the forefront of this activity, notably and often exclusively so in the rural and remote regions where fewer GPs are accessible to patients on a daily basis. Allied Health Professionals also work within the PPIE domain. Accessibility to AHP services is similarly constrained by provider-patient ratio demography, exacerbated in much of the country by exceptional challenges involving distance/transport/power, internet connectivity and terrain.

1.3.3 Limitations of current healthcare models

Humphreys and Wakerman, noted for their research into Australian rural and remote healthcare services, highlight the inadequacies of a system devised for urban application, stating that among other considerations regional primary care models must be devised and implemented based upon geographical context[14].

Essential to treatment and care intended to improve upon the best prognosis for the patient, is the application of self-management, i.e. lifestyle disciplines to prevent complications and mitigate the daily detrimental effects of T2DM.

Routine regular actions, strict self-risk management and invariably changed emphasis on dietary and exercise factors can appear to be simple remedies to the uninitiated. The complexities and the spectre of serious life-threatening events arising from comorbidities combine with the need for modifying relationship habits. Within the ambit of the patient health threat environment are family and other carers; regular social acquaintances and places of resort. The enormity of communicating the relevant information, of variable interpretations in conversation and in unpredictable contextual circumstances, brings its own complexity and risk of misunderstanding.

In this research, attention has been paid to the potential value of pre-encounter and post-encounter communications surrounding the PPIE. This is an extremely challenging scenario and poorly managed T2DM consequences are too often witnessed in emergency department and hospital admissions. The differences in cognitive capabilities, age factored illness, and cultural communication disparities together with PPIE time constraints place a very high expectation of expertise and effectiveness on the practitioner. Figure 1 depicts a common scenario in which the patient is subject to the requirements of the medical culture PPIE system of engagement.

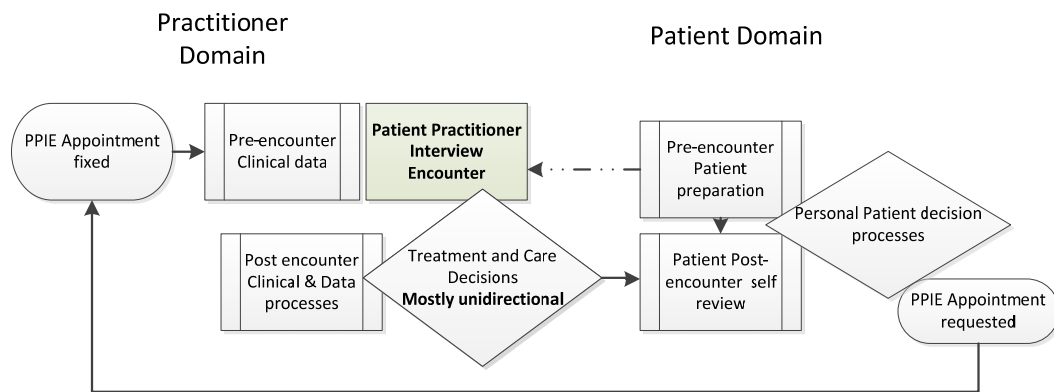


Figure 1: Current General Practice PPIE engagement flow in Primary Care

The dashed line connecting the patient with the PPIE denotes the likelihood of a dilution of quality and quantity of information arising through such factors as time constraints cognition/memory issues and other barriers to communications including cultural power distance. Most particularly the information and knowledge transfer is biased toward meeting the practitioner’s service constraints and unidirectional processes. Accordingly the patient both before and after the consultation, has limited opportunity to impart potentially valuable healthcare information in detail. This information, for example elaboration of signs, symptoms and anxieties, exists within the patient domain. The reason(s) for seeking medical advice and the thought processes of the patient before the face-to-face PPIE event merit preservation for detailed explanation to help the practitioner. Similarly retrospective reflection and review by the patient of what has occurred in the PIE may generate new information. But this information may not be successfully transported and communicated from the pre-encounter and post-encounter stages of the patient thinking process to serve as part of the PPIE engagement. No universally dedicated system exists for extending the scope of the PPIE to capture pre and post encounter information. In intercultural engagement involving socio-culturally disadvantaged patients the consequential detriment to best health status knowledge is exacerbated. This thesis aims to address these communications weakness.

Health care is an information and knowledge intensive industry; but ICT investments found elsewhere are virtually absent in the primary care communications protocols.

Primary care ACT applications specifically occupy little space in published research. For T2DM and other chronic disease management GLs there is an available and accessible foundation for constructing the necessary shared knowledge serving what might be considered as both the regular and temporary ‘stakeholders’ in a patient’s care.

The primary care setting is chosen as the environment for problem-solving concentration because it is the starting point for the great majority of patients and for any hope of introducing successful preventive care. The ultimate reach of the concept however will encompass PPIEs in hospital emergency departments, outpatient clinics and hospital admissions.

The challenge of Australian healthcare accessibility more generally is illustrated in Figure 2:

Figure 2: Australia Access to Health Professionals

1. Based on numbers of people employed, not FTE. 2. As at December quarter 2007 (PHIAC) 3. As at 2004 (ABS)

Source: Most recent data on health practitioners provided by Federal Department of Health and Ageing; figures available on request. Private Health Insurance Administration Council (PHIAC), *Quarterly Statistics, December 2007*; ABS, *1301.0 Year Book Australia 2006*; ABS, *2068.0 Census Data 2006*; AIHW, *Male consultations in general practice in Australia 1999-2000* (2003); Klimidis et al, *Mental Health Service Use by Ethnic Communities in Victoria, 1995-6* (VTPU, 1999) **Australia 2020 Summit** Long-term Health Strategy (April 2008)

This thesis reference: [15]

1.4 Modelling Communications Systems for Healthcare

One service enhancement option reviewed was that of telehealth, a relatively modest and under-developed state government system when compared with electronic remote care services operating in other parts of the developed world. The following paragraph is taken from an independently published paper incidental to this research on the subject of consumer engagement with new rural and remote telehealth services.

The terms telehealth and telemedicine are somewhat interchangeable and can share or differ in meaning according to the functionality and scope determined by national, state or regional healthcare service providers managing these systems. Along with ‘Telecare’ a variety of circumstantial scenarios apply to the use of live video linking patients at a distance from their service providers. Some of these systems include electronic health monitoring devices and digital communications directly connecting patient homes with health care service locations.

I return briefly to telehealth later in this chapter in the context of future patient-practitioner communications options and research priorities.

The respected informatics research author Enrico Coiera in a journal article titled ‘When Conversation Is Better than Computation’ wrote: ‘While largely ignored in informatics thinking, the clinical communication space accounts for the major part of the information flow in health care. Growing evidence indicates that errors in communication give rise to substantial clinical morbidity and mortality’[16]. Coiera’s paper examined whether understanding the dynamics of communication between human beings will help to improve the design of information systems in health care. Identifying and applying the principle of common ground in conversational concepts, Coiera proposes opportunities for modelling common ground interaction between computer information systems and human users.

Pursuing the common ground interactions theme, this research describes efforts to build a conceptual framework with the ultimate aim of providing navigable interactive health care guidance to assist people such as Aboriginal and ethnic

minorities disadvantaged by the inter-cultural psychosocial barriers that are present in medical consultations. Principally, this is based on an Assistive Communications Technology (ACT) concept that envelops and centres on the Patient-Practitioner Interview Encounter (PPIE) in primary care.

Assistive Technology (AT) has been defined in the recent past and in regulatory descriptions as a tool intended to help people with disabilities. The pace of advancement in information and communications technology (ICT) together with imaginative mass societal uptake has, however, quickly transformed the pragmatic application of assistive technologies into a more ubiquitous presence. Computer magazine articles point to AT growth in the education market, and to leading software companies such as Microsoft and Apple as having embedded assistive technologies in their products [17]. Mina Nagy commenting on e-health programs writes that AT offers society a new lifestyle; that it's view of 'disabled' is misleading, and that AT should be seen from a broader 'enabling' perspective [18]. Vanderheiden perceptively tells the reader that the best situation would arise if AT is designed into all products so that regardless of abilities or disabilities, all people will benefit [19]. This research utilises Assistive Communications Technology (ACT) as a contemporary description in which 'disadvantaged' ultimately replaces 'disabled'.

1.4.1 Improving patient-practitioner understanding through better communication

Western Australia (WA) has yielded much of the data supporting the broad sphere of the combined elements of primary care consultation; equitable cross-cultural health care service management of T2DM and development of communications system concepts.

WA presents extreme service delivery logistics obstacles that can stimulate problem-solving opportunities for Australia as a whole. These include extraordinary demographics, i.e. very large land mass, variable extremes of population spread, climate and terrain; and an exceptionally difficult environment for delivering equitable health care. Collectively the most challenged health care patient communities are referenced in a variety of ways and descriptions here and elsewhere may include 'Aboriginal'; 'Indigenous'; 'ethnic minority culture'; 'minority culture';

‘culturally and linguistically diverse’; ‘socio-economically disadvantaged’; and ‘non English speaking background’. For reasons that will be elaborated, the microcosm for study within the framework is Australian Aboriginal-English (AE) also known as ‘Aboriginal-English Home Talk’ (AEHT). This comprises pragmatic dialectal engagement in PPIE from the perspective of the cultural background of the patient. For further clarity, the words ‘Aboriginal’ and ‘Indigenous’ when used in the Australian Aboriginal English home talk context, encompass people of Aboriginal and Torres Strait Islander (ATSI) cultural groups.

Before the design effort for technological intervention can begin, a serious attempt to acquire a clear understanding of the nature of the communications barriers must be undertaken. Health care consultation processes in primary care and in other facets of health care service delivery are filled with cognition, language, dialectal, socio-economic, psycho-emotional, and innumerable other sub-factors that characterize unique human encounters. Collectively research reported in Chapters 2 and 6 convey the uncertainty, illusion or self-delusion of common understanding between provider and consumer as the principal barrier to health care communication. Fundamentally, language differences alone do not explain barrier causal outcomes.

1.5 Multiple inter-related meanings of Communication

The words ‘communication’ and ‘communications’ frequently appear in human spoken and written exchanges with a range of meanings according to the circumstances of those exchanges. The proliferation of technological communications media methods, channels and devices over the past several decades has introduced new terminology and novel influences that have increased the volume and layers of meaning when communication(s) is the subject of attention. Dance studied multitudinous definitions of ‘communications’ from the perspective of ‘concept’ found in the philosophy of science literature[20]. He contrasts features of the world that stand out and which are relatively easy to name, with other features that are discernible only by ‘a subtle and devious examination of the nature of man, and society’. Using a sample of definitions Dance published a list of fifteen conceptual components, thirteen of which appear synergic with this thesis, i.e.as in Table 1.

<ul style="list-style-type: none"> • Symbols/Verbal/Speech • Understanding • Interaction/Relationship/Social Process • Reduction of Uncertainty Process • Transfer/Transmission/Interchange • Lining/Binding • Commonality 	<ul style="list-style-type: none"> • Replicating Memories • Discriminative Response /Behaviour • Modifying/Response/Change • Stimuli • Time/Situation • Power
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Table 1: Selection from F.E.X Dance Communications Concepts [20]

This section returns briefly to Dance’s findings and contributing statements in the Chapter 4 Solutions discussion. This includes taking account of cognition in that process step, as referenced by Schwartz who states that ‘central to a conversational analysis of human judgement is the distinction between the semantic meaning of a sentence and the pragmatic meaning of an utterance’ [21]. He asserts that ‘designing an utterance to be understood by a given listener requires extensive inferences’ on the part of the speaker. In this research my aim is to support communications efficacy through a reliable inference discipline that can help facilitate spontaneous user design of utterances.

1.6 Aboriginal English (AE) factors in cross-cultural healthcare

The documented experiences of Aboriginal patient-practitioner encounters in Australia illustrate a rich foundation of culturally challenging human communications in healthcare that predate the instances and accounts of PPIE communication barriers involving other ethnic minority patients. The ancient civilization and cultural landscape of Australia’s Aboriginal peoples stretching back more than 40,000 years was first confronted by predecessors of the white European colonists as early as 1770 [22]. The subsequent immigration wave came predominantly from Northern Europe. It was close to two hundred years later that Australia abandoned its ‘White Immigration’ policy. Notwithstanding that policy, Australia had become more diverse due to comparatively small numbers of migrants from southern Europe, Asia and the Middle East. Today Australia is much more multicultural. Besides English and the estimated sixty surviving Aboriginal native

languages, more than 200 other languages are spoken in the homes of Australian residents[23]. The damaging impact of colonisation is not part of this thesis discussion except to point out that emergence of the dialect referred to as Aboriginal English (AE) Home Talk (HT) represents a significant cultural survival mechanism. It provides an historical lesson and the working base for the development of human communications by extremely disadvantaged communities and individuals; as opposed to their governments, overseers or benefactors.

In 2006 the ‘Close the Gap’ campaign was first conceived and led by a group membership of Aboriginal and Torres Strait Islanders[6]. This aims to ultimately bring Aboriginal life expectancy and general health in line with non-Indigenous levels. In 2008 the campaign was formally ratified by the signing of a statement of intent between the Government of Australia and The Australian Human Rights Commission[24]. The disturbing prevalence of chronic disease and premature mortality rates persisting in Aboriginal communities together with the research literature on PPIE however suggests that *bridging the communications gap* has yet to be realized. Knowledge of the history of Aboriginal communities in the health and health care context is of vital import to this research. Coupled with a study of Aboriginal communications with primary care providers this history goes some way to explain the persistent failings in cognition, and the consequential misunderstandings, mistakes in attempted knowledge transfer and miscommunication outcomes. While it is possible for non-Indigenous practitioners to learn a few Aboriginal English words these may not be reliable or appropriate if used without credible guidance within the PPIE. The unsatisfactory risk revolves around cultural and contextual semantics. This thesis will provide the framework from which practitioners can be enabled in their effort to secure precise AE information and meaning within the PPIE.

1.6.1 Aboriginal English explained

This work concentrates for modelling purposes on Australia’s usage of the dialectal form of conversational communication known as Aboriginal English. Interest in the PPIE communications experience with Aboriginal patients is justified by the exceptional T2DM and comorbidity incidence in the Indigenous population of

Australia. Since the early nineties, university and education department Indigenous and non-Indigenous researchers in Western Australia have been building what today is a substantial body of knowledge of Aboriginal English usage, its grammatical diversity and its broad societal engagement implications [25]. It is the author's good fortune to receive the advice and guidance from members of this group. Among the linguistic and educational experts in this field of study, Aboriginal English is also coupled with the affix 'Home Talk'. This denotes the presence of a hybrid dialect and of the practice of code-switching that occurs when Aboriginal people adapt their communications styles according to their immediate circumstances and need [25]. This is illustrated for example in the public schools of Australia, where Aboriginal children are forced to communicate in Standard Australian English and to observe formal grammatical protocols when speaking and writing. For the majority of them this unnatural state does not persist, and they are generally adept at orally switching back to their preferred form of Aboriginal English, firstly that which works among indigenous friends; and ultimately the form of 'home-talk' that occupies the greater part of their existence and family life. Aboriginal native languages do survive across Australia. Eades [26] writes that about 250 languages were spoken before the arrival of the British, with at least 600 distinct dialects. The history of colonization and the complexities of an imposed dominant English language culture brought about the gradual adoption of words and phrases combining Anglo-Saxon and Aboriginal expressions, beginning with evolving Creoles and what is known as Pidgin English.

Survival for the Aboriginal community and the need to communicate with those in power led to the emergence of the hybrid dialect termed 'Aboriginal-English'. Interactions with English, Irish, Scots and Welsh convicts transported from Great Britain were also a facet of the imposition of a foreign culture. This necessitated forms of language and dialect adoption that were not particularly representative or respectful of the Standard English spoken by the educated classes of Britain in the 18th and 19th centuries. Gradually the dominant culture influence overwhelmed Aboriginal communications culture and native languages became less common even within the family home. Exceptions exist as a small minority where native languages have survived in the most remote parts of Australia that are less exposed to routine daily use of the English language [25,26].

The Aboriginal English ‘home talk’ form is known to be common in Aboriginal homes across Australia, with localized variations, especially where proper nouns are brought into use, e.g. non-Indigenous people are called Balandas by the Yolngu people of North Arnhem Land, and Wadjelas by the Nyungar people of south west Australia[25-27]. Similar words and sounds that differ in meaning may also be encountered from region to region, justifying caution before application. Pragmatically the use of Aboriginal English for health care related conversations is not purely a linguistic challenge. Grammatical constructs, family, gender, spiritual/religious and ceremonial influences all differ sufficiently to create a barrier for PPIE involving non-Indigenous health care practitioners. Professor Ian Malcolm, the eminent Applied Linguist and Aboriginal English communications research leader, defined Aboriginal English in 1995 as

“The name given to a range of varieties of English spoken by many Aboriginal and Torres Strait Islander people and some others in close contact with them which differ in systematic ways from Standard English at all levels of linguistic structure and which are used for distinctive speech acts, speech events and genres” [25]

Malcolm and others [28-33] have since offered a variety of expanded explanations of Aboriginal English, with emphasis on the inherent cultural differences that influence the Aboriginal English dialect and which contribute to misunderstanding and sometimes conflicting outcomes between Indigenous and non-Indigenous conversational participants. Research attention has been drawn to the linguistic adaptation that occurs according to shifting circumstances of conversation. One simple example is the Standard English demands of ‘school-talk’ affecting classroom interactions of Aboriginal children and youth with non-Indigenous teaching staff, and the transition to the common forms of expression in the family home, known as ‘home talk’.

In the research work context, dialectal and lexical adoption is a continuing process of adaptation in common with societal practice generally, e.g. as new technologies introduce new products and applications leading to new descriptive terms, Aboriginal English versions used in the home may also induce novelty expressions from the Standard English form. Establishment of working relationships and trust between

non-Indigenous researchers and Aboriginal community members is essential for gaining insight and implicitly requires a long period of dedicated effort to achieve that end. It is recognized in the literature however that Australian Aboriginals often hold cynical views of researchers and of the merits of many aspects of research.

Whereas this work is ethics approved (Curtin University HR 72/2010) it does not consist of a study such as might be found in Humanities or Health Science disciplines, in which a large percentage of research time and effort might be devoted to time spent in company, interacting with or observing Aboriginal people. In short, it is not a comprehensive study of the Aboriginal culture. It does however comprise of a learning process in which human communications barriers are identified in order to assist culturally disadvantaged patients in their primary care cognitive engagement, viz. PPIE.

The crossover of study disciplines from minority culture to health science and ultimately to serving the goal of developing technology applications has meant that time constraints have prevented the opportunity to establish sufficiently diverse relationships across the Aboriginal population; or to spend a large part of this effort in those rural and remote regions. These are the places where conceptually the application would elevate health care service delivery for the most vulnerable T2DM patients. Notwithstanding this, this research has benefitted from the privilege of help and mentoring from members of the Nyungar people of Western Australia, including Aboriginal Health Workers and trainers; and education specialists. The Aboriginal English content of this thesis in the health care context is primarily influenced by the Nyungar (also spelt and pronounced 'Noongar' in some regional variations) contribution.

1.7 Broader scope of cultural communications issues

Australia's ethnic diversity is considerable, with multiple languages spoken in the home[34, 35]. Taking into account the continuing dominance of English in public and private health care and in Australian life generally the prospect of building an intercultural communications bridge based upon simplified English holds out greater hope for progress than other 'purist' translation options. Attempting to construct a

large and diverse multi lingual, multi dialectal and very complex assistive communications tool presents formidable obstacles not only in the effort required but in the essential of achieving user receptivity.

1.7.1 Non-Indigenous ethnic minorities

Socioeconomically and culturally disadvantaged patients of additional concern are Australia's ethnic minority migrants whose non-English speaking and non-westernized cultural origins present significant and potentially harmful barriers to sought-after health care outcomes. As a country with established humanitarian refugee policies and practices, the shift in the balance of English-speaking and non-English-speaking cultural groups is continuous.

The health care communications difficulties for patients from these minorities and from Aboriginal communities coincides in some important aspects, beginning with the limited effort on the part of the health care service provider community to determinedly invest in support for successful and reciprocally purposeful acculturation. The Merriam-Webster online dictionary provides the definition of acculturation to which my research philosophy applies:

*Cultural modification of an individual, group, or people by adapting to or borrowing traits from another culture; **also:** a merging of cultures as a result of prolonged contact [36]*

The research process attempts to show why this inadequate investment is the case, thereby identifying the pathway toward a more precise understanding of the critical communication deficits and the remedial options.

The precepts illustrating the barriers to overcome and therefore the areas for integration are explicit and implicit within the findings shown in Table 2 (next full page) which displays the earliest research effort iteration of communications barriers. This became the foundation for a deeper Qualitative Gap Analysis (QGA) described later in this thesis.

In the literature review, research into the use of communications technology has sought to identify work undertaken that will strengthen the contribution and value of the patient's participation in PPIE. Gradually the search drills down through the generalities of chronic disease care; captures and preserves essentials from those general elements; and brings in T2DM management and cultural communications specificity. In the research process it is also necessary to consider those technological communications developments that may have direct or incidental applications to chronic disease management and care. An example is the use by Alaskan health workers of smart phones and social media; and the ability to identify and possibly adopt culturally unique digital messaging practices by design. In this cited case digital storytelling is part of the care regimen for cancer patients[37].

Ethnic Minority Patient Cultural Characterization	Practitioner Cultural Posture	Additional Data
Native and hybrid language/dialect, verbal and non-verbal communication	<ul style="list-style-type: none"> English educational bias Westernized Medical Education/Training Uni-directional and provider-dominant conversational tendency Metaphors, acronyms, jargon 	<ul style="list-style-type: none"> Language, dialect, variable differences in speech and listening Cognition error capture and correction is limited and uncertain Practitioner techno talk and jargon reinforce cultural barriers Metaphor mismatches e.g. expressions of International Medical Graduates (IMGs) from different countries working within remote Aboriginal communities
Disadvantaged Socio-Economic Status of many patients	Socio-economic 'superior participant' power distance – an unconscious/unwitting or purposeful interaction phenomena	<ul style="list-style-type: none"> Unequal perceptions include patient self-limitation of contributory role
Holistic, Self- and- illness- focused patients	<ul style="list-style-type: none"> Disease focused Absence of or very limited empathy and social engagement 	<ul style="list-style-type: none"> Diagnosis sometimes unsatisfactory – high risk of incomplete history of complaint from the patient or carer Treatment and Care plan – high risk that delivery does not secure patient confidence and adherence
<ul style="list-style-type: none"> Community/Family awareness and involvement in wellbeing highly valued, often a priority Religious/spiritual beliefs may (and often will) transcend compliance; and conflict with western medicine treatment 	<ul style="list-style-type: none"> General practice in PPIE does not accommodate or adapt to non-patient family influence Awareness of ethnic origin beliefs and practices is patchy, depending upon specific experience per ethnic minority 	<ul style="list-style-type: none"> Western shared family concerns for the health of a patient have diminished favouring 'independence' 'freedom' and 'privacy' EM ceremonial obligations can displace treatment and care plan agreements and adherence
<p>Temporal</p> <ul style="list-style-type: none"> Time, e.g. in the context of providing information for complaint history taking, is not a quantitative or linear measure, but most often will relate to events/happenings/occurrences in the life of the patient and/or patient's family Appointments, punctuality and other time dictated processes may not meet westernized interpretation/expectations 	<ul style="list-style-type: none"> Time definite or approximations are preferred in the patient history taking and follow the westernized linear pattern of hours, day, weeks, months etc. Practitioners are invariably time-limited in patient consultation context. 	<ul style="list-style-type: none"> Practitioners may tend to hasten the PPIE/ limit conversation. This constrains the quantitative and qualitative information, thereby the clinical knowledge value. Patients need more time i.e. storytelling/yarning versus western concept

Table 2: Initial identification of Ethnic Minority (EM) Cultural Condition Barriers in Patient-Practitioner Interview Encounters (PPIEs)

Failings in the physician-patient consultation process globally are reported in a considerable volume of literature. These and other factors briefly touched upon in this section page are described and referenced later in Chapters 2 and 6. Within Australia this displays the almost unremitting dominance of western forms of clinician PPIE behaviour and its known or estimated negative effect on PPIE treatment and care outcomes. This observation is however further compounded by the inadequate treatment of the subject by researchers when arriving at conclusions suggesting models for improvement in PPIE. This has influenced the course of this research, through the discovery that reports of past studies are conspicuously weakened by wrong assumptions. For example, most if not all recommendations for improving PPIE persist with the long established clinician's direct questioning mode, albeit with more effort injected to generate an improved air of empathy. In many ethnic minority cultures, demonstrated succinctly within the Aboriginal culture, direct questions are frequently regarded as invasive, rude, and generally offensive to the forms of engagement familiar to the patient.

Another consistent observation in the PPIE related literature is that the common use of medical jargon by practitioners is a primary cause of confusion and consequential lack of confidence in clinicians on the part of patients, especially for those whose health literacy is not highly developed. From this work however, it is apparent that the connective words and phrases that form comment and conversation but which are not specifically techno-clinical in nature, often create barriers to cognition. Different cultures use unique expressions that include euphemisms and metaphors. Even with practitioners who have accomplished their standing through a high level of literacy, articulation can fall short in shared cognition value due to personal or work culture habits. For example a physician or nurse may unconsciously use figures of speech, metaphors and acronyms that pepper a consultation, simply because these stem from personal upbringing and work culture influences.

Acknowledging the desirability for retaining and protecting the benefits of established and effective clinical interventions, the foundation for cross-cultural communications bridge building begins with simplifying clinical English for a more equitable power relationship within cross-cultural healthcare discourse.

One extraordinary characteristic affecting the path of this research and included in Table 2 is the distinct difference in temporal perspectives between the health care provider community and the minority culture patient. From the initial explicit and implicit PPIE barrier data it is concluded that while language remains an important component other key drivers determine the course of effective ACT development. For example semantics; empathy; emotion and time; are ingredient coactions for consideration within ACT design concepts. Collectively all of these coactions influence reasoning. This is revisited below in the introductory explanation of the ACT development concept.

In the literature review Omachonu and Einspruch [38] are cited for their work on systems innovation in health care. The authors discuss cognitive science in context and point out that this *'draws upon multiple empirical disciplines, including psychology, psychiatry, philosophy, neuroscience, linguistics, anthropology, computer science, sociology and biology'*.

The word 'culture' is applied here not only in the ethnic connotation, but also the implicit presence of different backgrounds and experiential knowledge that affect perceptions and cognition. Examples of weakness in published accounting of intercultural PPIE discourse [39-44] however may help uncover the possible roots of and identify the potential counters to inadequate communication. The absence of these essentials invites gap analysis investigation, discussed in greater detail later. Accompanying this process, through examination of alternate options and communications-support methods applied or considered by others, is the effort to simplify, in order to achieve sharing and adaptation by all end-users/participants in and 'around' the PPIE.

1.8 The new era of Information Communications Technology (ICT) in healthcare

Parallel and converging streams of learning and knowledge building activity are both formal and informal. The advent of Web 2.0 has brought about interactive internet opportunities, the sharing of online information and collaborative communications.

The creative freedom for knowledge transfer and innovative application has elevated the contributory role of the patient community in the dialogue on health and health care. Patients and practitioners meet in the virtual world; but sizeable numbers of socio-economically and culturally disadvantaged members of society are not full participants in this discourse. Patients also collaborate and share information with other patients, without having in all cases a prior personal relationship, and commonly without a professional practitioner being involved in the interaction. Accepting and implementing medical advice outside of medical-professional consultations is perilous.

Earlier statements describing the parlous state of health care service delivery in rural and remote regions of Australia beg an urgent question:

What alternative strategies are seriously worthy of study and preparation to counter the multi-layered threats from uncontrolled growth in the numbers of patients suffering from chronic disease and comorbidities?

The implications of early age onset of chronic disease; the increased numbers of obese patients living in urban areas and at high risk of T2DM; and the burgeoning cost of diagnosis, treatment and care affecting established health care service; all are additional persuasive arguments for seeking new innovative avenues and systems.

This research has first taken a critical look at assumptions that dominate the literature and methods that have long been considered as robust and reliable in the PPIE process, regardless of socio-economic status or ethnic origin. A logical expectation of progress in enhancement of PPIE communications within the most disadvantaged patient communities is that this will also benefit the wider community. This approach to communications takes a bottom-up perspective.

Substantial intellectual investment in Information Communications Technology (ICT) within the health industry has been and is still predominantly focused on internal clinical or administration system support and therefore is not intended or for use or access by 'ordinary' people outside of the health care professions. The Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT)[45]

provide clinical terminology with clinical content and expressivity for clinical documentation and reporting, with no patient user interface. Similarly health Level 7 (HL7) [46] is an interoperability protocol allowing healthcare applications to share clinical data and was initiated to introduce consistent global standards. Even in the case of claims that systems are designed to be ‘patient-centric’, too few are generated from a consumer perspective. Rather, they appear to be the provider interpretation of what the patient wants from the service.

Meanwhile, it is noted that increasing and large numbers of Australians are searching the worldwide web for health information, [47] potentially following a similar track to that found within the PPIE, i.e. history taking, ‘diagnosis’, with treatment and care decisions to follow. The latter may be entirely self managed or involve a practitioner. One of the differences from pre-worldwide-web days is that the web-savvy patient can be better informed about the condition or complaint before during and after the PPIE appointment. It is relevant to this research that the gap between Indigenous health and non-Indigenous health in Australia, referred to as ‘health disparities’ affecting ethnic minorities in the United States, is at risk of widening due to the exponential advances in medicine and health care technology. Those who are *comparatively* socio-economically advantaged, to a great extent demonstrated by their familiarity with and access to ICT devices and social networking capabilities, increase their knowledge of health care treatment and care options. With the advantage of English fluency, the majority are much better equipped to articulate a health complaint, break down territorial jargonized barriers, understand and comply with practitioner advice and with safe and effective medication instructions.

Information retrieval and interactive systems for health care advice are available and easily accessible with information in abundance, beginning with the worldwide web. For the majority population of Australia the prevalence of English grammar, words and phrases published on health care websites and hard copy literature offer a navigable and for the most part a comprehensible resource. For ethnic minorities and for many Aboriginal people, the opposite is true. Accessibility and comprehension are two major barriers; yet these population groups are receptive to using ICT devices such as mobile phones and are capable of peer group monitoring of health

conditions via voice and text message exchange activity. This is a pragmatic socially driven outcome as opposed to a formalised engagement process devised by health care providers. In the literature review the backdrop to these ICT/ACT developments is found through discussions about

‘The Age of Semantic Medicine’ [48]

‘Prescription for Change [49] and

‘Social Media in Health literacy’ [50].

It is acknowledged that the web has a major information role to play in the field of societal health and that ICT/ACT systems merit prominence for the capability to overcome physical distance and accompanying logistics obstacles in a timely way. The means to achieve the desired goal and justification for building the component systems that will place Aboriginal and ethnic minority health care on a new and productive plane is within reach.

In 1.4 the Information and Communications Technology (ICT) service delivery topic of telehealth was introduced. Early research attention to telehealth was premised on identifying a potential service solution to counter the extreme health and wellbeing adversities experienced by Aboriginals. This was based upon the hope that the research effort would stimulate the efficacy and expand the scope of remote monitoring and consultations. It was soon realized however that before telehealth and multifarious ICT devices, systems and processes can achieve the desired outcomes, a major obstacle must be negotiated and a plethora of related barriers overcome. That obstacle fundamentally is the cultural dissonance in the primary care communications practices in Australia. This is present across a broad intercultural ethnicity related landscape; and significantly so in the Aboriginal patient community context.

1.9 Objectives and Contribution

In order to achieve the aims of this research a primary objective was set with three sub-objectives. These provide structure for the work concentrations and process flow, enabling the formation of a classification system in which the principal domains of T2DM and AE can successfully merge into a diverse-user assistive

communications technology application. Fundamentally the ACT approach will serve as a reciprocal sense-making support system which in turn will enable greater mutual confidence in shared PPIE decision making.

1.9.1 Primary objective:

The primary objective of this work is to introduce a shared knowledge representation model and data transformation process as a conceptual foundation for the future development of intercultural communication technology systems capable of overcoming ethnic socio-cultural disparities in healthcare consultations.

Within this concept modelling initiative there are three component research sub-objectives all of which are consequential upon Australian healthcare:

1.9.2 Sub-objective (1):

To conceptually structure formal Type 2 Diabetes care guidelines (GLs) as preparation for mapping with Aboriginal English dialectal data.

1.9.3 Sub-objective (2):

To conceptually structure Aboriginal English dialectal data as a base for development of ICT supported intercultural communications.

1.9.4 Sub-objective (3):

To conduct bi-directional communications problem and solution analysis leading to cross-cultural understanding using specific Aboriginal English dialectal data and inter-domain relationships with type 2 diabetes healthcare guideline protocol elements.

1.9.5 Contribution

This dissertation is focused on the search for interactive systems of communications leading to best prospect outcomes for healthcare patients. Notwithstanding the global and diverse population implications of healthcare communications research, this work is dedicated to building a conceptual framework from a study combining four principal elements that merge together to deliver:

- Efficient machine-assisted knowledge transfer for Patient-Practitioner Interview Encounters (PPIEs), including pre and post encounter user requirements.
- An easy to use digital education tool to augment collaborative management of Type 2 Diabetes Mellitus (T2DM).
- A system enabling equitable health care communications and participation for Aboriginal patients.
- The development of Assistive Communications Technology (ACT) systems to sustain the foregoing and remote patient connectivity supporting primary health care service capabilities.

The research described here ultimately contributes as an application concept in which assistive communications technology development is intended to help resolve unsatisfactory health outcomes and unmet healthcare service demands. The application is termed as the Patient Practitioner Assistive Communications (PPAC) system.

The problem to which it responds is the existence and complexity of healthcare communications barriers. More specifically, the managed corpus from within this framework captures and analyses the many healthcare efficiency related issues encircling Aboriginal T2DM patient interactions with clinicians in Australia.

1.10 Reasoning and Cognition Objectives within the PPIE

Reasoning in response to interactive encounters is a uniquely human capability constrained by differences in cultural and intellectual cognisance; and in historical knowledge of the parties attempting to achieve mutually relevant understanding. Pragmatic characteristics introduce further constraints when the actors do not share familiar recognition of the other's conversational style. Such is the case with implicature as proposed by Grice for example when figurative expressions, sarcasm, and perhaps self-deprecating styles are adopted as opposed to expressing direct, obvious and explicit meaning[51].

If interacting parties are able to extend a period of engagement, i.e. PPIEs are conducted with the same participants over time; those of a similar cultural and educational background can expect to successfully negotiate implicature. In the human-machine encounter, semantic accuracy will present a disciplined state in which implicature is largely absent. For disadvantaged poorly educated users articulation by providers using formal words, syntax and pronunciation can be a barrier to understanding, e.g. if the practitioner style is more typical of an Australian broadcast media news reader.

In the process of deciding the best course of development, the ACT coactions identify the primary elements, beginning with Semantics. Cregan [52] refers to Semantic Technologies as “using explicit representation of meaning to enable data interoperability and more powerful and flexible information services and transactions”. Writing of the more complex relations, she observes that ontologies have formal logical semantics facilitating automated deductive reasoning. A considerable amount of work is underway to develop semantic technologies compatible and interoperable with the World Wide Web while expanding the content and scope toward user sharing of applications. It is sometimes referred to as a web of data.

Nesic et al. [53] propose an ontology-driven approach to semantic annotations, initially by lexical expansion of ontological concept descriptions to ‘enhance syntactic matching’. Che-Yu Yang and Hua-Yi Lin [54] are working toward ontology and Resource Description Framework (RDF) based automated approach to semantic annotation for the Web of Data; arguing that if text data is linked to vocabulary, the data can be understood by machine while reasoning can be accomplished through the defined inter-vocabulary relationships. A number of resource acquisitions and developments are required for this to be achieved and in common with other emergent ICT and semantic web activity is not yet mature enough to accommodate PPIE healthcare type applications.

The prospect of machine-conversational simulation is attractive but too complex in the contemporary environment, i.e. not achievable in the near term to satisfy the

equally challenging and complex nature of PPIEs. In this research however, it is important to identify the path and purpose of other work, as already inferred in the hope to steer opportunity for future technology convergence.

Attention has been paid to the work of Bickmore, who with alternate others is widely published for his work on reusable automated health counselling dialogue systems; and on the Boston University work on relational agents as 'computational artefacts designed to build long-term socio-economic relationships with users'[55, 56]. This particularly references disparities in diabetes and treatment, the serious social threat from T2DM with the health literacy context as a backdrop factor.

Viewing relational agent web based demonstrations of this development it is however apparent that the educated level, phonology and overall presentation of the simulated human articulations in the interactive model are close in conversational style to that of the real-life dominant clinician culture. In this form it does not accommodate people with limited English proficiency (LEP). Whereas the relational agent work offers great promise and along with other Bickmore related research findings is synergic with objectives of this research work, it is one more factor influencing choice of formulation for using ontologies in the conceptual construction of Aboriginal and ethnic minority ACT. The contemporary status of such work is that it is intended to promulgate support for the push and pull of purposeful knowledge flow through the knowledge supply chain, for widely shared user applications from evolving next generation networks.

1.10.1 Empathy and emotion

Simulating emotion and thereby empathy also presents considerable difficulties in AI development. Context can often determine what degree of empathy and how this and other emotions are expressed. Emotion however should not be regarded as insignificant in the PPIE; or out of the question; or unnecessary; in computing. Combining empathy and emotional intelligence Ioannidou et al. contend that empathy in communications is 'a teachable, learnable skill that has tangible benefits for both clinician and patient'[57]. A heavily cited and respected article authored by R.W.Picard opens with remarks about computers acquiring the ability to express

and recognize effect, and the anticipated ability for computers to “have emotions”[58]. Picard claims that emotions have a stigma in science but asserts that there is room alongside science for “non-interfering” emotions. She gives examples as those involved in curiosity, frustration and the pleasure of discovery. Acknowledging that humans cannot as yet access another human’s thoughts or feelings, Picard applies thought to ‘Sentic state pattern recognition’ in which effort is made to try and identify thoughts and feelings expressed through words, gesture, music, and other modes of expression. (Sentic shares the Latin sentire root of ‘sentiment’ and ‘sensation’).

Kleine-Cosack says that simulation of emotion ‘is a desirable task in the field of Human-Computer Intelligent-Interaction (HCII)’[59]. Referring to the development of humanoid robots in socialized environments he believes that acceptance of robots will depend upon them having emotional and therefore reasoning skills. Kumar et al. have reported development of Context-based Task Ontologies (CTOs) to help automate Computer Interpretable Guideline Models (CIGMs) for the execution of tasks in the World Health Organization (WHO) Guidelines for hypertension management[60]. Hypertension is an accompanying condition with T2DM and the CTO is of interest in the context of shared ontology opportunity.

In the earlier statements about ACT coactions ‘Time’ as discussed is proffered in a dual relevance context. Insidiously, abstract notions of time involving inter-cultural exchanges are often not shared and that fact is also not often realized during the PPIE. In addition to the barrier effects already stated, ‘time’ affects PPIE participant perceptions that can complicate understanding when engaging in semantics, empathy and emotion.

1.11 Linguistics and paralinguistics

The concept framework has steered away from Aboriginal and ethnic minority linguistic translation modelling for reasons given earlier, i.e. the complexity of multiple individual patient differences in culture, cognition and health status circumstance. Moreover, PPIE variables include non-verbal expressions known as paralinguistics; and communicative acts with relational and inter-personal meanings

occasionally referred to as pragmalinguistics. Linguistic translation alone will not reliably represent such abstract terms[61], nor serve the bi-directional PPIE communications objectives, even when one of the ontology domains is drawn from a formal schema. The transformation of syntactic data through a semantic contextual process places priority on shared cognition by patient and practitioner. The concept is focused on RACGP GLs as the source of domain objects; the properties of those values/objects are semantically annotated in a format that offers enlightened guidance to the user using simplified English that will integrate with or dialectally morph into Aboriginal English. The relationships between the properties will support interpretation of the guidelines pertinent to the user. Annotation work uses AE and AEHT as the modelling sample for natural language grammatical constructs, including nouns, verbs, adjectives and connectives where these are available in the Nyungar generated data and from the Aboriginal English study, teaching and learning literature.

1.12 Other users of the proposed PPAC system

Besides the patient other proposed users have been identified. These are practitioners, patient carers, patients' families, health care interpreters and emergency paramedics. In the patient-centric environment as perceived by the patients and consumer communities, the ACT taxonomy would be navigated as a tool for management of PPIE and for PPIE agreed T2DM care. As an example, a practitioner would rely upon the ontology-driven system to finetune the cultural profile of the patient; receive and view patient-generated data online or from a device download in the PPIE clinic; and style the appropriate competent and safe mode of leading the PPIE. If a patient is too inclined to repeat 'Yes' to enquiries about personal experiences and conditions, perhaps without matching confirmation from facial or other body language expression, the ACT will attach instances acting as flags recommending alternative modes of enquiry.

Ontologies are designed for knowledge sharing and reuse. Perpetual input and connectivity between ontologies will allow growth in health care purpose-designed Aboriginal and ethnic minority Assistive Communication Technology applications. A significant influence on the solution work here is recognition of the growing

insinuating integration of consumer orchestrated manipulation. The Web 2.0 interactive dimension touched upon earlier is finding its way into the underserved communities through remarkable levels of user adoption and functional innovation. The subject of Aboriginal exploitation of mobile phones and internet search applications, high uptake of digital devices and web usage by low health literacy and ethnic minority communities has brought researchers to consider the extensive potential for improvements in healthcare education, and self management. [62-66]

In summary the research contributory objectives have been organized as a series of steps, moving through a methodological approach to transform domain knowledge and data from two diverse schema sources into a shared structure as a preparatory process toward assistive communications technology applications adoption and adaptation. The tasks undertaken:

- (i) Identify and qualify the communications and cognition barriers within the cross-cultural PPIE.
- (ii) Sub-categorize the constituent elements of the barriers.
- (iii) Seek out the indicators of remedial opportunity to overcome barriers overall and per constituent element.
- (iv) Identify and qualify the primary stakeholder role(s) for contextual orientation of the assistive communications conceptualization.
- (v) Utilize Type 2 Diabetes Mellitus (T2DM) RACGP Guidelines as the 'complexity of care' clinical communications re-modelling source.
- (vi) Select Aboriginal English Home Talk dialectal grammar constructs that will facilitate and enhance shared PPIE cognition.
- (vii) Using semi-automated software tools populate and map the T2DM GL and AE domain ontologies to initiate the framework concept for Patient Practitioner Assistive Communications (PPAC).
- (viii) Outline an end user framework model to enable further development work for a system that will eventually enable applications to capture and deliver diverse communications and learning capabilities consequential to, from and within the PPIE.

1.13 Thesis Outline

Chapter 1 sets the research scene and rationale; introducing issues, motivation and contribution. It provides a framework focus on the meaning, purpose and functionality factors affecting health care communications.

Chapter 2 is the principal literature review of healthcare communications. It examines existing healthcare communication generally and T2DM specifically; research materials that provide communications concept contributions from the health care service sector; and others that provide knowledge from inter-domain relationships. Brought into play are the Aboriginal English and Standard Australian English confluence and conflicts; and identification of literature sources describing barriers to healthcare service delivery. Included is a review of contemporary healthcare communications technology; approximated work responding to similar problems; and the integrated system view. Figure 2A below provides a summarized guide to the literature review sequence.

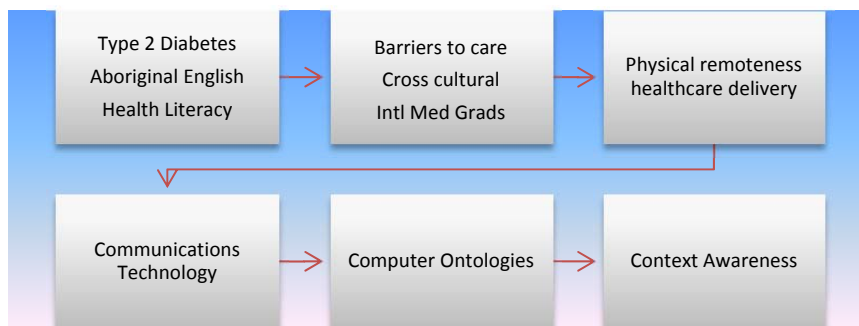


Figure 2A: Topic sequence of the literature review

Chapter 3 illuminates the problems defined within and by the research, including practical real world issues; unsatisfactory contemporary communications; and problematic change implications arising through the availability of emerging communications technology systems. It addresses problems affecting research options and the impact on choice of solutions-seeking methodologies.

Chapter 4 opens up the solutions proposal covering the itemized domain and process dimensions from prior chapters, and specifically the problems defined in Chapter 3.

It describes ontology solution principles and the proposed integrated communications architecture system.

Chapter 5 provides an overview of the Patient Practitioner Communications (PPAC) conceptual framework. It offers the scope of design goals, science and engineering methodology employed and an alternate, user function view of the PPAC system architecture. Figure 18 on page 193 provides an illustration of the research structure.

Chapter 6 reports the detail of schema research and concept abstraction sources. It includes T2DM guidelines; Aboriginal focus group output; communications barrier characterization through qualitative gap analysis (QGA); and Aboriginal English study contributions; and prepares for mapping with the Aboriginal English communications domain.

Chapter 7 presents the construction process and tools for building the PPAC framework. It includes a case study scenario which projects the interactions and PPAC system assistance for PPIEs.

Chapter 8 pulls together the foregoing chapter content to validate the PPAC. It describes how application objectives are to be achieved; continues with case study illustrations and suggests conceptual end user guidance. It demonstrates the ontology user query tools, process and system using competency questions; and summarizes the intended function of the ultimate PPAC application.

Chapter 9 is a recapitulation and final set of statements relating to future directions stemming from this work. It touches upon the domains covered by the research, and ongoing research barriers as problems requiring solutions. It describes specific ontology enrichment actions to be taken together with an engineering pathway toward a PPAC-supported suite of web based and portable communications systems prototype models.

A note regarding references

The several different domains and dimensions of focus here have been as far as possible organized in an orderly manner to enable ease of access and understanding. Inevitably due to the complexity of actual and conceptual relationships under discussion there is some blending of otherwise less congruent subject matter. This is the consequence of working with key characteristics of structuring and re-structuring of intercultural communications and the goal of machine translation. Accordingly thesis references are published following each chapter in order to ease access to relevant citations. There are consequently some duplicated entries in the thesis as a whole.

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Chapter 2: Literature Review of existing healthcare communications

2.1 Introduction: Literature review

In the literature review research concentrations the concept framework has been best served by searching for and identification of previously unexplored or hidden PPIE intercultural communications domain deficiencies as well as explicit and widely published barrier data. In the attempt to characterize enumerate and evaluate communication *in the context of Aboriginal and other cultural minority patient communities* several questions are of importance in the identification process for eventual assistive technology modelling.

What is working or not working in the T2DM PPIE communications process to achieve good outcomes?

What aspects of failings/weaknesses in communication are most significant/serious and merit priority attention?

What is already being done to remedy/improve upon communication inefficiencies?

What healthcare communications gaps remain and require resolution?

What limitations affecting existing healthcare communications practices justify ACT supported interventions?

What priorities should be observed in ACT design formulations and why?

2.1.1 Order of discussion

The research sub-objectives listing at 1.9.2, 1.9.3, and 1.9.4 provides a sequenced approach that determines the literature review arrangement. First, the role of health and healthcare articulation of type 2 diabetes clinical practice guidelines terminology in the patient-practitioner communications setting; and by inference the health literacy impact on PPIEs, places emphasis on the seriousness of the current T2DM epidemiological picture. The next sub-objective, the function of the Aboriginal English dialect, is an examination of the intercultural healthcare communications dimension, identifying disparities. These two domains of research combine in the sense of problems arising and solutions options, in the third sub-objective, which principally is focused on critiquing and thereafter seeking out systems to elevate the

quality and value of intercultural communications in PPIEs. Incidental to and accompanying the sub-objective discussions, the primary objective as stated at 1.9.1 embraces a review and assessment of relevant technological developments and the ICT user paradigm that have a bearing on the PPIE communications problem-resolution choices.

As a reminder, the acronym PPIE is used variously in this writing, to accommodate both the concept application description and instances of patient-provider consultation. In the latter context, for ease of understanding PPIE is also used when referring to past accounts of consultations found in the literature; even though these events pre-date the existence of the patient-provider interview encounter (PPIE) acronym.

Considering the broad scope of such diverse subject matter, this work has revealed from voluminous materials reviewed that sources have in large part circumvented the dynamics of cross-cultural communications barriers. Listings under currently popular policy headings such as ‘cultural competence’ and ‘cultural safety’ too often enter into philosophical and repetitive discussion of a generalized, non-specific nature regarding health care. Many of these do not merit nor justify citation. Other than conventional training recommendations, it is rare to find any literature that elaborates on, and targets specific processes to counter, the intricate contributory elements which in their variable permutations create barriers to shared understanding in and surrounding the PPIE. Articles that ostensibly deliberate on topics typically titled ‘patient-centred care’ or ‘patient-led care’ most commonly fall short on intercultural considerations.

2.2 Type 2 Diabetes communications complexity

The incessant demands of self-management of T2DM impose a multiplicity of daily tasks and the need for vigilance and maintenance of relevant care knowledge for patients and their carers. That vigilance is a shared responsibility, predominantly residing with the patient but dependent on consistent professional support and advice. The Diabetes Australia Royal Australian College of General Practitioners T2DM care guidelines (RACGP GLs) have 43 (forty three) main group headings.

These set out processes and related advice. A selection pertinent to the PPAC framework is reproduced in the Chapter 6 ontology schema source discussion. Sixty sub group headings use clinical terminology to describe disease conditions; and a more extensive explanatory sub group detailing what the clinical terms mean by way of health threat, treatment and care need [1].

Filled with possible permutations the presenting patient condition confronts the practitioner with the need to work through time-consuming processes, aided by Point of Care Tests (PoCTs) that barring the physical processes such as blood-taking today are mostly conducted using digital measurement instruments. The high risk of comorbidities is accompanied by anxieties and stress that also adversely contribute to actual and perceived wellbeing.

Miscommunication is not uncommon within professional groups, even those where cultural and language differences are ostensibly absent [2-4]. Doctors and nurses struggle with a vocabulary which is accommodating an ever-growing clinical terminology system replete with acronyms. The vocabulary of medicine has its roots in Greek, Latin and Norman wordage, littered with complex labels and strings added over time as the science of medicine has evolved; and technological change has brought new nouns, adjectives and verbs to the lexicon. The pace of that change is quickening and the challenge to equitable shared patient and practitioner understanding of biomedical information is increasing. Research and development take time and staged processes.

Anticipation of exponential change that will affect the design of an effective ACT (PPAC) system has included contemplation of and an attempt to qualify and quantify user application problems that may arise in the future. The discovery of new drug treatments and of disease mitigating/worsening lifestyle factors affecting T2DM patient care for example requires system adaptability.

The Mayo Clinic is heading-up the effort to produce the 11th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), scheduled for release in 2015 [5]. The previous 10th edition was published in

1992 when the worldwide web was only just beginning to emerge. The new edition work is focused on simplifying and codifying linguistic variation, abbreviations, and synonyms so that standardized recording and transactional detail becomes semantically consistent and valuable to professional practitioners and patients. The prospect is that a healthcare practitioner will quickly identify keywords and thereby instantly access guidance for those treatments that have worked the best, statistically, for other patients with similar complaints around the world.

The ICD work however is predicated on a fairly high audience and user level of health literacy and does not necessarily offer a direct solution where health literacy barriers impede the quality and value of PPIE. Notwithstanding this, it will ultimately represent a valid source for the formal import of medical domain thesauri in the process of PPIE information mapping semantic layering and the primary knowledge representation and exchange objectives. The literature review of health literacy is recounted later in this chapter.

Moving on to consider reported problems in Aboriginal healthcare I suggest as prompted generally by Lopez et.al [6], that there is also a risk that the pace of change represented by ICD-11 will further exacerbate the ‘digital divide’ that adversely affects Indigenous communities already disadvantaged through low levels of engagement with ICT and limited health literacy. This exponential risk identification accentuates constant societal change and the need to view the problem as one that is not static; but instead occupies several separate yet connected planes of communication capability from the personal to the mass market level. In other words this is ‘best-guessing’ while trying to predict future consumer habits acceptance and use of communications systems to successfully determine the most viable design models. To offset the weakness of guesswork as a design factor, this work concentrates on reviewing and identifying gaps in the specific communications environment in which Australian Aboriginal rural and remote living patients interact with contemporary forms of T2DM information and healthcare delivery services.

2.3 Health Literacy and T2DM Aboriginal patient care

A core element within PPIE communications is health literacy. While a significant number of barriers with variable communications related complexity have been identified and are disclosed in detail within this thesis, health literacy is a dominant influence in achieving cognitive consonance in the PPIE. There are several definitions of health literacy. The most widely quoted are from Nutbeam; and from Ratzan & Parker.

Nutbeam defines Health Literacy as:

'The ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.' [7]

Ratzan and Parker:

'The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions'. [8]

Statements about the history and usage of Aboriginal English tacitly suggest that both literacy and health literacy barriers place the Aboriginal population at a disadvantage.

Australia's health literacy status is generally unsatisfactory. The following data points are taken from Australian Bureau of Statistics reports of population health literacy survey findings:

- Measurement scale: Skill levels ranged from Level 1 (lowest) through to Level 5 (highest).
- Skill Level 3 is regarded as the minimum required to allow individuals to meet the complex demands of everyday life.
- 41% of adults were assessed as having adequate or better health literacy skills, scoring at Level 3 or above. This was lower than other types of literacy.

The unsatisfactory status is illustrated by Figures 3 and 4 and the accompanying annotation, taken from the same data source [9, 10].

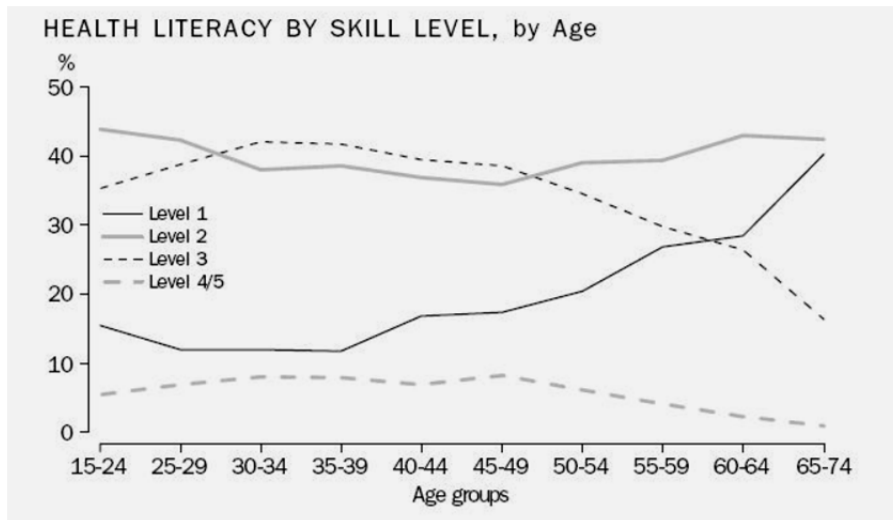


Figure 3: Australia’s health literacy by age

Source: Australian Bureau of Statistics, Health Literacy, Australia. Canberra: 2008. Report No.: 4233.0

Notes: Around one-fifth (19%) of adults had Level 1 health literacy skills, with a further 40% having Level 2. These people had difficulty with tasks such as locating information on a bottle of medicine about the maximum number of days the medicine could be taken, or drawing a line on a container indicating where one-third would be (based on other information on the container).



Figure 4: Health Literacy Skill Levels (a) - 2006

Source: Australian Bureau of Statistics, Health Literacy, Australia. Canberra: 2008. Report No.: 4233.0

Shahid et al. conducted interviews in a 2006/2007 qualitative study of Aboriginal cancer patients in Western Australia to report hospital patient experience views of communications between patients and providers[11]. Interviewee responses revealed a number of impediments to communication, including

- language barriers
- inadequate provider information offerings
- failure to develop a continuing relationship
- differing styles of communication and
- inadequate concern for privacy

A New South Wales focus group of General Practitioners (GPs) reported by Rose et al. discussed the management of diabetes among low socio-economic position (SEP) patients[12]. This research was pursued in the light of limited knowledge about GP capacity to manage diabetes affecting low-SEP patients. Two improvement strategies were identified by the GPs. First was the provision of educational material that match low-SEP patient literacy; the second was to introduce financial incentive schemes for low SEP patients. The acronym SEP today is more commonly replaced by SES, referring to socio-economic status.

In the course of this research, several documents in the form of booklets and leaflets designed to educate patients in principles of self-management of type 2 diabetes have been retrieved from health care education sources. These also comprise a mix of hard copy sources targeting Aboriginal patient communities. I have had the benefit of reviewing some versions of these patient-information resources during the Credentialed Diabetes Education four-day course within the Enrolled Nurse Diploma (Aboriginal) program at Marr Mooditj Training, Waterford, Western Australia in June of 2010. The purpose in reviewing these resources is to evaluate, collect and refine concepts and concept relationships, for future population of the PPAC ontology information system.

Most of these documents appear to have been written for an educated highly literate audience. That assumed audience capability for working through numerous pages of text, creates the impression that the authors and publishers are pitching their message to urban, as opposed to rural and remote dwelling Aboriginal patients and their communities. Accordingly no acculturative engagement value by way of Aboriginal English forms of expression for the PPAC design work materialised from this process.

In what appears to be an effort to rectify the problem of educating and guiding Aboriginal patients with lower levels of English proficiency, other fairly substantial and physically bulky education, train-the-trainer and patient participation documents have included what is perceived to be ‘Aboriginal-friendly’ colourful artwork and

graphics. It is proper to observe that few such documents are intended for direct access by rural and remote living Aboriginal patients; but are instead produced as tools to help Aboriginal health workers (AHWs) who engage with these communities. Notwithstanding this, the density and complexity factors confronting productive articulation and successful communication of the material content with LEP patients are at best considerable. Of the many documents examined and in the context of qualifying communication problems I mention two sources in particular. These have different objectives in that one is more of a trainer information source; the other is more an instrument for patient and trainer engagement.

The '*Start Stronger, Live Longer*' resource manual guide package is intended for use as an educational training and reference tool for Aboriginal health workers [13] The guide contains nine booklets covering a broad range of Aboriginal health care advice available in both hard copy and online formats. It does not however enter into any detail about type 2 diabetes care, and while contained within an Aboriginal artwork cover, offers little as a visual aide to good cultural communication with the more disadvantaged and vulnerable patient communities. At the conclusion of reviewing this material the perception emerged that it is possible if not conclusive that the dominant westernized clinical culture is an invasive influence in the formulation of education and training materials. This barrier factor is explored in Chapter 6.

The second source mentioned here comprises a corresponding trainer and patient learner set from a program titled "*The Journey of Living with Diabetes*"[14]. This program and product of the (Perth) South Metropolitan Public Health Unit represents a significant effort to simplify the education and training process, using Aboriginal culture-oriented colours, graphical illustrations and a more moderate use of text compared with other sources. Whereas it is a better example of a program that has been devised for joint participation between diabetes educators, Aboriginal health workers as trainers, and Aboriginal patients, in common with other existing and conventional resources it demands a continuous level of labour intensity and repetition for best effect.

A significant amount of cost time and effort has been invested in these booklets and other publications in a genuine attempt to improve T2DM care related health literacy and resultant wellbeing for Aboriginal patients and communities. This laudable effort however is today much less efficacious in supporting the communications and cognition objectives. The physical volume; literacy expectation and limited interactive nature of reading and tutorial materials does not offer easily accessible convenient versatility in an age when increasing numbers of Aboriginal as well as mainstream people are spending appreciable amounts of time engaging with humans and machines using digital media [15]. This thesis and the PPAC framework will overcome the shortcomings of hard copy materials by enabling more interactive media options for T2DM healthcare education and health literacy systems of communication and learning.

2.3.1 T2DM terminology and AE pragmatic synergy challenges

Developing a merged domain schema concept for ACT machine functionality requires synergic qualification and classification of inter and intra domain classes, their attributes and explicit relationships between concepts. T2DM clinical terms from the RACGP guidelines need sufficient syntax flexibility in order to correlate semantically with AE pragmatics in the PPIE setting. The literature does not readily provide a single source or central collection of research that can be regarded as a pathway to this synchronization. In particular, there is no comprehensive Aboriginal English dictionary; and in the search effort no AE published document containing Aboriginal English linguistic or paralinguistic healthcare data has been located. Acknowledging that the core AE dialectal focus here relies upon the Nyungar (also known as Noongar) Aboriginal communities of south west Australia, the search has found three Nyungar native dictionaries, two of which contain illustrations of anatomy and biological flora and fauna examples [16-18]. These dictionaries however have been studied and it is concluded that they have very limited contemporary value for AE healthcare communications, as discussed later in this thesis.

2.3.2 Cross-cultural healthcare research

Before entering into a fuller review of Aboriginal English literature contributions, I have studied the broader implications and lessons learned from cross-cultural communications in healthcare. From a 2010 series of systematic literature reviews, Garrett et al. deduce that mainstream healthcare research can be perceived as neglecting cross-cultural interest[19]. It is inferred by the authors that over many decades the literature has been devoted to fairly shallow healthcare concerns affecting non-English speaking immigrants including refugees.

Bradby studied multilingual settings in Scotland, specifically in the minority ethnic group of British Asians viz. people of Punjabi descent living in Glasgow[20]. Bradby writes of the long-standing history of English speaking in the Indian sub-continent and explains how Hindi/Urdu and Punjabi spoken by migrants in Glasgow has developed differently from non-migrant peers in India and Pakistan. Bradby's exposition includes elaboration as to the reasons and influences for the changed forms of expression, of young people of Punjabi decent using Glaswegian street vernacular that is not recognizable to elders of the same family. The difference in cultural acculturation outcomes when comparing the British colonial history of Australia with India also prompts academic curiosity about the similarities in the linguistic adaptation practices of UK immigrants and the Australian Aboriginal experience.

Anthropological perspectives of the relationship between culture and health are offered by Kagawa-Singer and Kassim-Lakha[21] who stress that most clinicians lack understanding of the influence of culture on PPIEs. The authors observe that 'Eurocentric' adoption and implementation of cultural competency policy and practice still retains the unidirectional philosophy of providers dictating the PPIE processes while lacking adequate respect for personal beliefs of patients. Their proposed solutions however retain much of the flawed assumptions and expectations that are criticized as inefficient communication. These ignore the fact that many ethnic cultures do not customarily anticipate, expect to be asked, or comfortably entertain, many of the more personal and probing questions. As is the case with Australian Aboriginals it is not unusual to encounter a patient who does not know his

or her date or even year of birth. This is not necessarily due to ignorance or lack of education but may be a characteristic of cultural beliefs and practices[22, 23].

The Kagawa-Singer article and its weaknesses for my purposes assist with emphasizing the importance of professional understanding and *finding a method for documenting accessing and retrieving representations of cultural beliefs values and biases according to user needs*. It is a reminder for the design work of this thesis that an assistive technology approach will require a navigator style of support to find the appropriate advice, unique contextual semantic considerations and communication options, rather than an absolute translational information search process.

The two prime participants in the PPIE, the patient and the practitioner, both have perspectives, however rich, informed or limited, of the respective domains within the framework of T2DM, AE, and PPIE interactivity. These are effectively scattered across the literature, often dealing with one aspect, many dealing with two and some bringing together all three. This review is intended to critique current healthcare models in the specific framework domain communications context, aligned with my primary and sub-objectives. It is my intention to identify gaps in communications effectiveness and to help elicit ideas and methods that can be applied to counter these gaps, thereby optimizing development of the ACT concept model.

2.4 Aboriginal English (AE) and Standard Australian English (SAE)

In 1993 Eades wrote that Aboriginal English is the name given to dialects of English which are spoken by Aboriginal People and which differ from Standard Australian English in systematic ways[24, 25]. For my brief introductory purpose here, the additional word ‘Australian’ is used to differentiate the comparison I am making from research usage applicable to Aboriginal peoples and their communications contact with first-language English speakers outside of Australia, e.g. in Canada. In 2000 Malcolm described Aboriginal English as a dialect of English which is widely spoken by Indigenous Australians, and which differs from Australian English in pronunciation, vocabulary, idiom and in the ways in which it is used[26]. Many other localized dialectal differences exist globally where English is the primary language, e.g. the United Kingdom, the United States of America, Singapore, and New

Zealand. Hereafter I mostly refer simply to Aboriginal English and to Standard English.

2.4.1 The Aboriginal English Idiomatic History

Malcolm et.al write of Aboriginal English as the dialectal result of development in Australia since 1788, from which time many English expressions and words that declined in use among non-indigenous inhabitants were retained and adapted by Aboriginal people though not always preserving their original meaning[27]. Aboriginal English speakers inheriting this development visualize different mental images compared with English speakers when using words in common use, such as ‘bird’ or ‘long’. They also visualize in terms of very different metaphors. The authors note that there is a compound identity in Australia and state that ‘two forms of English which have developed here are doors respectively into the two sides of history’. Recognition of the history and significance as a communication vehicle of Aboriginal English received its first serious attention by linguists in the 1960s. Consequently in a societal environment dominated by Standard English and Standard Australian English, respect for Aboriginal English as a credible conversational form is not widely shared. The dialect has been traced through stories of evolution and transition from and through pidgin, Creole and Kriol language forms that represent the means to communications and survival from a minority and culturally disadvantaged perspective. Treatment of the Aboriginal dialect in the general population and even among members of the teaching profession reflects the view that it is not ‘normal’ and is even ‘bad language’.

Sharifian has revealed how the conflicting cultural conceptualization experience of speakers of Aboriginal English and Australian English (predominantly Anglo-English) can lead to damaging miscommunication[28]. He points out that features of the Aboriginal English dialect appear to derive from spiritual beliefs, practices and experiences unique to the Aboriginal culture. As non-Aboriginal researchers we have to be guarded in our interpretation of the meaning of such words as ‘spirit’ and ‘spiritual’ as among many other words and phrases, these do not semantically translate exactly as will be understood across cultures.

In addition to analysis of comprehensive research literature sources on studies of Aboriginal English, Sharifian interviewed, or rather had conversations with, several middle-aged native Aboriginal English speakers. None were speakers of their ancestral native languages. His data generates aspects of syntax, semantics and pragmatics and these disclose the hybridised nature of Aboriginal and English expressivity. Excerpts are from 'yarns' that come in a storytelling form and are the preferred, historically natural way of discourse of Aboriginal people. Sharifian's work contains valuable anecdotal and analytical illustrations of the inherent and rarely recognized disconnection between the worldview of Indigenous and non-Indigenous individuals. He reports ten individual Aboriginal English narrative Schemas in an effort to explain conceptualization differences. None specifically relate to health care communication, but several may implicitly affect a PPIE and increase the risk of miscommunication.

As an example, in the Spiritual Medicine Schema, the yarn describes how the storyteller's mother was 'real crook' (i.e. very unwell). She had said that "they come an' give me some medicine last night..." The author advises that without the requisite schema, the audience would be likely to think that the word 'they' refers to medical professionals and administration of some form of prescribed drug, when in the Aboriginal patient's mind/conceptualization, this was a visit from her deceased ancestors who used special powers to treat her.

Another Aboriginal discourse schema of interest here is that of 'Singing'. The example given is of a man falling in love with a girl and trying to obtain a personal possession such as a piece of her hair or a photo, in order to 'sing' her. It is believed that if the girl does not respond as intended, it may bring her serious even fatal, illness. Moreover it is believed that Western medicine intervention may not help if this outcome emerges.

In his conclusion, Sharifian states that 'Language acts as a repository of cultural conceptualizations' and that it can undermine communication between those who do not share certain conceptualizations. From research interpretation, this is not a

challenge that can be resolved through linguistics alone, or through simple glossaries of word and phrase translation.

2.4.2 Aboriginal English and framework modelling

Along the pathway to identification of healthcare communications barriers and potential remediation it is necessary to review the broader aspect of interpersonal communication challenges. From this it is manoeuvred into a closer examination of Aboriginal English Home Talk (AEHT) literature as the effective cultural-knowledge-laboratory and a platform for fuelling and launching the concept model. In short, healthcare communication is placed in its human cross-cultural interaction context, in readiness for ICT/ACT conceptual framework modelling. This accentuates the combined value dynamics of flexibility, open accessibility, interoperability and reusability of ontologies for knowledge-sharing. The permutable versatility of ontology construction and its expected relationships with known and as yet unidentified future ontologies presents an exceptional opportunity to overcome cross-cultural human communications complexities.

Aboriginal English cross-cultural engagement pragmatics generally, as opposed to engagement within the already complex T2DM domain, present intricate and unique encounter-specific variables. Ontology development for Aboriginal English assistive communications technologies requires attention to and familiarity with the formative conversational syntax and interactive style favored and practiced in the homes of Aboriginal families. A large collection of AE research and lesson materials has been reviewed [25, 27, 29-36]. These have been principally (but not entirely) developed as part of a WA state education teaching and learning investment in a long standing effort to improve secondary school attendance rates, literacy and numeracy standards among Aboriginal children.

Table 3 is a (non exhaustive) listing of Aboriginal English speaker schema title differences when compared with Standard Australian English, as headings drawn from my review of the aforementioned literature. My studies have focused on gaining an understanding of these elements and the consequential barriers to

intercultural communication. They are the main collation and semantic guidance source for the purpose of domain ontology design and development.

Aboriginal English Grammatical rules and structure (e.g. tense, word order)
Aboriginal English sounds
Aboriginal language words
Asking questions
Background knowledge/schemas
Beliefs
Code switching
Code-switching,
Contextualization
Control stories
Discoursal practice
English words
Eye contact
Family relationships
Language function
Listening behaviours
Non-specific quantification of time and space
Nonverbal language
Oral genres
Oral traditions
Phonology (sounds) including Accent and Intonation
Pragmatics
Pronunciation
Question forms
Semantics
Sharing of knowledge
Speech patterns
Speech, writing,
Spirituality
Turn-taking
Vagueness versus precision
Vocabulary,
Worldview
Yarns

Table 3: Aboriginal English schema title and construct differences

The process of merging and structuring domain terms and relationships through interpretive semantics toward functional coactions is the creation of a lingua franca; which is defined in the Oxford dictionaries as a language that is adopted as a common language between speakers whose native languages are different. In this research, the lingua franca term might be better expressed as a pragmatic lingua franca. Ciccia in her clinical pragmatics study describes pragmatic communication as ‘the use of a set of sociolinguistic rules related to language within a communicative

context; that is, pragmatics is the way language is used to communicate rather than the way language is structured'[37]. She identifies three major aspects of pragmatics as:

- Use of language to secure different goals
- Use of information from context to help decide how conversation can achieve goals; and
- Management of interactions between people to begin, pursue and close conversations.

These encapsulate many of the communications deficits that this thesis is intended to resolve.

From these launching points I move on to the review of pragmatic interaction literature in primary care consultations (PPIEs).

2.5 Communications generally in care consultations (PPIEs)

Barriers to effective care are commonly referenced throughout the literature. These describe

- Generally experienced difficulties applicable to all patients
- Special problems affecting those with lower cognitive capabilities or health literacy deficits, and
- The language and cultural barriers affecting patients from disadvantaged groups including Aboriginal and ethnic minority communities.

Identification of barriers is a multi-layered contextual exercise. The complications and difficulties challenging the general population persist while becoming even more complex in those other communities. While much of the literature details the many barriers, it is necessary to narrow down to the content that illuminates obstacles to cognitive communication.

A study by Nagelkerk et al. reported perceived barriers to and effective strategies for self-management of adults with T2DM in a rural setting[38]. Top ranked findings of greatest relevance were:

- Lack of knowledge and understanding of a specific diet plan

- Lack of individualized and coordinated care

Under ‘effective strategies’ findings:

- Developing a collaborative relationship with a healthcare provider, and
- Maintaining a positive attitude that prompts proactive learning

The words underlined for this thesis are emphasized as they personify the desired PPAC design remedies and objectives emanating from successful PPIE communications.

The role of the patient in contributing ideas about the management of his or her disease has been considered by Theunissen et al. [39]. Manipulation of the patient-provider interaction is contemplated as a method to improve adherence. Patient adherence, i.e. the ability and willingness, or the contrary, to follow medical advice, is a common topic in the medical literature. Theunissen et al. employed Leventhal’s Self-Regulatory Model of Illness to seek out relevant aspects of patient-provider communication about adherence[40]. Cognitive and emotional processes were postulated as forming part of the processing system. The authors set out to convince the reader that ‘lay models of health threat can help us understand adherence to treatment regimes’. The model is concentrated on a common-sense representation of illness and adherence, and is partly premised on the observation that patients may have difficulties reconciling their symptomatic bodily experiences with abstract information provided by health practitioners. Most significantly (for this work) the authors conclude that many physicians seemed unaware of the value of patients’ ideas; patients too often do not explicitly convey their dislike or non-adherence habits in regard to taking medications. The authors observe that when patients do voice concerns or beliefs, these are effectively ignored by the practitioner. These findings are then linked to misunderstandings arising from unsatisfactory communications between GPs and their patients.

The value of narrative for care consultations (PPIEs) is entertained in the literature regardless of the intercultural dimension; but it is introduced here as another common PPIE factor that in a variable form is arguably more critical in cross-cultural interaction, notably so in the case of Australia’s Aboriginal patients.

Writing about illness narratives, Hyden and Bulow[41] identify the central problem for studies as the relationship between ‘the voice of the lifeworld and the voice of medicine’; concepts introduced by Mishler[42]. Mishler refers to the struggle for control over the PPIE discourse, ascribing the voice of medicine as ‘expressing a technical, biomedical frame of reference’ while the voice of the lifeworld reflects the patient’s personal, ‘contextually-grounded experiences of events and problems’. Hyden and Bulow write about illness narratives as stories told by the ill persons themselves, usually referring to chronic, life-threatening diseases. The authors form the opinion from the literature that self identity and social interaction processes are harmed by illness; and narrative is a powerful cultural resource for helping to rationalize one’s own health condition. They also remind the reader that *time* is central to chronic disease. Narratives set out events and experiences that are illness-connected but may not have been previously related in a health status context, i.e. at the time of occurrence. Knowing when an illness started, and enduring continued, protracted chronic disease bring temporal issues and estimates to the forefront of PPIE discussions.

Clark and Mishler have attempted to reframe the clinical task for PPIEs[43] by showing that patients’ stories can aid practitioners in ascertaining concerns and understanding of their illnesses. When used in a hospital-based PPIE, the authors describe story telling by the patient as ‘a momentary shift in the social alignment of the interview to a relationship in which the patient assumes authority and the physician becomes the attentive recipient’.

Addressing the clinical interpretation of stories, Clark and Mishler bring the reader back in part to the *temporal relevance* of PPIE consultation and narratives. They point to the primary necessity of historical reconstruction to aid diagnosis, treatment and management, stating that ‘the presentation of a patient’s condition typically requires assembling relevant data chronologically as an account of an underlying, unfolding process’.

The qualitative evaluation constructed from the PPIEs in this instance shows that the PPIE for one patient's condition (seizures and epilepsy) 'was located within the lifeworld of the patient'; whereas the second PPIE with a female patient 'locates diabetes within the woman's body'. Characteristically, the transcripts and analysis show that in the latter case, the resident doctor 'repeatedly asserts his medical authority' and 'assembles relevant clinical historical facts, while interrupting the patient's attempts to formulate a coherent story with those selfsame facts'. These authors lean toward the hope that social relations have a place in clinical relationships. Their work shows that there is a continuous struggle between priorities and styles of professional clinical engagement. This may be interpreted as meaning that it is unrealistic to impose and thereafter expect without exception a PPIE experience that always accommodates the patient narrative, in the terms and manner determined by the patient.

Barry et al. employed a complex data collection approach consisting of patient and doctor interviews, and consultation transcriptions[44]. Four communication patterns emerged:

- Strictly Medicine
- Mutual Lifeworld
- Lifeworld Ignored; and
- Lifeworld blocked

Working from a patient-centred perspective the researchers devised an investigation method using ten defined endpoint outcomes. Findings at first suggesting a high rate of success with the voice of medicine approach were eventually moderated by the unsatisfactory end of two consultations in which lifeworld techniques would have been more appropriate for part of the PPIE. The case study material of most interest here is the evidence of a disconnection or miscommunication between patient and practitioner. The authors found that real problems occur with chronic physical conditions. The patients had adopted a lifeworld view of these, whereas the doctors applied the voice of medicine, perceiving a physical issue to the extent of blocking or ignoring the voice of the lifeworld, apparently finding it inconvenient or a nuisance. The researchers note that some of the doctors, without the benefit of further

explanation showed they could operate in both voices but did not always use the voice of the lifeworld.

All of the foregoing research offerings provide system ACT design guidance; specifically the need for the system to counsel and provide user support for acculturative engagement in the introductory PPAC interface user process.

2.5.1 The Intercultural Patient-Practitioner Interview Encounter (PPIE)

In the search for a workable assistive communications framework, most particularly in the cross-cultural discourse and disadvantaged socio-cultural environment, it is essential to adopt a grounded posture that takes account of the diversity of dialects. Sharon Lee makes the point that language has mistakenly been treated as a proxy for culture[45]. She cites the examples of Spanish speakers who come from a variety of countries with distinct cultures; and Asian immigrants to the USA who speak a variety of languages that in some cases such as Mandarin Chinese vary in spoken forms between those from China, Taiwan and Singapore.

Due to the growth of the United States' diverse migrant populations Lee examined language, cultural and other communications barriers in health care reviewing the literature to gauge health care quality. Using a Limited English Proficiency (LEP) classification she reports that

- LEP and culturally different patients are underserved by the U.S. health care system; language barriers have been more extensively studied than cultural barriers.
- Research on Spanish-speaking patients in the USA dominates the literature on language barriers.
- Language differences become barriers by making communications difficult in a variety of system engagement activities such as scheduling appointments and understanding care advice.

Lee also concludes that current research places emphasis on ethnicity and culture issues without explanation or justification. She criticizes the literature for its serious lack of research on interventions designed to reduce communications barriers. Many writings are pre-occupied with a form of measurement based upon clinical service communication protocols. In retrospect, the Lee paper examination of case study literature tends to illustrate the underlying causal factors for poor communication. There is an inference of providers ignoring or blocking the patient contribution, as

mentioned in the Barry et al. and Mishler offerings, with the main difference being that Lee's literature findings relate to patients already disadvantaged by language and culture.

Linguists (as distinguished from interpreters) have had limited involvement with health care communications. Candlin and Candlin, both linguists, describe health care communications website content as problematic in the sense of achieving practical relevance and an ongoing commitment to improved communications[46]. Advocating more linguist collaboration in health care, the authors bring particular attention to nursing journals as having greater value for linguists than many others. This is reinforced by the observation that nursing is important for understanding the challenges of health care communication, with special mention of cultural and linguistic diversity and the nurse-patient relationship. The research focus on the doctor-patient relationship is regarded as disproportionate when nursing is seen to be an ongoing 24/7 activity, with interactivity extending over protracted periods of time, far exceeding the encounters between the doctor and patient. Similarly, the Candlins say that it is clear that nursing and allied health professionals do not enjoy the same autonomy or professional discretion as physicians. This is pertinent to the design of assistive communications technology lexical content while accommodating and facilitating the shift toward patient-initiated conversation and storytelling in PPIEs. In other words, the rich potential of nurse-patient exchanges and to a lesser extent of allied health professional-patient interactions is that many more lifeworld lessons and nuances can be identified and harnessed in some workable form.

2.5.2 Patient-centred and culturally competent care

The descriptive phrase 'culturally competent healthcare' first surfaced in the United States as a policy instrument to counter health disparities affecting ethnic minorities. The terms 'patient-centred' 'patient-centric' and 'cultural safety' also appear in the literature and in care policy and protocols in several developed countries, including Australia [47-50]. The philosophical application and expressions attached to these labels tend to overlap and may confuse those working within the health care environment, and their patients.

Lifeworld and medicine linkages examined by Lo are conceptualized by the author as ‘on the job cultural brokerage’[51]. Referring to different sets of schemas forming information and meaning, Lo writes of the ‘mix and match’ of patients’ available schemas, and their practice of occasionally picking up new ones as they navigate the PPIEs. Although Lo uses the ‘patient-centred’ label for patient communication, from this research perspective that may still convey a practitioner-dominated subjective approach, rather than a patient-led or more equitable balance between the participants. Lo in her 2010 paper appears to concur with much earlier research findings, including the work of Sharon Lee [45] on the inadequacy of practical research and strategies for inter-ethnic, intercultural settings.

The Lo study is based on qualitative analysis of interviews with primary care physicians in California recruited for their considerable experience with LEP patients. The Lo cultural brokerage concept comprises four mechanisms:

- Translating between health systems
- Bridging divergent images of medicine
- Establishing long-term relationships; and
- Working with patients’ relational networks

The Lo work identified significant engagement difficulties for physicians and highlighted the need for more bridging work between western medicine practitioners and ethnic minority or socio-culturally different patients. In some instances, religious and family power structured cultural practices presented unresolved barriers to best PPIEs.

2.5.3 Australia’s immigrant intercultural health care communication

The relationship between Aboriginal English and languages spoken in the family homes of Australia’s minority immigrants is one of the hybridisation of original ethnicity and host country languages and dialects. Within the problematic linguistic complexities challenging health care service efficiency are the cultural metaphors that differ in their meaning and application across cultures and do not easily translate within conversation. Lê and Lê report a study of Vietnamese migrants’ perceptions of health concepts used to interpret health issues in a metaphorical expression

context[52]. The authors advise that the Vietnamese culture is mostly influenced by Taoism, Confucianism and Buddhism, and these philosophies surface in conversation. They refer to ‘affective communication’ as a rich domain of intercultural interaction, incorporating ‘expressions of feelings, emotion and self-esteem’.

The Buddhism philosophy affecting the Vietnamese view of life is not the western linear view, but one of a natural cycle in which birth, death and rebirth interact. It is comparable in some respects with Aboriginal cultural beliefs and concepts as described by Malcolm et.al and illustrated in ‘Two-Way English’[27] and ‘Tracks’ by Aboriginal English researcher Glenys Collard’s drawing of ‘Family continuity through the spiral of time’[29] as shown at Figure 5.

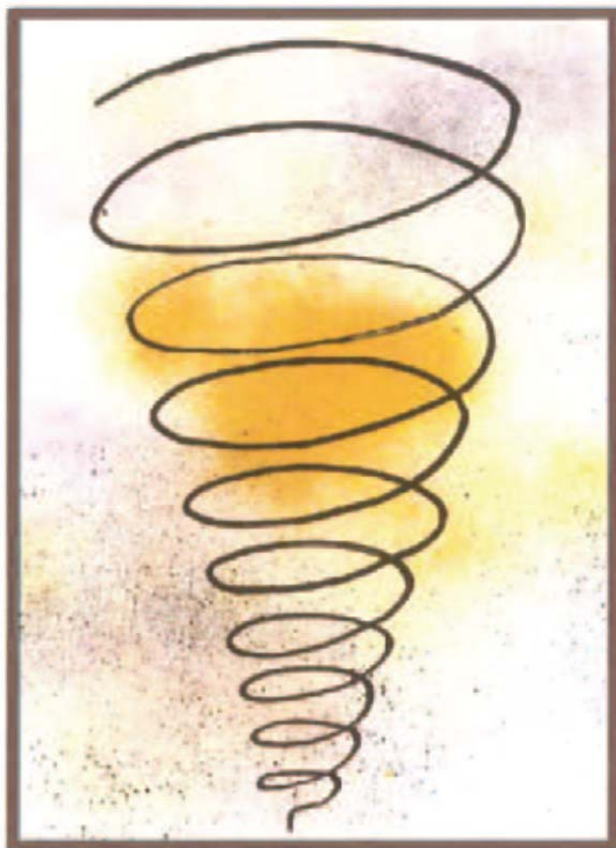


Figure 5: ‘Family continuity through the spiral of time’ Reproduced courtesy of Patricia Konigsberg, and Glenys Collard, Institute for Professional Learning Western Australia Dept. of Education [29].

Lê and Lê explain that health is perceived metaphorically as a journey. In a later paper one of the same authors, Quynh Lê makes the point that cognitive meaning is used to present factual information suited to scientific data exchange and should not include personal feelings or opinion[53]. She pursues the assumption that formal health care terminology thereby has a greater chance of matching semantics across language cultures; but culturally-embedded language discourse outside of that frame does not achieve the same degree of knowledge transfer and mutual understanding. As examples she cites five words that differ in meaning between English and Vietnamese cultures, i.e. ‘old’, ‘mental’, ‘partner’, ‘privacy’ and ‘police’. In another cultural perception statement, a further similarity with the Aboriginal community refers to the concept of family. The common factor is that the word ‘family’ means extended family and includes grand-parents, uncles, aunts, and grand children.

2.5.4 Use of Interpreters

The PPIE Aboriginal and ethnic minority communication barriers logically prompt service providers to consider and include interpreter and translation services. Demographics and logistics together with other complexities diminish the prospect of achieving interpreter and translation efficiencies in Australia. In simple terms, interpreters convert oral statements from one language to another; translators provide a written form of language transfer. The former may be directly engaged in conversational parts of PPIEs; the latter involved in publication of language translations of health care and medication media guides. Options for overcoming inter cultural communications barriers are bound to include the use of interpreters. The literature review spotlight has sought out the limitations of health care interpreter assistance in order to attempt discovery of the related reasons for continued weaknesses and unsatisfactory outcomes in cross-cultural PPIEs; and for the express and/or implied gaps that may or may not rest cross-cultural bridging by interpreter services. Many articles draw attention to persistent failures of health professional to engage professional interpreter services even when these are provided at no cost; and to the over-use of family members, children, carers, and bilingual health care staff as ad hoc interpreters with the consequentially increased danger of serious error in diagnosis, treatment and care advice. [54-60]

Government work in Victoria has reported facets of demand for interpreters and inadequate supply with examples drawn from new and emerging numbers of African language and dialects that cannot be met due to the lack of assessors capable of accrediting interpreters. The consequential absence of interpreters meeting the standards of the National Accreditation Authority for Translators and Interpreters (NAATI); and the unsatisfactory use of rudimentary skills applied by interpreters provided by commercial agencies compound the problem [61].

In 2010 Zimbudzi et al. employed a multi-method examination of the interactive environment involving health care professionals and dialysis patients of a Non-English Speaking Background (NESB) in the haemodialysis unit of Monash Medical Centre, Victoria[58]. The study identified inadequate utilization of interpreters and gaps and failures of care involving communications between NESB patients and health care staff. Only fifty-percent of health care workers had accessed an interpreter for NESB patients over a period of six months; and of the observed PPIEs interpreters were used in only 25% of cases. Medical records showed that there was no interpreter engaged in 32% of cases. The study reported that the shortage of interpreters is the fundamental barrier working against engagement. Observational findings in the Zimbudzi et al. article and which contribute to understanding but do not entirely explicate the broader contextual dimension of PPIE cross-cultural need are illustrated through two sets of variables, reproduced below in box format Figures 6 and 7

Effectiveness of communication
Non verbal behaviour
Level of patient participation
Power balance between staff and patients
Time taken to complete specific procedures
Interpreter use
Was an interpreter used?

Figure 6: Box 1: Variables recorded during observations of patient-staff interactions(Zimbudzi et al.) [58]

Demographic data (age, sex)
Date of dialysis commencement
Flagging of the record by an 'interpreter required' label
Are occasions when an interpreter was used documented?

Figure 7: Box 2: Variables extracted from medical records (Zimbudzi et al.) [58]

The conclusion from this aspect of the research is that although interpreters provide a service that in many instances is satisfactory, healthcare patient and provider demographics and service logistics ratios in Australia impose a level and rate of demand that cannot be met through human interpreter services supply alone. The PPAC system presents a standalone patient user application and a scalable tool for use and further development by qualified interpreters supporting practitioners.

2.6 Barriers to healthcare service delivery

This section draws out the findings from literature across the PPAC domains while continuing to bring the focus back to the context of PPIEs involving Aboriginal patients; the pragmatic use of Aboriginal English; and the taxonomical process for giving structure to dialectal expressivity.

2.6.1 Remoteness

In Chapter 1, Figure 2 illustrates the demographic weaknesses in access to healthcare across Australia. In the 2006 census the Remoteness Area (RA) classification[62] showed that altogether

- 48% of Indigenous people are resident in Outer Regional Australia (RA3)(22%), Remote Australia (RA4)(10%) and Very Remote Australia (RA5)(16%)
- 21 % of the balance of Indigenous people live in Inner Regional Australia (RA2) and
- 32% live in Major Cities (RA1)

Patients in the latter two groupings have significantly closer proximity to healthcare services compared with the other three RAs. In the 2011 census Australia's Indigenous population distribution is reported under Aboriginal Demographics as two groupings, i.e. Capital City and Rest of State[63]. The Western Australia Aboriginal population is shown as a total of 69,666, with 42,101 (just over sixty per cent) of this number described as living in 'Rest of State'. Remoteness, consequential poor frequency of health care access and much less interaction with English speaking doctors compared with city and urban dwellers, compounds the barrier effect. Figures 8 and 9 are maps that illustrate WA remoteness factors.

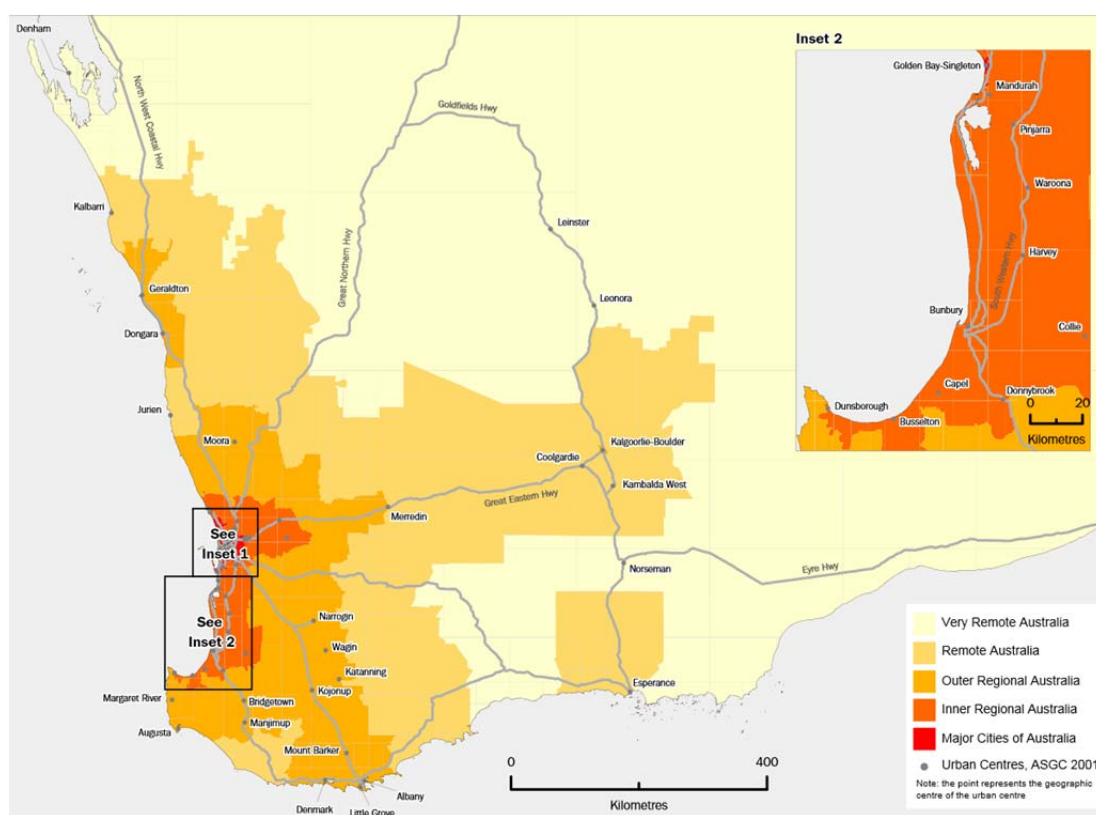


Figure 8: Perth and South west of Western Australia: Australian Standard Geographical Classification

Source: ABS Census paper Western Australia remoteness areas C3.01 - ASGC Purpose and Use 2003

[http://www.abs.gov.au/Websitedbs/D3110122.NSF/0/f9c96fb635cce780ca256d42005dc02/\\$FILE/WA_map.pdf](http://www.abs.gov.au/Websitedbs/D3110122.NSF/0/f9c96fb635cce780ca256d42005dc02/$FILE/WA_map.pdf)

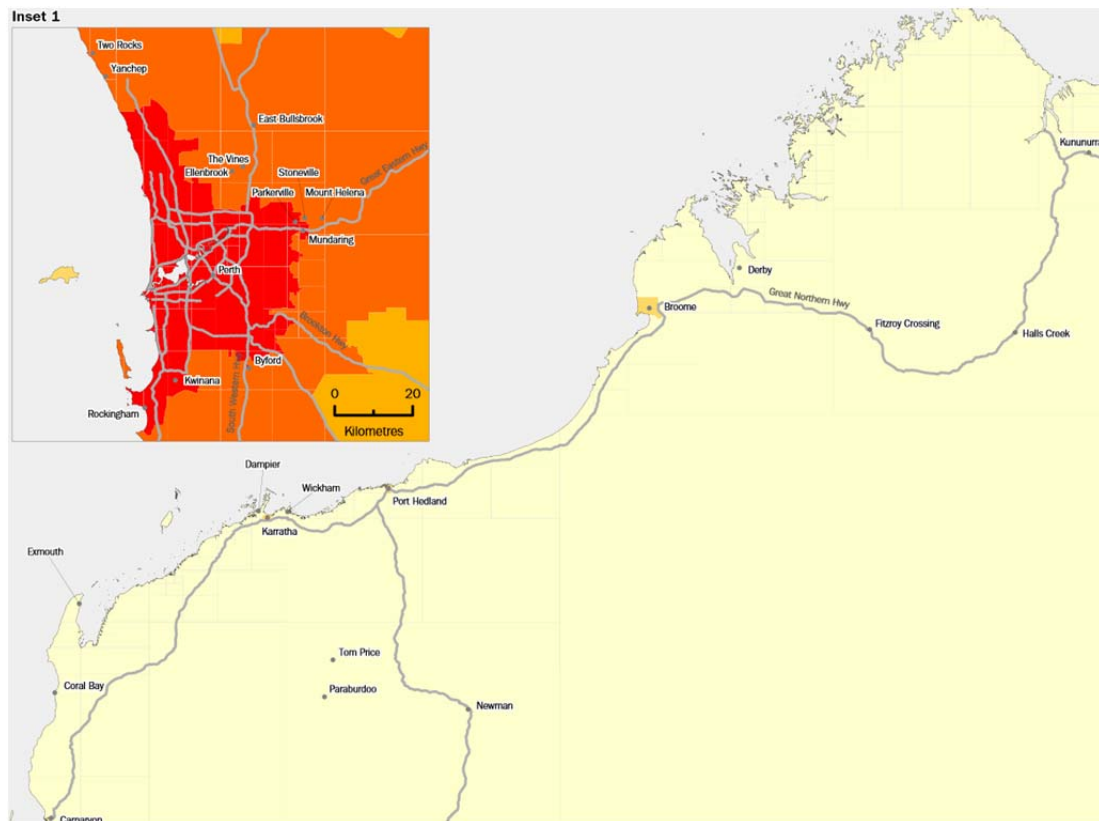


Figure 9: Northern Western Australia with Perth (Inset1) for comparison:
Australian Standard Geographical Classification

Source: Western Australia remoteness areas ASGC 2001 edition
[http://www.abs.gov.au/Websitedbs/D3110122.NSF/0/f9c96fb635cce780ca256d420005dc02/\\$FILE/WA_map.pdf](http://www.abs.gov.au/Websitedbs/D3110122.NSF/0/f9c96fb635cce780ca256d420005dc02/$FILE/WA_map.pdf)

2.6.2 Lack of Cultural Competence

Betancourt states:

A “culturally competent” health care system ‘has been defined as one that acknowledges and incorporates—at all levels—the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique need.’[64]

Cultural competence has received attention in recent years as a skill of value for overcoming disparities in health care delivery for ethnic minorities. Analysis in a later paper by Betancourt et al. revealed a number of active cultural competence initiatives[65]. The study group addressed training of future health workers, highlighting cultural competence as an educational strategy to care for diverse patient

populations. Additional measures proposed improved recognition of empathy, socioeconomic factors and bias in the PPIE.

In Canada the health status of the indigenous Aboriginal people (First Nations, Inuit, and Métis) is comparable with Australia's indigenous population, i.e. it is worse than that of the general population. Semi structured interviews and focus groups held by Towle et al. [66] found the most frequently coded themes to be

History: as First Nation citizens in a society dominated by Western thoughts and values affects their communications with physicians

Trust: Distrust by patients is connected to the historical legacy and consequential cultural knowledge by the practitioner determines the extent to which the physician is trusted, and

Time: Aboriginal patients were very aware of the amount of time physicians dedicated to their interactions and accordingly related practitioner 'time' to 'caring'.

History reflections demonstrate the culturally embedded harm from having a Western dominated society thrust upon the communities; and from time spent in residential schools. Trust directed at the doctor-patient relationship also referred to historical experiences, and to the impersonal manner of practitioners. Time included concerns about the non-Native westerner being fast paced, resulting in hurried consultations; and the impression that doctors simply wanted to get rid of them. Patients made observations about the fact that they sometimes have to think quietly in their own language, and when they do so, the doctors and nurses often do not understand what is occurring.

Similar work in the United States of America has been undertaken by Kalbleisch writing about Native American populations in North America and Hawaii [67]. She confirms that the difficulty of effective health communications is compounded when communicating across cultures. Storytelling as a means of communication is a common practice among Native Americans, and is in conflict with the western

medicine consultation process. Storytelling augments the patient's natural inclination to describe one's own body and life, which does not fit with formal medical terminology in the PPIE process.

A clear account of miscommunication in the Australian Aboriginal healthcare context is confirmed by Cass et al. [68]. Five clinical encounters over a period of five months, in Darwin, NT, providing diagnosis and chronic disease management of Aboriginal patients were videotaped. Each PPIE was followed by in-depth interviews, of individual patients and the involved health workers. It was concluded that miscommunication is pervasive; trained interpreters provide only a partial solution; and a shared understanding of key concepts '*was rarely achieved*' while '*miscommunication often went unrecognised*'.

The Cass study gave light to the phenomena of 'gratuitous concurrence' i.e. the patient giving a yes/no type answer to a health worker question in either an unconvincing or a convincing and less questionable manner. Offering a response that the patient thinks the health worker prefers to hear, this tendency became apparent through the videotaped method of qualitative study; but may not have been known or recognized without the benefit of retrospective review of the PPIEs. The Cass paper clarifies this quite simply: One nurse remarked '*I never even considered that they might be saying "yo" (yes) when they are really saying "no". I never even thought of it.*' [68]

Among the alternative approaches to improve Aboriginal health care in Australia is the deployment of Aboriginal Health Workers (AHWs). In an exemplar on culturally safe nursing practice, Blackman illustrates the superimposition of numerous social issues on routine clinical expectations, for Aboriginal patients [69]. She lists isolation, homelessness, racism, language barriers, cultural obligation, unfamiliar and non-committed health professionals, under resourced Aboriginal health services and lack of AHWs as a confusing medical and social welfare picture.

Wingard and Lester are two Australian Aboriginal authors who in their book carefully and succinctly illuminate the different approaches of Indigenous and non-

Indigenous people toward health and healthcare[70]. Their description of the necessary philosophy to be adopted by mainstream services for consultation is explained thus:

'There is much room for error when dealing with Aboriginal people, whose beliefs, understandings and perceptions are so different from non-Aboriginals. Our body movement, eye contact...is very different. Aboriginal people say that non-Aboriginals talk, but don't communicate.'[70]

Li-Chuen Wong speaks of Aboriginal relationships with and concepts of the land, time, language, kinship obligations, spiritual beliefs, death and ceremony[71]. An experienced dermatologist working with Indigenous community in Wadeye/Port Keats she concludes that the most important lesson from her work is to realize that interactions are based on trusted relationships built over time. She compares this with the conflicting experience of westernized acceptance of efficient, detached and depersonalized ways of dealing with patients. Her 2011 article describes how she searched the Centrelink website without success for information provided in any of the estimated 250 Aboriginal dialects of Australia. Centrelink is a government run department providing a number of human services including help with the cost of prescription medicine Australian government funded medical services, and access to state, territory and local government health care service concessions.

Saras Henderson has written of the community nurse relationship with Aboriginal English, emphasizing the critical importance of good communication in community assessments[72]. AE and SAE speech and cultural differences confront the community nurse with communication difficulties. Henderson references the case of an Aboriginal man complaining of headache as an example. He was administered Panadol the painkiller analgesic but continued with his complaint. It transpired with the help of an interpreter that the patient had family problems that were figuratively and mentally, not physically, giving him a 'pain in the head'. As with other authors,[27, 32, 73] Henderson refers to periods of silence by Aboriginal patients as part of the cultural norm for communication but which are commonly not understood or respected by westernized practitioners.

2.6.3 Conceptualizations of health

Perception and conceptualization differences can induce barriers to healthcare communications. Work by Sharifian (additional to that cited earlier) with different co-authors offers useful insight to conceptualizations of human biology across cultures[74]. The authors discuss the ‘locus of the mind’ as the source of human rationale and reasoning affecting cultural physiological perceptions. The abdomen region, the heart region and the head region are identified as three major types of conceptualization:

- ‘Abdominocentrism’ is found in various parts of the world including south Asia and Polynesia; Malay and Indonesian languages suggest the liver as the centre of emotional and mental activity. The liver is found to be of significant conceptual importance across parts of Chinese and Greek cultures.
- ‘Cardiocentrism’ is thought to have been the traditional view of Japanese, Chinese and Korean cultures.
- ‘Cerebrocentrism’ affording more importance to the brain, was a subject of argument and dispute over many early centuries.

Sharifian advises that in the western world a conceptualization known as dualism has persisted over time, representing a mind and matter combination of heart and brain. The perceptions briefly touched upon here are complicated by considerable culture diversity and shifts in conceptual thinking over centuries.

Aboriginal conceptualization of health is somewhat vague to western observers and very little descriptive data has been published equating to the three major types cited by Sharifian et al. One Aboriginal native language health publication, the Dictionary of Anatomy - Dhäruk Mala ga Mayali' Rumbalpuy, which includes English translations was first published in 2010 to help professionals working in North East Arnhem land, Australian Northern Territory (NT), with Yolŋu people who speak the Djambarrpuyŋu language[75]. There is no equivalent publication in

the Nyungar language of Western Australia; nor is there an Aboriginal English dictionary or glossary to assist non-indigenous health workers with Aboriginal English home talk forms of communication.

Becker et al. recognized that the United States' biomedical model is overly influenced by the mainstream culture, and that ethnic minorities do not always subscribe to the same values and tenets[76]. Chronicity, a biomedical concept meaning disease based illness of long duration, is not well understood by ethnic minority patient groups. The authors describe a five-year qualitative investigation of minority elders and their chronic disease coping and management experiences. These were African Americans, Latinos and Filipino-Americans, aged over fifty years. Each cultural group differed in their perceptions and management of their chronic condition. Principal differences from observations pointed to the need to understand

- that an illness is chronic
- how important the illness is
- variations in the required amount of explanatory detail on illness management practices

The authors directed their conclusions toward training of physicians in cultural differentials.

2.7 Cross-cultural adaptation

Cross-cultural adaptation for T2DM management is a persistent necessity to counter epidemic trends in chronic disease affecting socio-economically and socio-culturally disadvantaged communities. Multicultural population factors in developed countries enable learning from health care development work in those countries aiming at better engagement with ethnic minority patients. At first sight the existence of nationalities that have long been geographical neighbours as in Europe, or for example have a colonial relationship past, and which have centuries of readable recorded history, do not present the world with the same cross-cultural communication barriers. Languages that remain current and widely spoken among large populations have the advantage of well established sources for translation and interpreter support. But complexities in communication persist.

Kara et al. aimed to adapt a Dutch/English version of an internationally recognized diabetes management Self-Efficacy (SE) scale, having found that there is a scarcity of suitable Turkish language instruments compared with the overall international scenario[77]. A convenience sample of T2DM patients cooperated with a translation and back-translation of an English-worded T2DM SE instrument. An expert panel conducted the content validation; and the devised instrument was subject to psychometric testing. SE is noted as a framework to determine which behaviours a person will initiate, exert effort, and persist toward desired outcomes. Whereas technically speaking progress was made in matching the Turkish instrument scale with the established SE-Type 2 Scale, a weakness was disclosed in the cultural context of its application. Despite what the authors describe as ‘exquisite attention to detail’ it transpired from less than satisfactory scale correlations that the translated instrument may need further adaptation via linguistic and cultural variations. A case in point is the self measurement of weight and of blood glucose. The authors comment that this may be due to the fact that the profiled T2DM population represented by the participants mostly do not have the benefit of weigh scales at home, nor of any means to measure their own blood sugar. This is a common factor with Australia’s rural and remote Aboriginal communities.

It has to be said that the generality of the statement about cultural factors affecting applicability, is not adequately explored or explained. The two examples, of weight and blood glucose measurement, are of physical dimensions and do not directly clarify cultural barriers. It is reasonable to wonder how the researchers did not initially establish these factors, and whether a weakness or clinical culture bias was at play in the methodology. This study suggests lessons for securing data reliability in the ACT design process:

- No evidence of evaluation of cultural barriers within the project was offered
- The absence of a socio-economically disadvantaged patient correlation is surprising. Only 1% of the participants had a university education; 10% had a high school education; 65% were categorized as of low income
- No determination was reported as to the effect of implicit cognitive expectations derived from the original English-worded instrument

- It is not stated if and which data on self-management nuances of communication semantics were preserved, compromised or lost
- Research flaws may be the product of clinical culture bias, the research being devoid of a patient lifeworld contribution
- Unsafe assumptions may arise from weak investigation of cross-cultural cognitive correlations and can represent risks for the design of interactive healthcare applications, systems and devices

2.7.1 Semantics, Empathy and Emotion

In a 1978 discussion on the education of health professionals Engel bemoans the neglect of the study of patient behaviour and mental processes in favour of a biomedical model that prioritizes (inter alia) laboratory and sophisticated instrumentation findings over personal, psychological and social aspects of health care[78]. Engel proposed a comprehensive biopsychosocial systems model to provide a framework for conceptualization of multiple related levels of human anatomy, physiology, psychology, family, community and culture. He writes that ‘the key to optimal patient care is collaboration, communication and complementarity among all branches of the health professional’. While it might be claimed that instruments support evidence-based medicine, and that this may at times counter unreliability of patient utterances, Engel’s position adopts an holistic approach that does not exclude potentially valuable PPIE contributions regardless of source.

Human semantic translational error, misinterpretation and confusion both realized and unrecognized by participants are significant risk barriers encountered in cross-cultural health care discourse. Using discourse analysis and conversation analysis, Moss and Roberts examined how GPs and Limited English Proficiency (LEP) patients negotiate explanations and work together to establish meaning and thereby manage mutual understanding[79]. Their work is characterized as a research and educational intervention on patient-family interactions, with the acronym PLEDGE (Patients with Limited English and Doctors in General Practice). Together with a related qualitative analysis paper this account provides a worthy insight to misunderstandings in primary care multilingual settings.

Emotion is a human trait that historically has not been recognized as of sufficient significance in PPIEs with arguable exceptions related to patient consultations involving psychological disorders. It is likely that a patient enduring the pain, discomfort and unrelenting demands of chronic disease management will at some moment and to some degree, express emotion. Fixing his sights on therapeutic relations, Frankel has developed a framework of the role of empathy in patient care[80]. Identifying empathy, as opposed to sympathy, as a practitioner's response to patient displays of emotions, he links this to higher levels of patient satisfaction and to adherence with medical advice. He uses clinical case studies that illustrate through conversational transcripts and commentary, the types of exchange that employ or fail to employ empathy on the part of the clinician. A further connection from his studies alludes to a link between the lack of empathy and malpractice lawsuits filed against the professional, premised in many instances on what is termed 'relationship problems'. Frankel does not dwell on the patient emotion dynamic but on appropriately and usefully accommodating, versus countering, the patient's emotional manifestation.

2.8 International Medical Graduates cultural communications challenges

International Medical Graduates (IMGs), also commonly referred to as Overseas Trained Doctors (OTDs) are an important part of the healthcare service delivery cohort.

Data from 2009-10 shows that one-third (35% or 9,191) of Australia's GPs were overseas trained. This rises to 41% or 8,044 on a fulltime workload equivalent basis.

Several government sponsored programs exist to encourage doctors to work in rural and remote areas[81]. Writing about patient centred care (PCC) which is a model of care adopted by many countries including Australia, Dahm asks if international medical graduates are 'expert novices' in PCC[48]. In her observational study, Dahm found that many IMGs framed patient consultations as medical expert interviews that maintain topic control, disallowing digression that could occur and be of value in equitable conversations. As well as unfamiliarity with and failure to apply PCC consultations in the first instance, the requirement to adapt presented new

unforeseen difficulties arising from culturally conflicting perspectives. Criticisms of IMG method and style of consultation include insensitive statements to enforce treatment plans, and judgemental attitudes that disregard the patient- shared decision-making option. Contrasting observational findings showed an over-accommodation of patient concerns, resulting in repeated reassurances of a formulaic nature that then fell short on correcting misconceptions. This is closely identified with ‘gratuitous concurrence’ which describes the phenomena of unquestioning agreement, occasionally referred to as the ‘Yes syndrome’, well noted in the literature on Aboriginal English [34, 82, 83]. The uncommon characteristic in the Dahm study is that gratuitous concurrence does not usually emanate from professionally trained and qualified physicians. It appears to denote an over-compensation for cultural barriers.

In 2007 Arkles reported on the heavy dependence of Australia’s Aboriginal people on OTDs, (aka IMGs) drawing attention to the fact that they are increasingly coming from countries with variable English language and educational equivalency[84]. Stating that OTDs must learn how to negotiate multiple cultural domains in Australia, she highlights the limitations of shared knowledge of roles and experiences of the OTDs; and calls for research on the narratives of OTD work experiences in Aboriginal communities.

2.9 Physical context of Australia’s remote intercultural healthcare communications

For the most part, this discussion hinges upon the PPIE in which the patient is in attendance at a primary care clinic and is seen by a primary care doctor in a face-to-face setting. It will extend to other settings, such as the most common of rural and remote area encounters, when a registered nurse or Aboriginal Health Worker (AHW) represents the health care provider; when in most cases a doctor is not present. Within the ambit of intercultural healthcare communications there is a variety of settings:

- The use of GP and specialist tele-video conference and consultation facilities known as telehealth and telemedicine, occasionally interchangeable with other descriptors such as telecare, telehealthcare and telepathology

- The processes for emergency department and hospital admission PPIEs, and
- Interventional effort by paramedics, interpreters, patient family and carers.

In the time that has elapsed since this research began, consumer health care search trends and emerging preferences have increased both awareness of and service capabilities through telehealth. Great physical distances between patient and provider are not always a strictly-applied part of the criteria. The Australian Practice Nurses Association (APNA) website qualifies the scope for exceptions to rural and remote telehealth coverage by public health care services[85]:

An eligible telehealth area is a location outside an inner metropolitan area. The exception to this is where a patient is

Living in an eligible residential aged care service

At an eligible Aboriginal Medical Service (AMS) or

At an eligible Aboriginal Community Controlled Health Service (ACCHS)

This discussion leads consideration of what options as support systems are now or in the future available for patient care, treatments and self-management, regardless of physical distance barriers.

2.10 Healthcare Communications Technology

The mushrooming of information and communications technology in healthcare is and will continue to be, influential in the PPIE. As is the case of all societal change paradigms, different segments of the population learn and apply new ICT driven knowledge and practices at a different, largely immeasurable, pace and degree. Information systems support and knowledge transfer feature in a array of communication modes. While it is acknowledged that physicians such as GPs have the benefits of ICT from the desktop computer to other ICT devices, electronic records could debatably represent a widening of the communications disadvantage for the patient, and a power-distance factor in the PPIE relationship. Arar et al. studied the growing importance of electronic medical records (EMRs) from the perspective of their impact during PPIEs[86].

The Arar study aimed to determine how much time was spent on physician access to and reading of EMRs and how much time was spent on a range of relevant self-care topics from medication through symptoms, diet, exercise, physical and emotional distress, smoking, alcohol consumption, etc. The most common condition of the patient community sample was diabetes. The next was hypertension, a common co-condition with T2DM. Both require attention to a considerable list of health status checks and variables, including the risk of development of comorbidities.

- PPIEs averaged 22.6 minutes and two encounter types were identified
- Low usage of EMRs, with less than two minutes recorded; and
- Moderate to high EMR use, with 5 minutes or more of EMR usage
- Self care issues were applied in every PPIE, with *physical distress* being the most frequent
- *Emotional distress* was among the least discussed
- Family support/community resources were in 26% of PPIEs; and
- The lowest topic covered was alcohol consumption at 20%.

The article discussion fixed sights on the future service enhancement potential for EMRs in self-care management. Close to applications functionality proposed as emerging from this research framework concept, the authors suggest that the system could include patient self-assessments completed on tablet PCs for EMR upload and use in PPIEs.

2.10.1 Systems innovation

The balance between health care cost control and protection of service quality has been examined by Omachonu and Einspruch[87] in a conceptual framework study of systems innovation in healthcare delivery. The authors observe that while information technology is vital for innovation in health care, *attention has been much greater on medical devices and treatments than on networking and communications*. Distinctions between Research and Development (R & D) in the physical, engineering, and life sciences compared with R & D in the social sciences and humanities are declared as critical to the process of innovation in healthcare. In particular, reliance on cognitive sciences such as taking serious account of patients' experiences is seen as a way to construct new organizational practices that will take

clinicians into unfamiliar territory. It is recognized that this, along with perceived threats to autonomy can create barriers to acceptance by medical practitioners. Moreover, the authors point out that cognitive science ‘*draws upon multiple empirical disciplines, including psychology, psychiatry, philosophy, neuroscience, linguistics, anthropology, computer science, sociology and biology*’. This statement is a useful collective description of the montage of sources that can and will in the future contribute to the framework for PPIE, offering reciprocal understanding when low literacy, socio-economic disadvantage and/or cross-cultural conditions are in play.

Reiterating for emphasis here on statements in their 2010 paper Omachonu and Einspruch assert that ‘*despite the surge in innovation, theoretical research on the art and science of healthcare innovation has been limited*’[87]. Their article attempts to help clarify innovation for the benefit of policy makers and practitioners in their evaluation, adoption, and procurement priorities. The authors perceive the driving force behind innovation in health care as *the conceptual framework*.

Information technology is seen as the key driver of innovation in health. Citing Gupta [88], the lack of attention to networking and communications is highlighted, and is attributed in part to security and privacy concerns; and ‘because healthcare until recently was a service always performed locally and in person’. Research literature findings by Gard[89] indicate (2012) that 500 million Smartphone users will use a health care application by 2015; ethnic minority groups are increasingly using mobile phones to access health information; and with an estimated 5 billion mobile phone subscribers globally by the end of 2010, mobile health technology known as mHealth is changing the way that the world regards accessibility and servicing of health care.

Mackert et.al have reviewed Internet-based health education and promotional activity in the context of interventions to help low health-literate patients[90]. They employed two different types of health information websites and evaluated visitor responses. The authors sought among other objectives to find out whether websites designed for low literate and low health literate people could also help the wider

audience in improving healthcare knowledge. They made particular note of the potential benefit of digital media arising from customization of site content that would match cultural backgrounds and preferences of users, while observing that more work is required to achieve this end. Their study found that individuals with adequate health literacy appreciated the simple and clear nature of the two 'low literacy' sites, one of which was focused on diabetes health education for non-diabetics.

Gibbons looked at the potential of 'health IT' to address healthcare disparities in racial and ethnic minority groups[91]. His assessment of IT health usage among healthcare providers detected the presence of some bias that may prejudice service to minorities. With inferred misgivings about the provider emphasis on electronic Personal Health Records (PHRs) his literature research shows that a growing number of people in the consumer population are resorting for support to online and electronic health information sources outside of the formal health care establishment. He nominates the relatively new and innovative qualities of Web 2.0 as the magnet for this trend, 'enabling interaction, information sharing and collaboration'. His posture is also shared by Dihn et.al [92]. Web 2.0 is the term describing a second generation of the World Wide Web, which is focused on the ability for people to collaborate and share information online. Previously used as a synonym for 'Semantic Web' and while similar, they do not share precisely the same meaning. The Semantic Web is defined as 'an extension of the current Web that provides an easier way to find, share, reuse and combine information' [93, 94].

Social media and social networking also penetrate the user lexicon due to the applications facilitated by the semantic web, leading to the growth of online condition-specific and non-specific health interest communities. Referring to human factors engineering, and to the lack of empirical research into differences in processes appropriate for racial and ethnic minorities, Gibbons cautions that as the tasks and technologies of care processes continue to move into the self-management environment, safety, effectiveness and medical error risk will be impacted[91]. Critical research is required to prepare for and mitigate the exigencies arising from such dynamic change in service delivery.

Two particular aspects of technological innovation in the Omachonu paper [87] connect with, and may among the future prospects, impinge upon this thesis research. The first is an electronic Personal Health Record (eHPR) designed to enable consumers to self-record; and have discretion to securely share their own and close family health care information. In Australia this developing system and service is named the Personally Controlled Electronic Health Record (PCEHR) and is managed by The National E-Health Transition Authority (NEHTA)[95].

The second aspect from Omachonu refers to the work of Intel Corp toward technology that will help homebound patients with chronic disease management including diabetes, hypertension and heart disease. Offerings include computer and software packages to help patients monitor their conditions; integrated with digital devices such as weigh-scales, BP monitors and blood-glucose readers that will facilitate transmission of test results to health professionals via the Internet.

In much of the health care literature, these instruments are labelled 'Point of Care Test' (PoCT) devices because they were originally and almost exclusively used in a formal health care setting. The ubiquitous presence of these tools today allows and encourages timely testing regardless of the physical location of the patient. Self-management includes self-monitoring, self-testing, self-recording and reporting. For the sake of personal health and health care service cost efficiencies, this now combines with the capability to transmit test result data over distances via internet and integrated ICT systems. It is inferred from this that these devices represent a continuous component of self-management care. In concert with the PPIE process, test reporting supports the patient narrative as discussed earlier. The generation of data and the ability to understand it on the part of the patient appear to take different pathways when it comes to health literacy.

2.10.2 ICT and peer support

Among the prospective user engagement applications in health care, interest in peer support communications systems is gaining ground. Michele Heisler, MD in a paper describing research literature on peer support models identifies telephone support for

diabetes and other chronic diseases as attractive for reasons of time and cost saving; plus evidence of good outcomes from peer support; and the need to manage demands of growth in numbers of people suffering chronic disease[96]. She also identifies barriers to telephone systems of support. Principal among these is privacy, for example the reluctance of participants to share private telephone numbers. The author's team launched two randomized controlled trials of interactive voice response (IVR) peer support programs:

- One aimed to address resistance to insulin treatment, using experiences of peer partners who have learned to cope with the fear and anxieties that are common to this form of treatment.
- The other a low-cost intervention with matching pairs of patients confronted with similar diabetes disease severity and changes in their insulin requirements.

With additional informational and support processes Heisler's group based this upon empowerment theory[96]. Web and email-based peer support receives attention in the context of the increasing capacity of the internet to help overcome problems that some patients encounter with organising and managing face to face contact.

Identifying the promising potential of peer support, in her concluding comment Heisler places emphasis on the need for novel strategies *to increase support for patients between PPIEs*, using community based and telephone based programs, with new communication technologies for 'the large numbers of patients with limited health literacy'. Peer support is again alluded to in the next section in the context of access to healthcare advice via the Worldwide Web.

2.10.3 The Worldwide Web healthcare information communications resource

Gillam et.al[97]; Gupta[88] and an earlier Kamel Boulos[98] paper than that previously cited for the same author, bring together the trends and prospects for

- Accelerated and increased web access for semantically oriented consumer healthcare support
- Emerging and overlapping options for health care service delivery
- Improvements in health literacy through the effects of evolving social media peer-to-peer health care communications practices

Others, namely Fox and Lemaire, have contributed to reporting the growing peer support and self help groups using web-based technology in health care[99, 100]. Fox, elaborating on telephone and online surveys in the United States by the Pew Research Center, reports what she describes as ‘a striking finding’ referring to the extent of peer-to-peer activities of people suffering chronic disease conditions. Twenty three per cent of internet users within the chronic disease categories including diabetes stated that they had used online searching to find other people with similar conditions. The surveys showed that users 65 years and older and Spanish-dominant internet users are two of the groups less likely to use the internet for this purpose. Discussing ‘caregivers’ (occasionally referred to as ‘carers’) the national phone survey revealed that

- 26% of internet users caring for someone have searched online for others with similar health concerns.
- Emotional support and ‘quick remedies’, (59% and 51% respectively) were more likely to be sought through peer contact than from health care professionals.
- 91% of adults said that practitioners are best for diagnosis help.
- ‘Rare disease’ patients and their families who ‘gather online’ are becoming experts in certain health and health care knowledge fields[99].

2.10.4 ICT and human design factors for future healthcare

The conceptual distinction of Patient Practitioner Assistive Communications (PPAC) technology, taking account all of the foregoing literature findings is that it serves a multi-faceted function. In all cultural groups and especially in Aboriginal and other socio-culturally disadvantaged groups, pedagogical outcomes represent the ongoing value i.e. beyond immediate end-user needs within and contiguous with the PPIE.

Working with the individual domain literature sources has helped to merge and bring shape to the conceptual framework. The Four Habits clinical encounter model from Frankel and Stein[101] came about from studies of the literature on PPIEs and the conclusion that educating, stress counselling and negotiating as opposed to examinations and tests brought a higher level of patient satisfaction, and better

outcomes than the more formal processes. The habits mapped out by the authors are headed as follows:

- Invest in the beginning
- Elicit the patient's perspective
- Demonstrate empathy
- Invest in the end

The role of emotion in more general human discourse and as touched upon earlier (section 2.7.1) has been explored by research authors from different disciplines. One notable literary source, from Ortony et.al attempts to elucidate the cognitive structure of emotions[102]. Most important for this research purpose is the discussion devoted to the topic titled 'computational tractability'. One goal of Ortony the book was to lay the foundation for a model of emotion using this notion. The authors aimed to present examples of potential formalisms available from characterisations of emotion. The foundation in turn was to serve some of the deliverables of Artificial Intelligence (AI).

Debating the constantly questioned prospects for computers having emotions or feelings, the authors point out that in the absence of consciousness, it could become important for computers to use AI to understand and reason about emotions or aspects of emotion. Natural language understanding, cooperative problem-solving and planning are given as examples. These potential attributes are pertinent to this work in the context of identification of the necessary patient-friendly pliancy of assistive communications technology applications.

In a study by Choe et.al six clinicians and six patients were interviewed for the purpose of identifying possible design options for building empathy into health technologies[103]. In this ongoing project work, the authors identified customary PPIE features that invoked

- Ideas about health information interfaces that could be re-designed to contain personal characteristics
- Narratives to aid the clinician's memory of the patient; and information about the patient's home life, family or guardian

- Support with visual cues such as photos
- All features would be designed to humanize the patient.

This approach may help to introduce practitioner-empathy into the PPIE but it also may be prone to unacceptably labour intensive data input activity; and is exposed to risk of out-dated and biased personal profiling unless with reliable protocols the patient is a contributor to the interface output. The concept however may survive in another form and (for example) via system sharing is a potential companion to a variety of applications that aim to present contemporary patient information through a consumer-design-influenced product and service.

In the less domain-specific environment there is continuing discussion about encoding human knowledge of emotions for use in systems of natural language understanding. Hobbs and Gordon have developed a catalogue of English words and phrases related to emotional states and events as part of a larger commonsense psychology study[104]. The project program known as Core WordNet is contributing to design of automated tools for annotating expressions of emotion in English text. The authors draw attention to two characteristics from their analysis. These are the immense volume, many hundreds of English language words that reference emotion; and the low level of polysemy, i.e. the limitation of multiple meanings per word.

In an attempt to characterize twenty-six basic emotions through abstract causal situations and abstract classes of behaviour triggered by them, Hobbs and Gordon view emotions primarily as ‘mediating between perception and action’. They state that ‘natural language is very rich in emotional terminology’. This finding coincides with the literature on PPIE shortcomings in the sense that without anticipating and then accommodating emotional expression; or absent inferred emotional influence that may occur without oral or clearly visible expression; the PPIE shared cognition effort is incomplete.

2.10.5 Aboriginal Acceptance and use of communications technology

Some initiatives have included examination of Aboriginal access to and use of computers or computing devices in order to discover whether members of Aboriginal

communities have adopted or are willing to embrace ICT systems for personal communications. A legitimate question about a project of this nature concerns whether the hardware and software technology tools for delivering the intended outcome will be accessible, acceptable to and usable by Aboriginal patients and their communities.

Contemporary obstacles identified (Dyson 2004) include weak communications infrastructure, e.g. broadband connectivity, lack of current computer access and usage by Indigenous people [105]. This literature review examined the hypothesis that low adoption of ICT by Indigenous Australians was influenced by Western values embodied in the technology. The researchers found instead that there was an ‘overwhelmingly enthusiastic response towards computers’ by school children, and capabilities limited only by cost associated technology access difficulties, isolation, poor telecommunications infrastructure and low computer skills. UNESCO world studies report that the most obvious challenge to Indigenous people using ICTs for intercultural dialogue is their inadequate access to technology [106].

A preliminary study of mobile phone adoption on a remote island in the Torres Strait disclosed the unexpected use by the Indigenous community of text messaging on mobile phones, as well as calls and text messages in the local language. The tentative conclusion was that ICT must go beyond cultural oral strengths, to match areas of motivation such as communication with family [107, 108].

The Health Interactive Technology Network (HITNet) in Queensland develops and deploys creative media solutions to help reduce Indigenous health inequalities. These media concepts favour the use of ‘performative’ and participative content in Indigenous communities (as opposed to narrative text) because *they are more attuned to listening and watching versus literacy-based media* [109]. The HITNet module is a standalone touch screen application. It is not designed for PPIE use but as an independent use easy access information tool; usually located within Aboriginal Medical Service (AMS) facilities such as the Derbarl Yerrigan clinic in Perth, WA. The thesis author has visited this site and trialled the application.

It is recognized that ICT is intrinsically a management tool, not a panacea for healthcare inadequacies. Xie et al. caution that computer-based communications exacerbates ambiguity and misunderstanding among parties with different cultural backgrounds [110]. Thoughtful design of applications and User Interfaces (UIs) is essential, more so when intended users have had limited exposure to ICT and potential self-management of chronic conditions using electronic Point of Care (PoCT) and communications devices. These devices increasingly represent intelligent machine participation in PPIE.

Researchers are learning that westernized assumptions about the value of speech and written text are unreliable; and such limitations fail to optimize the conversational modalities available when engaging different cultures [27].

The earlier Cass citation[68] was included to accentuate the effect of miscommunication and to show that through the benefit of video recording it was possible for the participants to subsequently recognize when and in what manner PPIE misunderstandings occur when the patient is an Aboriginal person. Making the link between ICT user potential and PPIE experience as related in this work, this research has worked toward resolving the issue of how and why miscommunication transpires in these circumstances in order to propose a remediating concept.

2.11 Healthcare ontologies

Computer ontologies have been developed and some adopted by medical professionals, with a notable bias in the published research toward provider-centric systems needs [111-125] compared with the patient-practitioner relationship environment [126-129]. Ontology work is elaborated in the source synthesis at 6.17.

Context-based task ontologies (CTOs) have been created by Kumar et.al to form a core component of a Computer Interpretable Guideline Model (CIGM) intended to automate representation and execution of clinical practice guidelines (CPGs)[130]. Their specific task orientation follows the WHO guidelines for hypertension management. Whereas the work of these authors is concerned with clinical practice and not directly with patient or cultural interests or engagement, the development of

CTOs for CPGs is of consequence to assistive communications ontologies. The authors point out that an internal medicine team would need to supplement CPGs with implementation task ontologies aligned with workflow practices in the specific healthcare environment. Medical history taking is an example of this. In the clinical and professional applications workflow arena ontology construction relates to formal terminology sources, in the instance cited, the Unified Medical Language System (UMLS) Semantic Networks.

As CTOs involve multiple ontologies and multiple context-interpretations of guidelines it seems logical to argue that as communications and semantic sophistication advance, a gateway linking patient-practitioner healthcare ontologies will open up relationships with the technical and clinical medicine domains, for example in diagnostic procedures and outcomes. Kumar et.al mention merging various task ontologies from different guidelines as one of the advantages of their system. The ontology literature is revisited later in this review section in order to consider and pinpoint the role of ontologies in intercultural assistive communications particularly in the Aboriginal health care informatics and pragmatics environment.

2.12 Context awareness

Context awareness is a desirable core characteristic too often defeated by cross-cultural communications barriers when Aboriginal patients enter into PPIEs, with non-indigenous practitioners. In the course of a review of context awareness applications in interpersonal services Toutain et.al. note that context awareness is a very large research domain[131]. Similar to discussion on contrasting high context and low context cultural communications their article describes how a great diversity of data is needed and can be used as contextual information emphasizing the potential from the digital phone networks and smart communication systems. Accepting that integration of context awareness is in its embryonic stage, the authors pose four broad questions that are intended to prompt researcher thought and progress. These questions attempt to address

- Conversion of raw context data into high context knowledge
- Potential leverage for large context datasets
- Promotion of business opportunities from context services; and

- Gaining user trust for such services.

Although the context awareness research field is large no useful data has been found that will directly contribute to the PPAC design work, barring the acceptance that care with syntactic and semantic mappings should aim to accommodate user guidance for communications adaptation according to contextual circumstance. In other words, alternative meanings of words phrases and non-verbal expression should be available through prompts designed into the system.

2.13 Summary

This chapter has covered a broad interdisciplinary spectrum of literature sources addressing a mix of intercultural human communications and behavioral difficulties in health care service delivery. More specifically it has

- examined contemporary healthcare service models; and health education practice for communicating T2DM complications, prevention and management in Aboriginal communities
- identified communications and cognition gaps which disclose weaknesses in current intercultural healthcare models, particularly in primary care and pertinent to T2DM
- opened up the untapped potential of Aboriginal English dialectal pragmatics in the context of increasing efficacy in healthcare communications through acculturation
- reviewed the serious epidemiological and healthcare service implications of Type 2 diabetes care affecting both the Australian Aboriginal community and service providers when all of these facets come together in PPIEs
- noted shortcomings in the communications scope and style of conduct in PPIEs
- probed the ICT research literature for technological support solutions to communications and cognition barriers known or perceived to persist in PPIEs.

From this review process the work moves on to isolate and qualify the most pressing problems requiring attention; while also considering how these can be resolved, based upon analysis of what is the most promising usable output from the research data.

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Chapter 3: Problem Definition

3.1 Introduction: Defining the issues

The pivotal conclusions from the literature review confirm that patient-practitioner interview encounters require equitable improvement in the cognitive quality of communications; that significant improvements for the wellbeing of Aboriginal T2DM patients are urgently needed; and that acculturative ACT applications designed to overcome communications barriers represent promising opportunities to help achieve that goal.

Listed in the Chapter 1 thesis introduction (1.1) are the causative facets each with a problem effect contributing to the principal communications problem to be solved. A popular tool for illustrating cause and effect, and thereby a useful means to summarize the outcome of brainstorming, is the Ishikawa diagram, aka the fishbone diagram. Ishikawa is a Japanese quality control specialist who reportedly invented the diagram to help business employees overcome the distractive risk of addressing symptoms rather than identifying the greater problem to be solved [1]. Figure 10 is a basic fishbone diagram in which the primary problem areas are brought together, using adjective titles to describe the common noun ‘problem’. These represent the main roles in the problem profile consisting of People, Materials, Activities and Machinery. The People dynamic is labelled ‘Cultural’ denoting the existence of a cultural problem. Additions making up the particular problem causative factors are each shown attached to the four ‘ribs’ of the fishbone. The Materials rib is named Data; Activities named Research Process; and Machinery is named as Systems. The text rectangle at the right of the diagram represents the fish head and the principal problem to solve. This correlates to my primary objective: *To introduce a shared knowledge representation model and data transformation process as a conceptual foundation for the future development of intercultural communication technology systems capable of overcoming ethnic socio-cultural disparities in healthcare consultations.*

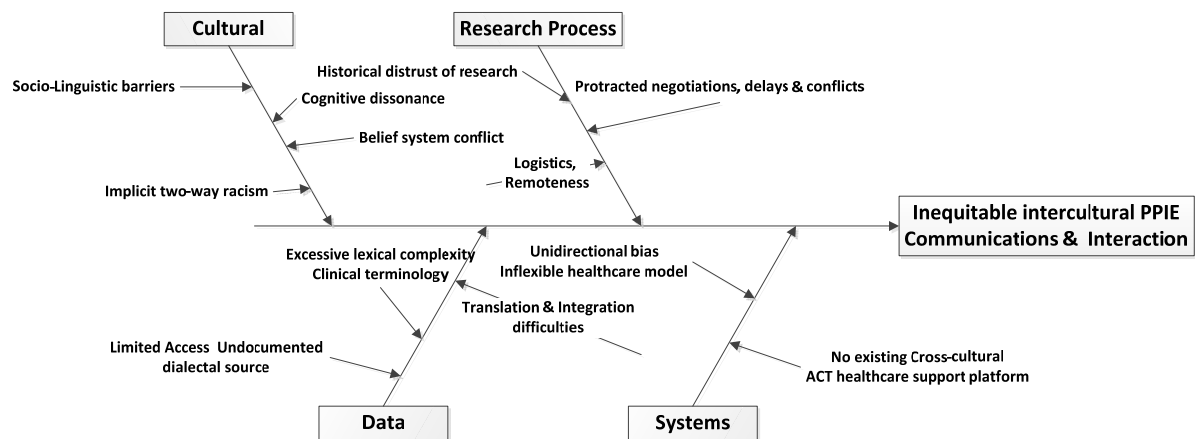


Figure 10: Ishikawa (fishbone) diagram of cause and effect; and main problem for this research

3.2 Problem characterisation

The problem characterisation occupies two overarching environments:

- The underlying question concerns inadequacies in *societal knowledge sharing*
- The focus on the difficulties encountered in *conceptualizing an assistive communications technology system* to significantly counter these inadequacies.

Within the latter environment, the problem solving effort will encounter research and design problems that are obstacles to progress. These are discussed in latter parts of this chapter not as principal problems but as learning contributions to justify my deviations in data gathering and solutions design.

The most important problems examined, first listed in Chapter 1; prompted by research reported in Chapter 2; and presented in more detail in this Chapter are:

- The communications and cognition barriers created by dominance of Type 2 diabetes clinical terminology and associated complexity of healthcare provider expressivity
- The severe limitations of communications and cognition adversely affecting patients whose best opportunity to converse with and understand practitioners is through the use of Aboriginal English

- The absence of a culturally competent model capable of achieving more equitable communications in the patient-practitioner interview encounter

At its core, there is a communications barrier that prevents patients who are culturally and socio-economically disadvantaged from receiving best health care. Within this spectrum these barriers are exacerbated by the complex knowledge and application demands of particular chronic disease management, specifically type 2 diabetes, sometimes referred to as ‘the lifestyle disease’. The problem characterization ascends to addressing pragmatic communication complexities. Aside from ethnicity and linguistic based cultural differences, institutional health care service workplace cultures are a significant problematic factor; as identified and characterized in a Qualitative Gap Analysis (QGA) of communications barriers described later. Intercultural engagement can be hindered when the more empowered participants (providers) rigidly represent an institutionalized domain where clinical terminology prevails and dominates. Members of the patient community who have little to no semantic knowledge or contextualized understanding of a practitioner’s conversational contribution add further weight to the communications and cognition barrier.

In the multi-dimensional setting of this research the work outcome goal can too easily be obscured. Offering a shared knowledge representation model necessitates pursuance of a data transformation process that will make sense of a somewhat cluttered and at times confusing data environment. As a conceptual foundation for the future development of intercultural communication technology systems the abstractions populating the proposed foundation framework must irrevocably contribute to sense-making when working with the merged domains, e.g. making and responding to queries regardless of the cultural status of the users.

Problems are identified initially in their separate domains and dimensions. Pursuing my sub-objective sequence, T2DM, AE and PPIE discussion are pre-eminent; and I subsequently confront ACT design problems linked to research findings in these primary domains. For example structuring relationships between domain concepts for machine agent use depends upon establishing logical compatibility for mapping.

Research into and with Aboriginal English speakers and their health care pragmatic inclinations shows that personal communications modes are variable unpredictable and prone to ambiguity. The mapping of Aboriginal English home talk expressions with relevant classes and properties of type 2 diabetes care guidelines through literal translation with Standard Australian English alone will not secure sense-making objectives. Each contributory source data analysis must therefore produce well-defined conceptual labels and annotative descriptions that complement related concepts, the relations between them and their individual and integrated functionality.

3.3 Problematic Type 2 Diabetes management care model

This section seeks out the problem features that confront the first sub-objective, which is focused on structuring formal T2DM GLs in a form that will enable mapping with AE.

In Western Australia the Endocrine Health Network Working Party of the state Department of Health published a ‘Diabetes Model of Care’ in 2008 [2]. Citing the Western Australia experience is a strategy for culturally and demographically aligning the research problems and solutions. It does however share many commonalities with unsatisfactory Aboriginal healthcare service delivery performance and outcomes throughout Australia [3-9]. The general tenor of this WA document is that unsatisfactory health care service outcomes must be addressed to counter a seriously adverse trend in numbers of diabetes sufferers and consequential chronic disease complications. The document reports that most T2DM patients are managed by GPs with variable participation by allied health professionals. It speaks of “gaps” in care which semantically and implicitly correlate with identification of service problems, premised on the known biomedical argument that much of the T2DM condition and its complications are preventable. Evaluation of escalating health and financial costs is also part of the societal problem equation. The model of care protocol discussed examines existing care practice and seeks remedial, higher performing care methods and outcomes Problems identified include:

- lack of systematic management;
- failing to meet the needs of adults and children across WA;

- wide variations in care delivery and outcomes;
- lack of coordination among large service organisations and individuals creating a major impediment to best management;
- lack of communication between service providers causing multiple adverse effects on quality of care; and
- very little electronic communications between the various component parts of T2DM health care service entities.

It was noted from this and other reports cited below that few if any references have been offered to include the patient dimension. ‘Failing to meet the needs of adults and children’ is a generalisation that in its detail might capture such matters as problems with mutually cognitive communications, and also intercultural engagement weaknesses. Regrettably the impression persists that a top-down paternalistic healthcare institutionalized culture is tending to overlook the value of the bottom-up, patient centred perspective. As such it highlights poor communication in T2DM care as a major problem.

In total this source provided a nine-page listing of twenty-one main, and numerous sub-recommendations. Much and more of the rationale and information supporting the recommendations effectively re-appeared in a later very much more comprehensive KPMG consultant study and document of 359 pages published in 2012 [10].

It is difficult to explicitly determine whether there has been real progress in addressing the service problems as described earlier, allowing for the difference in detail between documents, while also allowing for the changed service demand environment arising from the demographic trend in WA during the interim period of strong economic and workforce growth. Given the relatively large scale of the KPMG study however, this avails this research of a credible overview of Western Australia’s diabetes health care service logistics problems.

The report summarizes under headings for Statewide, Metropolitan regions, Rural regions and Remote regions. It paints a picture of a distinct access to service bias

favouring the highest populated state area of metropolitan Perth; and of a gradual thinning out of health care resources reflecting demographic patterns. Even in the metropolitan regions access to care depends upon where a person lives, as tertiary level diabetes clinics are all within the inner metropolitan area, depriving the diabetic complications sufferer from outer areas of the necessary immediacy of access to care.

In many areas there is a need to build capacity in secondary health care centres. In rural regions (South West, Great Southern, Wheatbelt and Midwest) these large geographic expanses lack permanent endocrinology services and rely upon a very limited number of diabetes educators. Local diabetes specialists are a sparse asset and health care workforce shortages compound service problems. Consequently there is a high reliance on visiting services, which also attracts a bureaucracy factor due to differing funding arrangements. The diabetes care service situation worsens considerably for remote regions (Goldfields, Pilbara, and Kimberley).

Very limited diabetes dedicated services combine with high diabetes demand due to prevalence and complexity. Services that include visiting specialist teams are described as ‘fragmented and infrequent’. In Western Australia, these profound demographic and logistical challenges for health service delivery commonly compound patient socio-economic and cultural minority disadvantages. Responses to these challenges has brought new difficulties, as migrant overseas trained doctors (OTDs or IMGs), on whom the state rural and remote health care system is heavily dependent, are often inadequately prepared for the acculturative impact of engagement with rural and remote communities and even locally trained graduates may experience culture shock [11, 12].

Turning to the overall Australia picture as reported by Katterl et.al for the Primary Health Care Research & Information Service, (PHCRIS) in 2012 creates further doubt about the efficacy of progress with remedial and preventive programs and resources to fight Australia’s T2DM epidemic[13]. Drawing upon data from The Australian Institute of Health and Welfare (AIHW) the report focused on potentially avoidable hospitalisations (PAHs) as “admissions to hospital that could have

potentially been prevented through the provision of appropriate non-hospital health services”.

In 2009-10, according to the AIHW report PAHs related to chronic conditions were the most common, due mainly to the high rates of hospitalisations for diabetes complications (24% of all PAHs)[3]. Further data from AIHW in ‘Australia’s health 2012’ discloses serious indicators that suggest the service weakness problems have not been mitigated:

‘In 2009–10, the average length of hospital stay was higher for hospitalisations with a principal diagnosis of diabetes (4.3 days) or additional diagnosis of diabetes (8.0 days) than all hospitalisations (3.1). Of hospitalisations with a principal diagnosis of diabetes, 71% were for Type 2 diabetes’. [13]

Scrutiny of the current practical and theoretical WA T2DM service model, while also acknowledging similar challenges elsewhere in rural and remote Australia, reinforces the hypothesis that the heart of the problem to be solved is ‘communications’. This is conveyed in terms of

- service distance barriers;
- poor cognition-based diabetes lifestyle education; and
- unsatisfactory performance in T2DM self-management.

3.3.1 Miscommunication, misinformation and misunderstanding in healthcare

The terms ‘dissonance’ and ‘cognitive dissonance’ are selected to help with placing the intercultural communications barriers in context. While barriers may be identified individually each may comprise several elements; dissonance being ever present in the case of rural and remote living Aboriginal patients in their relationships with health care providers. Cherry provides a modern day interpretation of the term ‘cognitive dissonance’ defining it as ‘used to describe the feeling of discomfort that results from holding two conflicting beliefs. When there is a discrepancy between beliefs and behaviours, something must change in order to eliminate or reduce the dissonance.’ [14]. The words ‘must change’ however are presumptive of the capability for one or both participants in a conversational engagement to adapt, adjust or achieve sufficient morphology to overcome cognitive dissonance. Unrecognized ignorance by one or both parties, effectively ‘not knowing what we

don't know' can constrain the expectation of change. In Chapter 2, the Cass et.al paper was cited as an example of dissonance-based miscommunication and misunderstanding [15]. The phenomenon of 'gratuitous concurrence' (e.g. answering 'yes' to any and sometimes every practitioner question) is a good illustration of this barrier element.

As there is no single reliable expectation of a patient's personal disposition, planning for improved cognition and communications must accommodate many unknowns. For example the newly diagnosed type 2 diabetes patient most probably will possess much less inherent knowledge about and confidence in the formal care processes. Assumptions or presuppositions about that knowledge and readiness status must be regarded as generally unsafe for an ACT design process. Random limited samples of words and phrases from within the RACGP GLs that are very likely to create cognitive worries if heard or read by country living Aboriginal patients include for example:

- Impaired fasting glucose
- Renal function
- Diabetic ketoacidosis
- Macrovascular disease
- Dyslipidemia; and
- Neuropathy.

As will be seen later, the sequential process of simplifying these terms in English, seeking out Aboriginal English pragmatic equivalents, and securing contextualized semantic integrity, is a deliberative approach. It is however hampered by the absence of sufficiently documented and published 'Aboriginal country' worldview ways of and words for expressing community and personal health and health care matters.

3.3.2 Guidelines complexity characterization

The complexity features of central concern in this research thesis revolve around the desirable but presently inadequate process of intercultural conversational metamorphosis. That transitional challenge to move PPIE engagement from elusive and discordant to accessible and concordant, presents the researcher with the need to identify problems found in the two major domains of interest. The first of these for

discussion here is the accessible, structured, and voluminous repository of clinical care data and advice about diagnosis, treatment and care management of type 2 diabetes.

The Type 2 diabetes care guidelines are published in Standard Australian English for the benefit of General practitioners; and implicitly for access by other qualified healthcare professionals. While not overly dominated by biomedical terminology the readership literacy level of the guidelines does not today accommodate low literacy readers and are unsuited to those with limited English proficiency. Examples have been cited in 3.3.1 in the context of miscommunication. Miscommunication can occur when words and their meanings have not been understood by the receiver of an utterance without the original speaker being aware of the communication failure.

The principal reasons for working with the RACGP GLs as the schema base are

- Health care practitioners are key players and equal partners in the PPIE communications process but are not appreciably engaged in communications and engagement innovation activity.
- The eventual PPAC system will recognize and respect accredited and structured professional expertise, but will need to counter institutionalized inflexibilities.
- The potential advancement in equitable PPIE communications which should anticipate disadvantaged patients achieving elevated cognitive and learning capabilities is not widely discussed in health care provider circles.

Remaining with the topic of complexity and with particular reference to the RACGP GLs I note that the terminology in the guidelines used to describe diagnosis, assessment, initial management, health care for diabetes, medication and other sections contains bio-technical and clinician-favoured words and expressions that vary in their capacity to simplify for the purpose of shared understanding with the general population.

In the process of identifying concepts for communications mapping objectives simplification must retain semantic integrity; and the patient experience of

encountering cognition difficulties can arise from a variety of circumstances, including attempts to decipher personal health records and related documentation containing clinical terminology.

C. Jason Wang writing of medical documentation in the electronic era and supporting the call for Patient Centred Care (PCC) allowing greater patient access to medical records reminds the reader that even for practitioners many medical terms are difficult to pronounce and to spell, taking time for professionals to learn and acquire confidence with ‘medical jargon’[16].

At the other health care stakeholder extreme Schillinger found that inadequate health literacy among disadvantaged primary care patients with type 2 diabetes is associated with worse glycemic control; higher rates of retinopathy and may be contributing to the overall disproportionate effect of T2DM on ethnic minorities [17].

3.4 Aboriginal healthcare information exchange issues

This section begins to consider problems associated with the second sub-objective; to conceptually structure AE dialectal data as a base for ICT system development.

The contemporary health care service delivery model for Aboriginal patients may justifiably be regarded as self-defeating; and a problem that must be evaluated in any effort to introduce new and equitable systems of communication; beginning with the pragmatic combination of language and culture. Aboriginal English is not a component of Australia’s healthcare information exchange systems and is absent from recognition or practice in PPIEs.

In 2012 Durey and Thompson interviewed non-Indigenous West Australian based medical practitioners with extensive experience in Indigenous health and health care [7]. Looking for insight into factors promoting or impeding quality health care delivery to Aboriginal patients, it became clear that ‘policies and practices favour standardized care where the voice of those who are marginalised is often absent’. The authors refer frequently to ‘Whiteness’ factors and ‘racism’ while explaining how the colonial history of Australia and the dominance of Anglo-Australian cultures

have continued to overwhelm the cultural and communications contributions of the Indigenous people of Australia. They describe ‘Whiteness’ as the ‘omnipresent norm’ and reveal through this focused research a wide range of inadequacies in the mode of health care delivery at the cost of Indigenous health; each attributable to that westernized norm.

One example given by Durey and Thompson about information processing barriers is that of standard forms used by hospitals. These forms seek demographic information from the patient but make no allowance for the complex Indigenous kinship structures or patients’ mobility between family members at different locations. Mobility of Aboriginal family members and recording of more than one address or next of kin, taking into account the common discomfort for a rural patient coming to the ‘big city’ are just two examples of the failure to intelligently accommodate the patient need perspective.

The statement by the authors, one of whom is an experienced and qualified former practising clinician, that governments ‘may excel at rhetoric, glossy policy documents and promises...’ resonates with my research findings. The research evidence supports the view that top-down institutionalized power hegemony unabatedly excludes the minority contribution from virtually every layer of health care service interaction.

Durey and Thompson touch briefly upon cultural education and in the context of educating professional practitioners aimed at achieving improved cultural competence, they write that ‘the challenge is to avoid tokenism where a service provider attends a cultural education workshop/lecture/seminar to ‘tick a box’ attesting that they have met institutional requirements....’. This observation is taken a step further, or more explicitly, to the level of educative interactions leading to the design of health care workshops. That tokenism is ever-present in the documents that have been reviewed; and may be reflected in the absence of a healthcare lingua franca accommodating Aboriginal English.

3.4.1 Aboriginal English and Type 2 diabetes care education aids

Bulky and expensively produced materials (examples cited in 2.3); published by health department funded sources; were scoured in this thesis research for useful Aboriginal English health talk to help conceptually populate the Assistive Communications Technology (PPAC) system. These have contributed little knowledge, and no data value. This has however confirmed the all too common argument in the literature, that health care information systems ostensibly designed to meet Aboriginal education and self management needs are effectively a problem in themselves. Tokenism appears to be the substitute; a shield for absent consultation and the failure to undertake demanding essential work of respectful bi-directional engagement in the knowledge sharing and communications system design process.

Placing faith in teaching and learning information systems that are essentially uni-directional perpetuates the supremacy philosophy and is an anathema to assistive communications development.

The literature and focus group research (described later) confirmed early on that anatomical and physiological experiences, feelings and conditions perceived and described by patients as a routine part of westernized primary care practice symptom identification and diagnoses are not commonly volunteered in a comparable manner by Aboriginal patients. As Trudgen advises, these descriptive expressions often do not translate reliably when they are discussed [18]. Western medicine explanations of the organs and the functions of the body have no equivalent perception, thereby complicating the dialogue of T2DM diagnosis, treatment and care. The experienced Aboriginal health researcher Lowell holds the opinion that it is the communication of diagnosis, treatment and care, not the health care process itself that needs to be changed [19].

One problem with T2DM education and training investment is that the impact of traditional teaching and learning methods cannot be measured over a short or medium term. ‘Impact’ is used here to label a metric measure of wellbeing outcome trends. The laborious nature of trying to maintain self-management knowledge and

outcome performance among rural and remote patient communities is heightened by other communications barrier components. Servicing the needs of these communities is constrained by the practicalities and economic realities of overcoming extraordinary logistics challenges. These include shortages of competent trained staff and the system strains of continuity in services to rural and remote areas that are distant from centres of population and mainstream services.

Variable educational and consequent literacy levels in the communities, working from a Standard Australian English benchmark, confront health workers and educators with more communications problems. SAE is a third or even fourth language in many communities, where the oral tradition of human discourse, not the printed matter approach, is commonplace and more culturally appropriate. AE is most often the bridging dialect. The numerous related problems of health care education and service delivery briefly recounted above are comprehensively addressed by Humphreys and Wakerman [8], but as in much of the Aboriginal health literature, communication is an implicit pivot rarely explored in great problem-solving depth.

3.5 The PPIE and semantic barriers

The third sub-objective, aiming for bi-directional communication and understanding in PPIEs is presented with a range of problem factors to counter in the design process.

Within the PPIE involving Aboriginal patients, the meaning of statements made by patients and practitioners may at times be ambiguous. If unrecognized, that ambiguity may impose harm or at least a less than effective healthcare outcome. There is also another potentially hidden bifurcation of semantics in the PPIE. Trudgen has alluded to it in his book ‘Why Warriors Lied Down and Die’[18]. Working and living with the Yolngu people of North Arnhem Land, a region of the Australian Northern Territory, as a non-Indigenous author he discusses historic failures of practitioners to discover and use ways of explaining the reasons that certain physical ailments occur; and equally the reasons for pursuing specific treatments and medications. In his chapter titled ‘The Essence of Human Interaction

– Communication’, Trudgen provides cogency on the lack of effective healthcare communication affecting ‘a marginalized minority cultural group’. In a section subtitled ‘Communication mores’ he states that ‘the communication crisis is more than just a war of words’. He explains in detail the Yolngu culture human interaction conflict-risk facets of

- limited eye contact
- indirect speaking, and deep meaning in a polite indirect manner
- active, full attention listening
- thinking through the response, taking great care before answering
- response times regarded as ‘response processing times’ as long as ten seconds
- body language which Trudgen states ‘speaks almost as loudly as words for Yolngu’
- not interrupting the person speaking, similar to Asian cultures whose view is that interruptions are ‘uncivil’; and
- problems with silence, related to the earlier listed response time issue.

In summary, the communications problem from the author’s practical knowledge and perspective largely stems from the poor cultural communications competence, unwillingness or intolerance on the part of non-Indigenous service providers who appear by practice to subscribe to the dominance of SAE forms of expression and interactions.

The sometimes less obvious divergent purpose of the Aboriginal patient lies within the high context Indigenous exchange culture. If a patient wishes to know and is prepared to ask what a piece of diagnostic information ‘means’, the likely response will be a clinically based explanation. If that explanation is also accompanied with a prognosis, a second ‘meaning’ is conveyed. In other words, “what does this mean?” becomes synonymous with “what are the implications for my future health?” These examples also simplistically skate over the AE and SAE communications barriers and circumstantial realities. In the following sections I continue to discuss characteristics of the research components in their individual contributory problem context; moving toward the central concern to identify and qualify problematic

barriers to progress in building a workable Patient Practitioner Assistive Communications (PPAC) system.

3.5.1 Limitation of the Interpreters option

In furtherance of the 'PPIE sub-objective' this work aims to identify the reasons why interpreter services have not been able to satisfy intercultural communications needs in the PPIE. It is also of interest to learn of the potential for a PPAC system to be adopted within the interpreter service sphere; thereby helping to preserve while augmenting, valuable expertise and service commitments.

In the intercultural communications setting an obvious option for improved performance is the use of interpreters. The Community Health Action Group (CHAG) in Queensland is the advocacy arm of the Multicultural Health Network. In a 2004 discussion paper (Lost in Translation) interpreter issues are covered by CHAG in practical and anecdotally detailed reports of minority patient experiences within the state[20]. Observations noted include an effective pattern of refusal by clinicians to call upon interpreter assistance in spite of direct request by or on behalf of patients. This gives rise to asking about the common characteristic noted by CHAG as the reluctance of GPs to use interpreters. The consumption of time; the complication of interpreter reservation arrangements; the lack of funding in some hospitals; and the tendency to downplay the need when a patient appears to have a smattering of spoken English ability, all contribute to a culture of resistance.

In the context of interpreter capabilities and availability ratio barriers, the CHAG report brings into play additional factors that the authors wish to highlight as qualifying the improved productivity scope for professional health interpreters. The CHAG authors make the point that current interpreters have a limited role, i.e. that of 'straightforward interpreting within a defined context'. The discussion then proceeds toward the argument that

'...health trained interpreters interstate and overseas are able to broaden their role from interpreter to interpreter-counselor-advocate when necessary to assist the clients. In addition, they have the mandate to provide advice to

health professionals on cultural or other environment factors which may progress of impinge upon their health status'.[20]

The foregoing expresses a hope and desire for expansion of interpreter capabilities, with the inherent implication for extensive development of training and accreditation systems that would justify and validate such resource applications. I contend that this is demographically and numerically unrealistic. In this research little evidence has been found to suggest that appreciable progress Australia-wide has been achieved in the years since CHAG reported. While it is recognized by CHAG that insufficient trained interpreters are available to manage different dialects, the emphasis on hospital staff failing to access existing interpreters is a strong message. It is important to note that the term 'health trained interpreters' is explicit enough to suggest that within the body of the professional interpreter population there are specialists. Moreover, within the medical and health ecosystem, innumerable specialist categories present a plethora of expert need which logistically does not exist and therefore cannot efficiently meet Australia's health environment multicultural and dialectal language and cognitional demands.

3.6 The Aboriginal English healthcare schema deficit

The foregoing discussion has outlined the several contributory factors resulting in unsatisfactory communications in the PPIE Aboriginal patient setting. It is surprising to discover that in spite of the acknowledged disparities in Australia's Aboriginal population health compared with the non-Indigenous populace, there is no evidence of a significant effort to close the communications and cognition gap in health care. To the contrary, as illustrated in the QGA reference sources in Chapter 5, this inadequate engagement paradigm appears unyielding. The educational research on Aboriginal English began in the 1970s and has since generated a considerable volume of literature published by researchers working in five Australian states and the Northern Territory. Although some tangential work has taken Aboriginal English knowledge development and practical application into areas such as criminal justice administration [21, 22], this has not been matched with an effort to bring AE into the healthcare environment. Accordingly this suffers an exceptional deficit in the availability of documented Aboriginal English pragmatic dialectal data and

taxonomic schema. As far as my searches have been able to establish, the attempt to counter this as reflected in this research; in the contemporary context; is unique.

3.7 Cultural barriers to research in Aboriginal communities

To collect and qualify undocumented Aboriginal English ‘healthcare talk’ type data essential for use by applications agents through increased concept numbers and semantically rich relationship identification, researchers must go to the user source. This means that effective engagement with rural and remote Aboriginal communities and individual Aboriginal volunteers is the only recourse to pursue over the longer term. This conclusion however was reached only after the early stage literature review and consultation with knowledgeable Aboriginal English education experts and Aboriginal health care industry professionals. Moreover it was discovered while engaging with these urban parties that code-switching capabilities that might otherwise help to ‘demonstrate country home talk’ are not comprehensive in the health and health care dialect sense. This has been in part attributed to the self-consciousness of urban Aboriginals whose use of their AE dialect has suffered the negative effects of condescension among non-Indigenous Australians, including members of the teaching profession who have treated AE as unacceptable bad grammar.

In the course of this research, several obstacles have surfaced to effectively block or divert the course of enquiry; and to delay the collaborative potential. For the sake of context, these are discussed briefly at the end of this section, which first will reference as explanatory groundwork, the problems encountered by other researchers.

Davidson et.al published a university research report on Indigenous research strategy in 2008 [23]. The discussion of lessons from past research opened with a statement that ‘research’ has a poor reputation among many Indigenous people and communities. Reasons given have been taken into account in the future work planning covered in Chapter 9. These are not elaborated here as the focus is on recognition of research barriers as a problem confronting the goal of this research. Several sources have been reviewed[23-27] itemizing the principal problematic areas

for the research. Three historical features of past work that tend to influence the prospect and extent of cooperation available from the Aboriginal communities were identified.

- Prior relationships initiated by researchers have lacked consultation with affected parties and have neglected Indigenous ethical concerns.
- Secondly, research has been or perceived to have been, ‘a one-sided exploitative relationship with no benefits flowing back to the Indigenous communities’.
- Third, poor quality research has failed to accurately reflect Indigenous experiences and realities.

Problems acknowledged in the Davidson report which face other researchers who are trying to counter these prior inadequacies include time and methodological constraints; and the difficulty of including Indigenous people in the design and conduct of research. The latter issue stems from limitations in numbers and quality of community contacts; and cooperative networks. The Davidson et.al university research paper points out that short-term project work lasting up to 12 months places constraints on the capacity to develop a community partnership and to fully gain Aboriginal perspectives. Aboriginal researchers are an important part of Indigenous community research projects, and their recruitment training and retention brings a special set of challenges.

Donovan and Spark offer guidelines for surveys by non-Indigenous researchers in remote Aboriginal communities [25]. Drawing upon their experience in the field of Aboriginal health promotion research the authors do not dwell on problems but strongly implicit in their advice, along with cautionary caveats, is the advice that community and cultural methods recommended should be purposefully designed to counteract known barriers. The caveats particularly apply to weaknesses arising from historical researcher inclinations to generalise about ‘the Aboriginal culture’ instead of recognising the diversity within the broad range of Indigenous differences which justify use of the plural ‘cultures’. The authors also state that the Aboriginal culture, as is the case for many other cultures, is constantly changing.

In offering guidelines for survey research, Donovan and Spark list nine main group headings while emphasizing that the guidelines primarily refer to ‘non-secret’ data, and not to the study of what is the type of deep and historical ‘cultural knowledge’ that is held closely by a community custodian. Working through these guidelines with intent to identify and qualify research problems from implicit as well as explicit statements, I confirm the influence of a collective over-arching principle, i.e. the effort to secure community engagement in a research project is fraught with obstacles for the uninitiated and unprepared researcher.

A research program that looks promising during early interactions may easily be derailed through lack of cultural competence. For example, choosing to regard the word of one community ‘chairperson’ as absolute without wider consultation with and representation of views by community elders is likely to lead to resentment and an end to the project. Another, anecdotal example is the unpredictable timing of events and interactions making up the project from day to day. Arriving at a community location for a previously agreed meeting and finding that a death has occurred in that community should always result in the immediate withdrawal of the researcher or research team. This has been encountered in the course of this thesis research when an Aboriginal education friend and mentor of the author in metropolitan Perth suffered an extended family member loss. This was an experience that also confirmed the real-world fact of frequency and number in the Aboriginal communities of what in non-Indigenous population terms would be regarded as excessive and premature deaths. In Aboriginal English, death and funerals are called ‘sorry business’. Awareness that this term is being used is a cautionary signal to the researcher to adopt a sensitive posture, and in most cases, to withdraw from further exchange, which will only be resumed at the time and choosing of the affected Aboriginal contact person.

The overall advice message from Donovan and Spark can be summarized as more than advocacy. It conveys the criticality for cultural competence knowledge and disciplined application on the part of researchers wishing to engage with rural and remote Aboriginal communities. Jamieson et.al, a group of ten researchers, echo a very similar ‘be prepared’ message in their article ‘Ten Principles relevant to health

research among Indigenous Australian populations' [28]. They place considerable emphasis on the past underfunding of projects; some of this also implicit in the impact of unscheduled activities, recruitment and high staff turnover problems. The New South Wales booklet titled 'Working with Aboriginal People and Communities' succinctly spells out the fundamental nature of the confidence barrier that faces the research planner:

Aboriginal communities have constantly met barriers within mainstream systems and Aboriginal cultural priorities have been largely discounted, ignored and undermined. If engagement seems difficult or time-consuming, remember that history has not given Aboriginal communities and families much reason to walk forward confidently in partnership. [28]

3.7.1 My Aboriginal research barrier encounters

During the initial research subject of this thesis personal professional contact enquiries as well as research literature disclosed the probability that engagement with Aboriginal communities beyond the urban perimeter would prove to be exceptionally time-consuming and exposed to the risk of failing to work within an acceptable academic research timeline. Two long road journeys to small rural towns on the edge of the bush north east (Yalgoo) and east (Kondinin) of Perth served as an early illustration of the time-consuming demands of a plan to conduct research interviews and focus groups in rural and remote communities. Time therefore combines with funding factors to create problems for data collection, collation and analysis research activity in this environment; and the cost factor is a further project stressor when viewed in the context of direct expenses incurred by researchers developing relationships with and staying near to communities. For example, cooperation of interviewees and focus group members create the expectation, based on showing respect for participants, that some form of financial compensation and the provision of 'tucker' (food and beverage) will automatically be provided by the researcher(s). Until successful negotiations are realised, the extent of this cost factor will not be known; and contingency provisions are always necessary to meet unexpected schedule and participant changes.

One unpredictable diversionary influence encountered was the ‘tall poppy syndrome’, which has in a limited manner acted as a deterrent against involvement with this research [29]. This is a social phenomenon historically present though not always visible in some communities with an Anglo-culture origin, i.e. Australia, Canada, New Zealand and the United Kingdom. It manifests in resentment, personal attacks and strong criticism of talented people; ‘champions’ who stand out for their exceptional successes. This is an unfortunate legacy of Australia’s colonisation and has been witnessed in this research, in the form of reluctance by potential Aboriginal and non-Indigenous collaborators to risk perceived public visibility or more specifically, being seen by their peers as associated with high level academic research.

As a simple example, an Aboriginal mentor at one stage advised this author to limit ‘name-dropping’ of helpful Aboriginal acquaintances when introduced to other Aboriginal people whose help is being sought. The reason stems from the risk of encountering without necessarily realising the existence of, the barrier of envy. Another example of the tall-poppy risk advice offered to this researcher is the inter-tribal type rivalry involving Aboriginal art. Paintings made within one community or ‘mob’ may not be well received or respected if these are featured in an engagement process within a different Aboriginal community. That engagement process may include some of the health care publications and education aids discussed earlier. This problem may apply between separate parts of the major Aboriginal grouping, e.g. the Nyungar of south west Australia traditionally occupy parts of both South Australia and Western Australia states and are made up of fourteen different language groups, names of each of may be spelt differently; and some groups have distinctive albeit fairly minor differences in cultural practices[30]. These rural and remote community differences are little known to the greater population of Australian researchers.

To summarize this section, the problem for the researcher seeking data from rural and remote opportunities comprises a combined effect from barrier risks, of cultural competence; the time logistics and cost of negotiation and skilful engagement with the communities; and the unpredictable qualitative and quantitative value output

from an as yet undocumented and unquantified field of dialectal healthcare pragmatics.

3.8 Design challenges as problems

For successful ICT systems adoption aimed at equitable intercultural knowledge sharing a formal sequential task process must be followed. Tomiyama et.al writing of the field of Design Theory and Methodology (DTM) discuss several design methodologies, each representing a scientific knowledge building process which begins with collecting facts through observation [31]. At the outset I had several separate components and their sub-elements that in my earliest conceptual hypothesis are considered necessary to assemble and integrate into one main upper level application. This solves a perceived human interaction problem. At that abstract starting point my posture was that I should anticipate discovery of theoretical weakness and expect to modify my design thinking during the upcoming stages in the research process. For information systems to be useable and useful in an ICT applications format it is essential to imagine and conceive the end product. The concept components therefore must be capable of enabling machine agents to accept and fulfil explicit tasks that contribute to the overall design goal. In their goal-oriented requirements engineering paper van Lamsweerde and Letier state : ‘goals are to be achieved by the various agents operating together in the *composite* system; such agents include software components that exist or are to be developed, external devices, and humans in the environment’ [32]. Heavy reliance on the literature, as opposed to a quantitative observation exercise of Aboriginal patients in the PPIE setting, has predisposed this research to maintain the original hypothesis, i.e. the belief that there is a serious and harmful communications deficit problem.

While this has been reinforced by focus group and personal interactions with Aboriginal acquaintances and mentors, the relatively limited volume and pragma-semantic range of AE data collected so far may conceal information and knowledge residing within the rural and remote Aboriginal community cultures. It is known from the literature for example that regional variations of the AE dialect exist; but little has been published about regional or community differences in cultural

behaviour as a consequence of health care interventions. That source when tapped through future work may justify application model design changes and variants.

In 2008 Saab published a conference paper titled ‘An Ethnorelative Framework for Information Systems Design’. Writing about cultural values, he describes values as ‘the cultural heuristics that drive much of our behaviour’ and that ‘we’ are ‘conditioned by culture to selectively perceive and attribute meaning to all of the objects, phenomena, and spaces we encounter every moment of every day’ [33]. He is emphasising the importance and influence of intended system users on the success or failure of a model for system design. He poses the following model design questions respectively under Embodiment, Information and Technology:

- How are cultural values embedded within cognition?
- How are cultural values embedded within information?
- How are cultural values embedded within technology?

The implications for design and a potential problem in this context surface as the preconditioned cultural bias and preferences on the part of the researcher. In this work by a non-Indigenous researcher that represents a risk; that may manifest itself in end-product conceptualization design flaws. Saab describes a scenario in which a United States designer with a cultural bias towards autonomy and individualism may find conflict with Guatemalan or Singaporean clients when designing a user interface. For the latter mentioned ethnicities personalization is less important than a single interface which reflects a harmonious collective user profile. The desirable objective for these cultures is reportedly very similar to that of the Australian Aboriginal people, for whom group tracking of processes and sharing of group goals are a priority.

3.8.1 Potential design problems related to technology acceptance

Although examples have been cited of the acceptance and use of ICT devices by rural and remote living Aboriginal people, the unknown issues that may prove problematic concern personal choice and the appeal or non-appeal of design features, especially if the design work is mostly determined by researchers and developers from a non-Indigenous background. A contextually helpful Australian doctoral thesis by Radoll contributes useful insight into technology adoption in Australian

Aboriginal households, including those in rural, urban and remote areas[34]. His findings relate to the refinement of the Technology Acceptance Model (TAM) which is an information systems theory on acceptance of new technologies by end users. Radoll refers to the original TAM principles stemming from work by Fishbein and Azjen's labelled theory of reasoned action (TRA) [35], and developed into the TAM theory by Fred Davis et.al [36, 37]. Radoll argues that TAM has led to some dysfunctional outcomes. His point is that TAM fails to take account of real human decision making dynamics. He favours the Venkatesh et.al version of model acceptance design theory titled the unified Theory of Acceptance and Use of Technology (UTUAT) [38].

Radoll conducted his research in urban, rural and remote Aboriginal communities and classified his findings as 'Inhibitors' and 'Motivators' for his interviews-based assessment of household acceptance of new technologies. Common areas of inhibition were found in each. These are described as

- 'Negative behaviour' which includes *substance abuse and poor financial management*
- Individual needs indicated *a preference for face-to-face communication*; and
- *Appropriate ICT training*.
- *Costs of acquiring and using ICT systems* were identified as an inhibitor; and
- *Racism factors* (experienced and perceived) were also a strong influence creating resistance to technology acceptance.

This is not an exhaustive list of Radoll's findings as there are many sub-propositions making up the acceptance problem, and apparent solutions, which will be discussed in the next Chapter. These do however coincide with the literature and focus group findings and represent the main practical Aboriginal data collection and contextualisation problems for the design and development of the PPAC system.

3.9 Problems with Aboriginal T2DM health care model delivery

The RACGP GLs provide a practitioner's model and processes for T2DM diagnosis treatment and care; but no specific Aboriginal culturally-oriented modelling is included in the guidelines.

From the research literature and government health care information sources it is possible to determine the general form of service model for patients in country areas including rural and remote Aboriginal communities. If an elicitation exercise permits construction of the unique circumstances and PPIE differences from the mainstream model of care, a fairly large list of variables affecting Aboriginal patient interaction will appear. Researchers have identified the need for adaptation of or more substantial change in, mainstream PPIE practices; in order to improve Aboriginal health care.

Humphreys and Wakerman in a comprehensive discussion paper report that ‘there is no one model capable of servicing the health needs of diverse rural and remote communities’ [8]. The paper criticizes the tendency for service providers to impose an urban health care service model on rural and remote patient communities. In common with other writers, they refer to impediments to primary and tertiary care that include

- ‘the tyranny of distance’
- lack of transport
- heavy cost burden on a dispersed population seeking access to care
- poor roads; and
- heavy reliance on ambulance services such as the Royal Flying Doctor Service (RFDS) and on the Patient Assisted Travel Scheme (PATs).

But the following paragraph from their discussion paper succinctly illustrates the central problem of the current service model:

‘...many small rural and remote communities require alternative approaches to health care and models of health service delivery different to those which have traditionally characterised rural Australia. Most importantly, service models must vary in order to take account of the specific geographical, social, economic and cultural contexts that differentiate the many rural and remote communities scattered across more than 71/2 million square kilometres and which are home to more than 7 million Australians’. [8]

Artuso et.al discuss health care utilisation (HCU) among Aboriginal cardiac patients in central Australia, reporting that ‘compelling barriers to HCU identified at the *Primary Care* and *Hospital System* levels included communication, organisation and racism’ [39].

In essence a key problem element of the existing model of care and my main focus is ‘communication’. In Chapter 1 I outlined the multiple inter-related meanings of communication. From that I outline three of Dance’s communications definition samples, i.e.

- Interaction/Relationship/Social Process
- Transfer/Transmission/Interchange; and
- Time/Situation help to expand understanding of the consequential effect of poor communications capabilities in the rural and remote health care delivery setting. [40]

3.9.1 Rural and remote telecommunications service

Australia has long experienced telecommunications limitations adversely affecting remote parts of the country. In 2012 the Australian Regional Telecommunications Independent Review Committee (RTIRC) received submissions and subsequently reported findings on rural and remote (collectively termed regional) telecommunications[41]. The report summary highlights the following coverage issues:

- A gradual decline in the number of fixed-line phone services over recent years.
- Indigenous Australians still suffer grossly disproportionate rates of disadvantage including inadequate digital literacy
- Regional consumers have concerns with customer service issues, including a lack of consumer awareness
- Reliability of communications during emergencies especially mobile communications, is a major concern
- In Australia, there is currently unequal access to healthcare services, particularly in remote and rural communities
- Predominant concern raised with the committee by regional Australians was adequacy of mobile voice and broadband services
- There are commercial limits to expanding mobile network coverage, but equally there is strong unmet demand in regional Australia for expansion of the mobile coverage footprint

- More than ever, people are demanding broadband through mobile devices
- The NBN Interim Satellite Service (ISS) offers immediate improvement in high-speed broadband availability and affordability to eligible customers
- The ISS will have capacity constraints but, given the benefits of better broadband services, the committee recommends a review of the program's eligibility criteria to enable remote schools, health facilities and Indigenous communities to access the ISS as soon as possible
- While telehealth offers great potential in the delivery of healthcare in rural and remote areas, there are barriers to the systemic adoption of initiatives

The Department of Broadband Communications and the Digital Economy (DBCDE) is presently pursuing investment in the Indigenous Communications Program [42]; and State governments are also investing in improved communications systems for rural and remote areas, for example the Western Australia Regional Mobile Communications Project (RMCP) [43]. The DBCDE has listed fixed phone services; mobile satellite services; and internet access and training as the priorities. Given the embryonic status of these infrastructure-based developments, the problem for the PPIE user environment is one of poor readiness. It is not yet prepared for equitable shared participation in health care applications and the essential cultural competence education need embedded in the remote services assistive communications system concept.

3.10 Healthcare service cultural communications transformation

Dependence on textual representation is at best unsafe for communications and cognition in health care settings involving patients with limited English proficiency (LEP). Where oral and body language tradition are the only or dominant forms of expression, ethnic cultures commonly hold a view of the world which conflicts with the communication conventions of the institutionalized western clinical culture.

Structured translation and linguistic based systems of interpretation require investment in contextualization methods in order to achieve shared understanding between two parties. Coming from very different formative learning environments

the patient and practitioner need access to a knowledge transfer system equivalent to a two-way pragmatic lingua franca.

Problematic for existing forms of type 2 diabetes health care in the subject communities is the lack of two-way oral and related pragmatic discourse. Audio visual methods of conveying information are rare, in common with the scarcity of documented or digitally recorded AE healthcare words phrases and other forms of mutually exchangeable cognitive expression.

The PPAC system will quite significantly depend on oral/aural and pictorial representations. These are yet to be physically and digitally created in order for it to have a reasonable chance of acceptance in and by the Aboriginal country communities. Such representations however are not freely available for use; in most instances because either they are extremely limited in number and applicability; or for specific treatment and care types they do not yet exist and have yet to be conceived and evaluated.

3.11 The validation model problem

In the first year of research activity the effort to bring structure to assistive communications on behalf of the Aboriginal rural and remote patient community, and thereby to prepare for machine-readable capabilities, was centred on a study of 'pragmatics'. Several authors have offered slightly varied definitions and guidance within their research work of the meaning of pragmatics, some in the realm of second-language teaching [44-47]. Bouchet (while citing others) provides an ample definition writing of the domain of pragmatics as:

'a scientific field often defined as the study of language in action, which deals with the study of the relations between what is said and the conditions of uttering, and pays therefore much attention to the context of reference, the situation of enunciation, the interpersonal pay., and (inter)-action'. [44]

Notwithstanding Bouchet’s chosen definition, the use of the word ‘pragmatics’ includes for my purposes the culturally based manner in which a conversation participant contributes to a personal interaction. The problem arising from validation of pragmatics comprises a complex mix of challenges to shared comprehension involving syntax, semantics, context, personal perspectives, and many known but often unknown differences of an experiential nature affecting interaction. In the process of concept discovery and mapping for ACT modelling and the construction of a supportive classification and relational system, this complexity was revealed as shown in my Figure 11 concepts map.

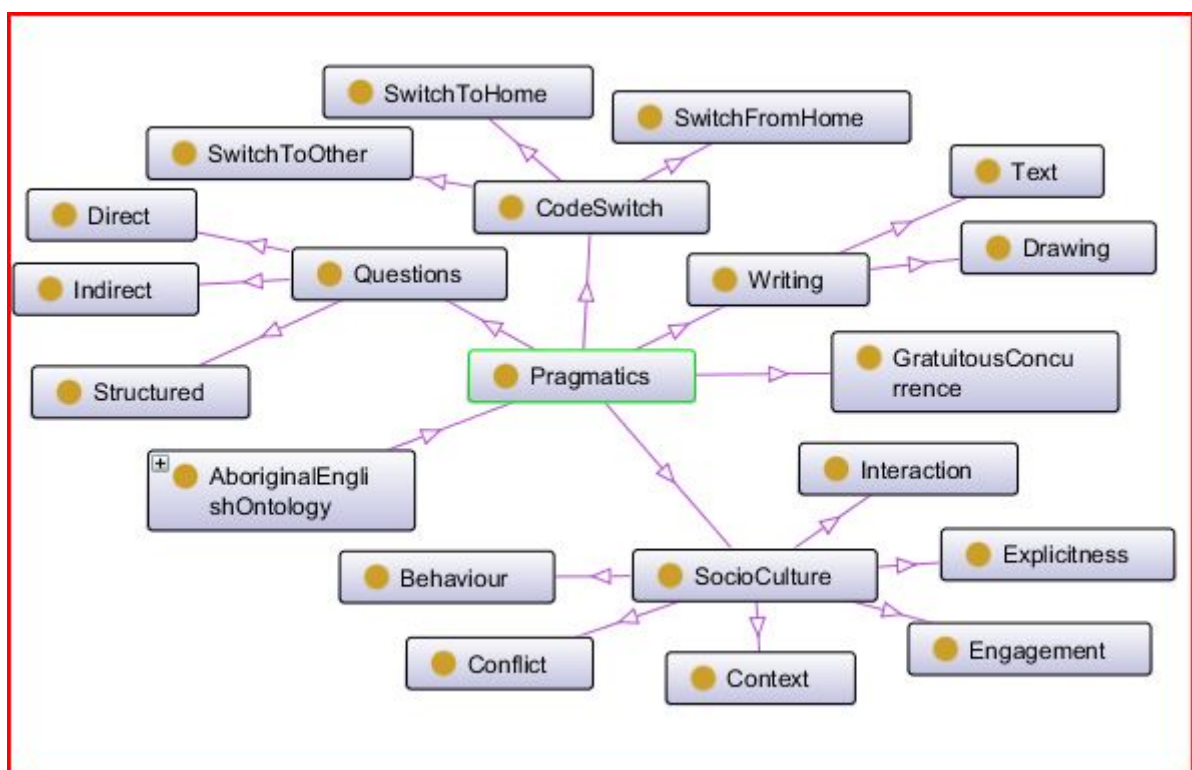


Figure 11: Early investigation Aboriginal communication pragmatics concepts map

With twenty concepts emanating from ‘Pragmatics’ the implications for greater complexity as a consequence of further sub-class concept development would create the risk of driving the course of research along tangential and expanding routes at the cost of constructing a useable framework for continued PPAC development. The overall framework approach is important to help secure objectives and goals.

The contemporary opportunities to flesh out the pragmatic lexicon to a valid source and communications instrument are seriously constrained for cultural research barrier reasons discussed earlier. The search for granular detail is regarded as a process to be dictated by the timing of other work, sufficient to move from conceptual framework to applications development. Validating the semantics and syntactic preferences with rural and remote dwelling Aboriginal people necessitates taking the field of pragmatics enquiry beyond 'home talk' and into 'health talk'. For this work I cannot rely upon urban Aboriginal sources alone; and future work aimed at quantitative scaled growth will require pragmatic knowledge testing in the communities that are the intended beneficiaries of PPAC.

3.11.1 ACT system evaluation

The design of an assistive communications system conceived as the PPAC will require validation testing. The framework is the foundation of the system and will not be presented in a commercial grade format that would involve end-user tests. The intention to take this work beyond the framework phase is discussed in Chapter 9. My design choice and process for this thesis as revealed in subsequent chapters rely upon software query testing of the mapped concepts and relationships. This work is reported in Chapter 8.

3.12 Summary of problems receiving priority

The primary research objective of a shared knowledge representation model and future development of intercultural communications systems stems from a triple-domain combination of communications needs; for improved Aboriginal T2DM care; use of AE pragmatics in healthcare; and more efficient equitable conduct of and outcomes from PPIEs. Present healthcare service methods in all three domains neglect investment in acculturative engagement systems and practices with the Aboriginal patient community; with the consequential overall effect of inadequate standards of communications and cognition.

Deficiencies in the primary care use of technologies to assist with communication challenges also deprive both T2DM patients and their practitioners of opportunities to capture relevant health status detail in a timely way. The processes and

discoveries which occur on the part of both stakeholder groups in the pre-encounter days and hours before an appointed PPIE; in the relevant post-encounter mental deliberations and physical experiences of the patient; are not systematically organized so that optimal healthcare data is shared and wellbeing outcomes improved. ICT is under utilized in this respect; and in the case of rural and remote Aboriginal T2DM patients few if any worthy options for improved and timely care exist that include the essential need for an Aboriginal English pragmatic lingua franca.

Meeting the T2DM mapping preparation sub-objective:

The abstraction of Type 2 Diabetes guidelines data for conceptual relationship, syntactic structuring and semantic mapping with Aboriginal cultural and Aboriginal English dialectal pragmatics is unprecedented; and without the benefit of prior documentation is a laborious manually conducted process exposed to risk of error. Clinical language is a major barrier to patient cognition with words and phrases presenting a conversion problem for concept mapping.

Conclusion: Design science and behavioural science in qualitative research mixed methods will help to locate and map schematic data.

Meeting the AE dialectal structuring for ICT objective:

Standard Australian English grammatical data constructs can create communications conflicts when cultural incompatibilities with Aboriginal English pragmatic healthcare data constructs are not recognized and/or inadequately accommodated.

Conclusion: Research and design work will mitigate conflicts by incorporation of AE healthcare semantics.

Meeting the bi-directional communications design objective: Analysis of Patient-Practitioner Interview Encounters (PPIEs) for the purpose of acculturative communications ACT design work is hampered by the absence of strong established and trusted research relationships with the country Aboriginal communities affected by the overall communications problem.

Conclusion: This can be overcome through focus on data gathering from qualitative evaluations including a small scale well-informed Aboriginal focus group.

The urgent necessity to improve chronic disease management and self-management applies at a time when exponential growth of health care knowledge and consumer use of digital device applications threatens to further exacerbate the socioeconomic ‘digital divide’ disadvantages affecting rural and remote Aboriginal communities.

Together these causes, effects and problems must be overcome in order to successfully combat the principal problem of inequitable communications in Aboriginal health care; thereby addressing the manifestation of the problem of unsatisfactory T2DM Aboriginal patient wellbeing outcomes.

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Chapter 4: Healthcare communications barrier solutions

4.1 Introduction: Behavioural Science and Design Science

This Chapter provides elaboration of the solutions design rationale. Prior to and relevant for subsequent chapter discussions on the conceptual framework, proposed ontology construction and domain schema sources, it begins to show how the methodologies employed toward solving the central target problem of PPIE communications involving Aboriginal T2DM patients were selected. The sequence of sub-objective discussion is changed for the solutions approach, placing T2DM and AE solutions later in the chapter. Priority is given to the primary objective, by examining the ACT capabilities and application potential from ontology support; and finding the human behaviour and interaction factors that subscribe to the PPAC system goals for PPIEs. Once these ‘delivery system’ components are identified together as the primary objective solution vehicle, the two domain schema can be systematically mapped to complete the framework solution.

Recognizing the interdisciplinary nature of this research, the work of Hevner and co-authors is worthy of scaffolding design support for the framework. More particularly, a significant commonly cited paper published in MIS Quarterly (MISQ) authored by Hevner et.al provides a substantive theory of note to aid me in my solutions orchestration [1]. This includes some opening observations about the MISQ Journal somewhat but in constructive vein inferring bias in its published research disposition linked to shifting perspectives on the use of technology:

- MIS Quarterly research often focuses on the behavioral-science paradigm.
- It presents a passive acknowledgement of technology, *‘often ignoring or “under-theorizing” the artefact itself’*.
- When MISQ research articles describe the implications of technology and its impact on individuals, groups, and organizations it regularly includes studies that examine how people employ a technology.

- MISQ reports on benefits and difficulties encountered when a technology is implemented within an organization; and discusses how managers might facilitate technology usage.

The authors go on to argue that acquiring knowledge to help with productive application of information technology involves complementary but distinct paradigms. Characterizing research in Information Systems (IS) they contend that two paradigms, behavioural science and design science, make up much of the discipline. They qualify this by referring to the IS discipline being ‘positioned as it is at the confluence of people, organizations, and technology’. Fundamentally a problem-solving paradigm, design-science seeks innovative ideas, practices and technical capabilities and thereby product outcomes drawing upon design, implementation, management and use of information systems. They affirm that ‘Such artifacts are not exempt from natural laws or behavioural theories’.

The Hevner paper conveys the perception that the combination of intellectual and computational tools can enable IS researchers to make a significant contribution ‘by engaging the complementary research cycle between design-science and behavioral-science’. Citing others (March and Smith)[2] the authors write of two design process and four design artifacts produced by design-science research in IS. In the original paper cited, March and Smith refer to dimensions. The first is based on broad types of design and natural science research activities: build, evaluate, theorize, and justify. The second is based on broad types of outputs produced by design research: representational constructs, models, methods, and instantiations. Hevner et.al choose to describe a shortened version of the first dimensions, as two processes, i.e. build and evaluate. Keeping the second dimension intact, they list these four as design artifacts.

From this research paradigm base, Hevner et.al claim that ‘the goal of behavioral-science research is truth’; and that ‘the goal of design-science research is utility’. Figure 12 offers a basic depiction of the PPAC design solutions coactive constituents merged into the behavioral-science and design-science research combined paradigm.

Paraphrasing Hevner et.al, I am illustrating visually how to ‘engage the complementary research cycle between design-science and behavioral-science’

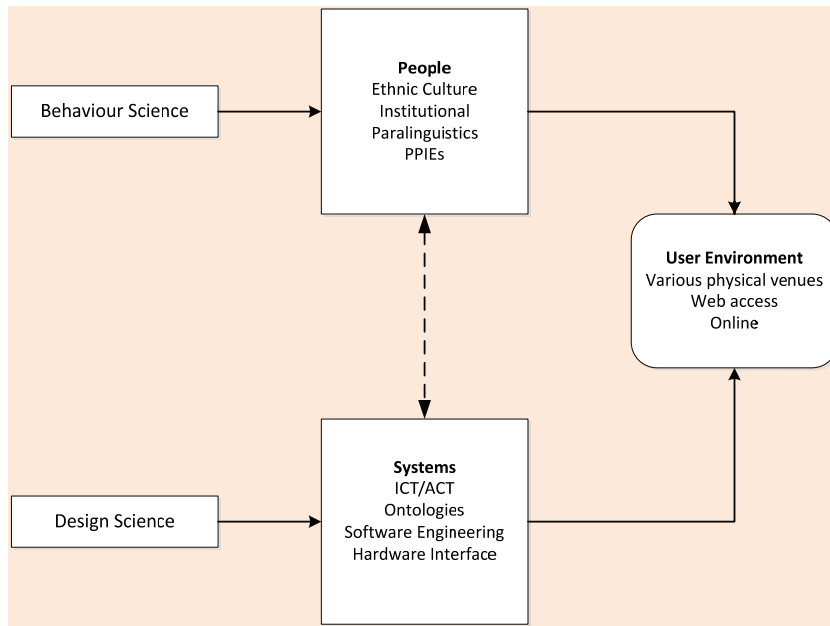


Figure 12: PPAC design solutions complementary coactive constituents

4.1.1 Problem-matching solutions orchestration

Information systems and their data sources constitute the major portion of, and introductory process for knowledge acquisition, knowledge assimilation and knowledge dissemination. The transition process from schema and database repositories of information to an intelligent, semantically dependable, true and precise source of knowledge is commonly littered with intricate diversions, complexities and anomalies. This is markedly the case when disparate domains have little or no historical depth of reciprocal investment in the development of practical formulae designed to overcome intercultural health care communications barriers. The search for ‘perfect’ knowledge is not necessarily the goal for researchers and designers who seek a solution to counter problems which are made up of a combination of flawed communications elements. Similarly, it is important to resist the temptation to believe that concise solutions are absolute and enduring. The goal is not perfection; it is progress towards perfection. Information systems provide the fuel for the ‘fire of creative imagination’; but converting that fuel into knowledge that justifies hypothetical concepts is a process of trial and error. End to end concept alignment, relational development and execution of a user-application; in a presently

under developed, almost non-existent plane of communication, must begin with a conceptual framework. In itself that framework (this research) is a substantial undertaking prone to re-definition of objectives and the end-goal.

4.1.2 Overall problem-solving objectives

The plan for solving the problems set out in the previous chapters embraces the following:

- Framework modelling for patient and practitioner user ACT development
- Focus on ontology work in the communications barrier mitigation PPIE context
- Mitigation of type 2 diabetes discourse complexity
- Pursuit of a disciplined ethical protocol for respectful collaborative two-way supportive AE data gathering
- Construction of an integrated ontology; mapping T2DM guidelines with AE pragmatic

Utilizing the output from the foregoing, the framework objective is to combat dissonance through the introduction of assistive communication technology to support PPIEs. This includes the notional future capability to overcome distance logistics challenges affecting rural and remote patient communities, e.g. telehealth compatibility for Aboriginal patient clinics.

4.2 Ontology as a framework solution foundation

This work aims to gain a firm foothold on the lower steps of the climb toward artificial intelligent (AI) computing, in which researchers and developers strive to achieve a workable man-machine relationship through simulation of hitherto uniquely human personality communication and interaction traits, reflected in the coactions abstract concept. It is important to remember that semantics, emotion, empathy and time are concepts and therefore are not constrained by the limitations of their vocabulary role. Although semantics, emotion, empathy and time may in time contribute to computer-simulated human behaviour output, as concept elements these serve as assistive navigational aids with relational attributes for devising human-machine communication schema influenced by contextualization.

Essentially the intended ACT will be supported by relevant values classified as domain objects; the properties (attributes) of those values/objects; and the relationships between them.

Accordingly this research embraces the unifying framework approach using computer ontologies to solve problems through agreement about shared conceptualisations. A key objective therefore is to assess the worth to this work of existing and prior communications related ontology projects; to learn from published accounts of their development; and to apply the most useful lessons arising from the constantly evolving and very active world of the semantic web.

The much cited originator of ontology in the context of computer and information science representational systems, Tom Gruber, defined ontology in 1993 as “an explicit specification of a conceptualization”. He also defined conceptualization as “an abstract, simplified view of the world that we wish to represent for some purpose”[3]. The World Wide Web Consortium (W3C) is an international community of diverse stakeholders and member organizations working together to develop high quality web standards for the benefit of all. Known as the Semantic Web in computer science the W3C standard provides formalisms for encoding ontologies (OWL)[4]. These enable the exchange of data among systems, query-answering services, publication of reusable knowledge, and services; in Gruber’s words ‘to facilitate interoperability across multiple, heterogeneous systems and databases’. This flexible, openly accessible, interoperable and reusable knowledge-sharing capability presents an ideal opportunity for development of assistive communications supporting health care. The fertile multicultural societal environment of web-based social media applications and services appears ready to take full advantage of improved articulation of health care knowledge. Today’s pervasive and growing demand for chronic disease management, imparts a degree of urgency to find alternative and assistive modes of PPIE that will replace traditional health care service consultations. The Type 2 diabetes and co-morbidity incidence and trend data compound that resolve for Aboriginal and ethnic minority patient communities.

The term ‘Ontology’ originates from philosophy, specifically the study of being or existence in basic category terms. Consequently it is used to refer to what exists in a system model. In computer science, ontology is the effort to formulate an exhaustive and rigorous conceptual schema within a given domain, typically a hierarchical data structure containing all the relevant concepts and relationships between those concepts. The need to explicitly represent and share increasingly complex information in electronic form has led to the creation of OWL 2 Web Ontology Language, informally named OWL 2. This serves ‘the Semantic Web’ through formally defined meaning in ontologies, documenting classes, properties, individuals, and data values. OWL 2 ontologies are primarily exchanged as Resource Description Framework (RDF) documents. The RDF is a family of World Wide Web Consortium (W3C) specifications based on a simple data model originating from a metadata system design.

4.2.1 Ontologies and the PPAC potential

PPIE is a distinct domain in which context is a core discipline for ACT coactions and relationships. Distant and closely related work by others will logically converge in time through delivery goal synergies and are likely to appear in optimal form and effect via Next Generation Networks (NGN) applications and devices. Gutheim [5] for example proposes the enrichment of mobile telecom applications through context information enabling cell phones to be context-aware. His context architecture model concept would provide high-level ontologies for context information and requires a distributed and registered sensor layer system that could possibly serve a mobile version of PPIEs. It is expected that ACT for PPIE development as the PPAC system will offer considerable user flexibility, so that time and timing factors now dictating many healthcare interactions will become redundant due to enhanced web service capabilities.

In the literature the subject of ontology in computer science, information systems and artificial intelligence has excited a large and very diverse field of study [3, 5-51][52]. In view of the diversity and rapidly evolving nature of global ontology developments it has been necessary to examine a great volume of work in order to find productive sub elements of information and practice knowledge.

The research knowledge gained about PPIEs involving Aboriginal patients shows the extraordinary complexity when a collision of cultures occurs in the domain of healthcare communication. The importance and criticality of securing accurate detailed information about the diabetic patient's condition, about the treatment and care options and outcomes, is an uncompromising standard that requires that explicit specification of the relevant clinical domain. Accompanied by the intent to achieve a simplified view of the world, implicitly a uniform perspective shared between Aboriginal patient and clinical practitioner creates a need for a design formula to overcome enormous complexity.

4.3 Ontologies as a potential solution to the problems enunciated

The recursive debilitating barriers for optimal PPIE outcomes confronting Aboriginal and LEP patients include healthcare provider time constraints that are common to all types of consultation [53-57]. These are compounded by cultural differences in interpersonal communication and by accompanying stressors arising from frustrated attempts at being understood in specific and contextual terms. The dominant paternalistic western healthcare system has also contributed to the barriers when a unidirectional 'doctor knows best' attitude has pervaded consultations and diminished opportunity for bi-directional equity. Aside from the culturally founded significance of a period of silence on the part of the Aboriginal patient, communications difficulties obviously consume PPIE time. In those instances when an interpreter is involved in the consultation, a variable additional consumption of time is imposed, dependent on efficiency factors that in turn are dependent on several dimensions of circumstance. It is abundantly clear that time constraints, with implicit and explicit cost implications demand much greater efficiency in PPIE productivity; and that the metrics for this do not rest on one dimension alone. Population and chronic care frequency growth impacting on health care consultation capacity is exacerbating the threat to PPIE efficacy. The ability to exchange reliable information while also accommodating idiosyncratic human communication variables; understand the intent, content and meaning of the exchange; and to secure best outcome opportunity must in essence be extensively bolstered by intelligent machine capabilities.

Upon analysis of the barriers as reported in the literature, I have sought to identify the most promising source of remedial and assistive concepts and systems that are capable of overcoming these obstacles while preserving the best and most valuable facets of PPIE in primary care general practice. The most fertile opportunity comes from the contemporary and projected ICT environment. There are researchers putting effort towards diabetes ontology development. In the following sections I contemplate the work of others for their conceptual contributions to the solutions formulae.

Chalortham et al. developed diabetes mellitus ontology which covers risk assessment, diagnosis and complication, treatment, and follow-up [20]. Based on the ontology the reminding system was developed as part of type 2 diabetes mellitus clinical support system. The diabetes mellitus ontology was developed based on Thailand Diabetes Mellitus Clinical Practice Guideline 2008 and suggestion of medical experts.

Buranarach et al. introduced the synopsis of chronic disease healthcare framework in which the importance of ontology for healthcare knowledge management system was pointed out [58].

Lin and Sakamoto developed Glucose Metabolism Disorder ontology which was classified into diabetes mellitus, diabetes complication, hyperglycaemia, hyperinsulinism, etc. [59]. The ontology was also linked to Geographical regions ontology and Genetic Susceptibility Factor ontology to describe the genetic susceptibility factors to Diabetes Mellitus.

Ganendran et al. developed ontology based multi-agent systems in which diabetes management was applied as a case study involving three agents i.e. specialist agent, patient agent, and web agent [28]. Shahar et al. developed Knowledge Based Temporal Abstraction (KBTA) focusing on shared knowledge representation and reuse [43]. However, none of the work focuses on assistive communications particularly for ethnic minority immigrant communications acculturation. In addition

there is no existing T2DM ontology developed based on Australian recognised professional healthcare standard guidelines.

4.4 The integrated design view

When considering the options available or potentially attainable for improvement in inter-personal cognitively equitable communications, the advent of new technologies and the societal receptivity to uptake of assistive devices invites the prospect of developing computer applications. Applications require software engineering activities, methods and practices of the design process to ultimately achieve implementation. Alonso writes that software development has become more demanding as applications have increased in complexity[11]. Because ontologies facilitate reliable definition of domain vocabularies and a working framework for both human and machine users and machine agent relations, they provide a means to reduce the complexity factor. Illuminating the several objectives and accompanying characteristics of ontologies making this attractive for software design and development, Alonso cites literature sources listing

Specification
Confidence
Reusability
Maintenance, and
Knowledge acquisition.

Citing several sources she also lists the benefits of using ontologies. Three of the benefits listed by Alonso of particular consequence for choosing ontology construction in this assistive communications system research are:

- *Ontologies allow for an easier knowledge acquisition process, by sharing a same conceptualization for different software applications.*
- *Ontologies allow to reduce terminological and conceptual mismatches, by forcing to share understanding and communications among different users during the ontological analysis*
- *Ontologies also provide for a refined communication between tools forming part of an environment. [11]*

4.5 Solution design goal rationale

Writing about the key strategies of semantic technologies, Cregan [Cregan, 2008] observes that if both structured and unstructured data can be directly linked in electronic form using a unique identifier, semantic technologies can work with them. Aboriginal English PPIE pragmatics comprises a voluminous and multi-level combination of structured and unstructured data. Noting that until quite recently information processing has been primarily at a syntactic or symbol processing level, Cregan leads her discussion into the promise of semantic technologies in using logical languages to provide explicit structure and meaning to data. Searching, querying and reasoning across interoperable ontologies could, for example, lead to automation of the assistive communications process. The aim for this work is to enable mapping of accurate information interpretation and explanatory annotations for the different cultural participants in the T2DM PPIE; with sufficient flexibility to stimulate the transfer of valuable knowledge through bi-directional interaction, described by the term equitability. In the following sections I entertain discussion of a number of offshoot design solutions which thereafter I set aside while focusing on goal priorities. These are however included in the framework explicatory breakdown because the fuller development and efficient use of the PPAC system consists of contiguous components each of which must be applications and functionally error-free. If for example the unique features of a telehealth/telemedicine PPIE interaction are overlooked and neglected from the design, communications barriers may not be overcome and the intended solution will be defeated. A simple case scenario for this would be the need to devise a walk-through menu with audio supported, dialect sensitive instructions.

4.6 Anticipation as a solutions discipline

Although the framework does not define the engineering detail, it anticipates a concise contribution and instruction to aid the process of software and hardware interface design. As shown in Figure 13, the ontology and ACT ecosystem priorities comprise five key areas of linked research and development activity, from concept to output. The principal offshoots considered as important to include in the solutions discussion context come under the category of Interoperability. These offshoots are listed with summarized descriptions of contiguous related solutions areas in Table 4.

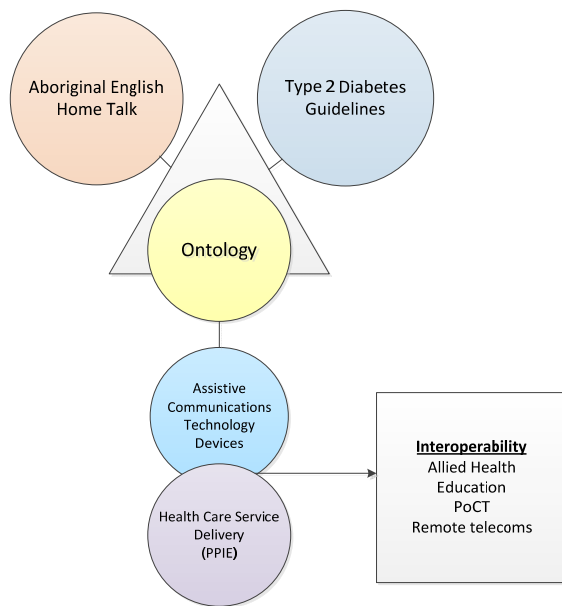


Figure 13: PPAC Research and Development Ecosystem

PPAC Design – Interoperability				
Allied Health Professionals	Education (inc. health literacy)	Point of Care Testing (PoCT)	Remote telecoms & telehealth coverage	
Impact on existing work practices, ICT systems, retraining requirements	Professional synergy and synchronicity with teaching and learning processes; training of carers and interpreters	Digital communications system compatibility. Standards and protocols, ongoing development and change in technological diagnostic capabilities	Coordination compatibility and integration with digital communications systems	

Table 4: Contiguous PPAC Design – Interoperability Solution Offshoots

4.7 Building the solutions framework

In the design formula search and research process, epistemology, the theory of knowledge, embracing methods, legitimacy, and scope; combines with **ethnography**, the scientific depiction of people customs and cultures. Saab’s paper introduced in the problem context in Chapter 3 of this thesis goes on to discuss design implications and the use of cultural analysis as a tool in the design process[60]. He cites Andrew Dillon who in a 1998 paper expanded a debate about

the value of cultural analysis in systems design. Dillon appears to hedge his position in favour of cultural analysis having a design contribution value while holding the view that some researchers are correct in their conclusion that it ‘yields knowledge perceived to be of little value by system designers’ [61]. He believes that system developers make errors that ‘systematically bias designers’ outputs’.

The key areas of Dillon’s effort to critique other articles on this topic concern two principal errors described as ‘the classic problem of designers assuming that users are somewhat like them’; and ‘the designers’ view of social life being describable in terms of rules, albeit complex rules, which enable interaction to be predicted’. He spends some of his discussion on the conflicting perspectives between social scientists such as ethnographers, and system designers, stating that the former are not trained to be system designers and are not usually required to deduce the relevance of their findings to this domain. Fifteen years on from that statement I do not believe it to be entirely true in the contemporary environment where IS/ICT and ACT design disciplines are being more frequently exposed to interdisciplinary research and their end products used by a large, diverse and growing consumer population. The author however is correct in saying that ‘the leap from data to design implication is complex’. Subsequently Dillon writes ‘an applied social science is of necessity a partial repackaging of the science base, as civil engineering re-packages physics, social work re-packages sociology etc’. Moreover, he effectively makes the call for social scientists to be trained about software development so that they can become more personally involved in the design process. Dillon does acknowledge that designers are able to understand that users are different and hold a different worldview from them; but he also makes the point that this does not always act to prevent or mitigate user stereotyping.

The foregoing provides a strong hint rather than an explicit direction on embedding component solutions within the overall design solution goal. Saab’s more recent ethnorelative framework ‘cultural geography’ design-offering points to the potential for an ‘integrative analytical framework for design, implementation, and use of IT on group, organizational and national levels’. He reminds us that IS design methodologies have potential for economic, technical and organizational changes;

and that built-in value biases reflect the values of the developer culture. Understanding cultural assumptions therefore assists with qualifying the disciplines needed to apply in order to bring design framework concept(s) closer in scope to the intended end-user worldview; and in so doing, to negate the risk of creating a culturally dissonant application. Most obviously, as non-Indigenous researchers we have to be consistently ready and able to ensure that communications semantics and reasoning design work adhere to the worldview and pragmatic perspectives of Aboriginal English speakers.

4.7.1 Cognition and Communication

The achievement of understanding, combined with justifiable mutually shared confidence in the intended semantics of a conversation between two people, is an elusive outcome when cultural distance barriers are involved. The morphological pattern of conversation cannot be predicted when entering into a phase of discourse between a health care provider and a patient of a different culture. If there has been no prior encounter the barrier to shared cognition will be greater as there is no experiential foundation that would otherwise contribute in some part to the interaction.

4.7.2 Health literacy accommodations

I have previously discussed the health literacy dimension. The health literacy (HL) of the T2DM patient is a component that may at its extremes either mitigate or exacerbate care complexity, influencing PPIE efficacy and the consequential effect on outcomes. The World Health Organization (WHO) adds its own interpretation reference included here as a reminder:

'Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' [62].

Several inconclusive studies have examined the possibility of a relationship of cognition with health literacy, a factor to be taken into account when assessing the potential for introducing a new health care communications interface for the benefit

of and use by, T2DM patients [63, 64]. Within the T2DM population there is no indisputable data to suggest that the disease alone directly causes or contributes to cognitive decline. How cognitive decline evolves remains uncertain. For the purposes of this research I assume that the majority of the patient pool for whom enhanced communications support is intended will not be suffering from impaired cognition.

Schwarz studying the logic of conversation declares that ‘there is a distinction between the semantic meaning of a sentence and the pragmatic meaning of an utterance’ [65]. He further observes that researchers’ evaluation of the judgements of conversational participants mistakenly draws upon the logical implications of semantic meaning. Where researchers themselves are participants, they fail to attach significance to the pragmatic implications of their own utterances. He points out that for a particular utterance to be understood, the intended meaning requires extensive inferences on the part of listeners. The speaker must provide those extensive inferences when devising an utterance for comprehension by a given listener. Inferences rely upon a set of tacit assumptions.

Schwarz directs us to these assumptions as the four maxims expressed by Grice, who introduced concepts of the logic of conversation in a series of lectures delivered at Harvard University in the 1960s [66]. Although Grice opened the way for considerable ongoing debate ranging from agreement to dissent, his work does provide a valuable contribution for communications technology researchers. Coiera’s Guide to Health Informatics provides further background supporting the Grice philosophy [67]. Coiera asks: “How is that agents, whether they are human or computer, manage to communicate effectively given the inherent limitations of message exchange?” Noting that poor communication can have a profound negative effect on health care delivery, he further enquires as to the nature of ‘a good message’. Grice’s suggestion, he reports, is that ‘well- behaved agents all communicate according to a set of rules leading to mutual understanding’. Formal logic justifies deduction from a set of axioms.

The core of the PPAC functionality is to support conversational semantics, albeit intercultural and inclusive of non-verbal forms of communication. I take Grice’s maxims into account as a guide towards bringing disciplined reasoning in building

the ontology relationships between unstructured and semi-structured data and concepts. The edited version reads as follows:

Maxims of Quantity:

1. Make your contribution to the conversation as informative as necessary.
2. Do not make your contribution to the conversation more informative than necessary.

Maxims of Quality:

1. Do not say what you believe to be false.
2. Do not say that for which you lack adequate evidence.

Maxim of Relation:

1. Be relevant.

Maxims of Manner:

1. Avoid obscurity of expression.
2. Avoid ambiguity.
3. Be brief.
4. Be orderly.

Schwarz also offers his 'Rules of the Communications Game' reproduced here as Table 5.

Communicators should:

1. *Take the recipient's characteristics into account;*
2. *Try to be understood (i.e., be coherent and comprehensible);*
3. *Give neither too much nor too little information;*
4. *be relevant;*
5. *Produce a message that is appropriate to the context and the circumstances;*
6. *Produce a message that is appropriate to their communicative intent or purpose;*
7. *Convey the truth as they see it;*
8. *Assume that the recipient is trying, as much as possible, to follow the rules of the communication game.*

Recipients should:

1. *Take the communicator's characteristics into account;*

2. *Determine the communicator's communicative intent or purpose;*
3. *Take the context and circumstances into account;*
4. *Pay attention to the message and be prepared to receive it;*
5. *Try to understand the message;*
6. *Provide feedback, when possible, to the communicator concerning their understanding of the message.*

Table 5: Schwarz ‘Rules of the Communications Game’

Author’s Note. Adapted from McCann, C. D., & Higgins, E. T. (1992). Personal and contextual factors in communication: A review of the 'communication game'. In G. R. Semin & K. Fiedler (Eds.), Language, interaction, and social cognition (pp. 144-172). Newbury Park, CA: Sage. Reprinted by permission.

(Original Schwarz Table 2.2) [65]

4.7.3 Patient Practitioner Interview Encounter stepped-process solution

Although the PPIE sub-objective has been described as the third in sequence, the subject is introduced here in the solutions building context because both the first (T2DM) and second (AE) sub-objectives are domains that in the framework architecture must be designed to fill the problem gaps and serve the functions within the PPIE. It is first necessary to identify and select mapping characteristics and relationship attributes based on the intended assistance that the PPAC will offer and deliver in the PPIE.

Building on the Frankel and Stein Four Habits model[68] cited in Chapter 2, in 2010 I devised part of a computer ontology output structure for Aboriginal patient-practitioner information exchange. This placed greater emphasis on the introductory and closing phases of the PPIE, resulting in six sequential components[69]. The opening ‘Habit’ of these is proposed as Patient Social Engagement (PSE); and the closing ‘Habit’ is the Self Management Compact (SMC), and these enclose the original Four Habits from Frankel. The PSE recognizes the value of empathy leading into the patient narrative contribution; the Aboriginal story-telling preference commonly referred to as ‘Yarning’ and a helpful element for an engaging, friendly (therefore non-threatening) dialogue [70]. The SMC denotes agreement on the shared

responsibilities and mutual trust as concluded at the end of the PPIE appointment session. The patient promise is to adhere to the professional advice on self-care recommended by the practitioner; the latter undertakes to ensure that the patient's progress is monitored and care plan adjusted according to prevailing need. The adapted PPIE 'Habits' version at Figure 14 shows the process as six 'pavers'

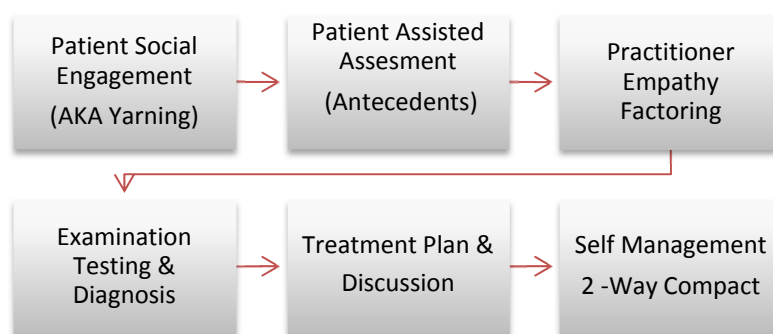


Figure 14: PPIE Habit Process Pavers

The first focus of attention for the work here is on 'Elicit the patient's perspective', in which the physician through social engagement asks the patient to help the PPIE process, seeks patient and family ideas, opinions, anxieties, and checks on context such as life or lifestyle impact. Under 'Payoff' the Frankel habits table lists respect for diversity, patient important diagnostic clues, uncovering hidden concerns use of alternative treatments, requests for tests, and improved diagnosis for depression and anxiety. Provider empathy is seen as an important and changing ingredient in the PPIE as promoted by the authors, with the payoff of adding depth to the visit, building trust to improve diagnostic and treatment adherence quality and facilitating limit-setting.

4.8 Building the ontology for PPAC

Embracing the tenets found within the foregoing ontology discussions, the construction of the PPAC ontology seeks to solve the problems that are to be addressed by the first and second sub-objectives.

4.8.1 Overcoming Type 2 diabetes communications complexity

Supporting the first listed sub-objective requires focus on the T2DM complexity challenges. In this context the needs of the Aboriginal English speaking patient

community are kept constantly in the solutions focus; while taking account of the struggle of the general population to understand the language and messages generated from within techno-professional cultural entities. The literature on engagement in the PPIE shows that Aboriginal patients want their providers to explain their illness, implications of condition and disease, and the rationale behind recommended treatments and care plans [71-78].

Much of the published research and comment on this is found under the descriptive title 'cultural safety'. Within the sphere of unsatisfactory encounters is reference to the use of medical jargon; side conversations by health care staff *about* rather than *with* the patient or the patient's carer. Consequential confusion, lack of confidence in service providers and other negative effects have contributed to less than effective care and wellbeing outcomes. The use of techno-clinical words can be interpreted as concealment of negative news for the patient, thereby creating suspicion that the patient is not being fully informed. For the purpose of assistive technology applications accuracy completeness and articulation of clinical information should be accessible to patients without arbitrary constraints being applied. Web search trends on health care tend to support this need. The historical paternalism of western medicine can no longer safely limit patient and patient community access to or understanding of, medical terms. The health and healthcare communications complexity solution lies within the already complex and demanding sphere of pragmatic simplification.

Interpretation and translation of clinical terminology into simplified language present serious difficulties and time consumption demands for the processing of natural language compatibility with machine-reading capabilities. This becomes more involved and difficult for assisting communications with and within minority ethnic groups and dialect speakers in disadvantaged communities. Where accredited culture-specific medical dictionaries or thesauri sources do not exist, as in the case of Aboriginal English speakers, a significant research and study effort is required; i.e. before the ontology mapping subject of this thesis can be developed *to fuller effect*, it must be taken beyond the conceptual framework to a greatly enriched viable user application status.

4.8.2 Simplifying T2DM care guidelines

The main attention for addressing clinical terminology as a barrier to communications begins with a lexical deconstruction of the foundation source, the Diabetes Australia/RACGP type 2 diabetes care guidelines. More generally known as Clinical Practice Guidelines (CPGs) a large number of these professional health care practitioner source documents exist globally as systematically developed assistance tools. Each has been devised for specific clinical circumstances and is supposed to represent appropriate professional instructions on health care service delivery. Graham and Harrison however, in a 2005 paper calling for more evaluation and closer scrutiny on the quality of published guidelines, advise that clinicians are having to choose from many and sometimes contradictory, guidelines [79]. The authors promote detailed quality criteria but maintain the clinician culture interest in their perspective, making no reference to any role on the part of the patient.

The date of the Graham and Harrison paper is purposely mentioned as a further observation about the changing pattern of patient-centre care, web based consumer health care data searches and more frequent elaborative research on the desirability and potential efficacy of self-management. Self-management assumes the ability of the patient to make good decisions. That capability comes from being sufficiently educated in the guidelines mode of preventive and treatment care processes; and from applying the skills necessary to comply with the practitioner's best advice. Eight years later van der Weijden et.al pose the title question: "How can clinical practice guidelines be adapted to facilitate shared decision making?"[80] The authors undertook an exploration through a qualitative key-informant study involving three principal 'opinion leaders' comprising health professionals using specific care CPGs; developers, researchers and policy makers specialised in CPGs or Shared Decision Making (SDM) ; and patient representatives who closely collaborate with relevant (Netherlands) health care institutions. Interviewees suggested three generic approaches to facilitate SDMs, to be described in a special, separate, CPG chapter. This chapter would make the patient' involvement in the decision process explicit to all; i.e. published in plain language. It would also encourage practitioners to use the same plain language in referral letters to their colleagues. A patient CPG chapter

version was then explored, with several different formats suggested. The first of these listed in the paper is that which is most suited for my purposes as it provides the simplest description and goal: *‘Patient versions could be entire CPG documents translated into lay terminology that would be useful to professionals and patients’*.

In the final discussion part of their paper van der Weijden et.al hypothesise that the most fruitful approach for fostering SDM is to adapt CPGs instead of producing new independently applied tools. The authors confidently concluded that their study had demonstrated how their key-informant opinion leaders are able to offer a variety of strategies to successfully adapt existing CPGs. The study did not however aim to achieve consensus and ended up with an extensive list of strategies, some regarded as contentious. But it is interesting to note their claim that so far as they have been able to determine, no strategies exist elsewhere for the use of CPGs to involve patients in clinical decision making. The foregoing did not involve intercultural, LEP-type challenges but indicates that investment in simplifying GLs as proposed in my research, is a viable solution to overcome the terminology barrier.

The framework solutions approach to T2DM complexity is to use an incremental, protracted, process for simplifying GL terminology. This seeks to move the textual data from its medical culture language to a point where it is as close as possible to synergy with pragmatic Aboriginal English. The RACGP GLs[81] however are resistant to pragmatics translation as they are not structured to aid conversation with patients, regardless of inter cultural or cognitive ability factoring. Accordingly my solutions process has adopted an annotations development approach, which has the dual benefit of enabling population of the ontology properties and individual instances schema. At the first solutions step stage, while working from the RACGP GLs as the disciplined foundation, I have trawled, analysed and appropriated English words and phrases from several other accredited varied and relevant medical language sources. [82-87]

The solution output from this is initially a set of type 2 diabetes care annotations that do not immediately accommodate the equitable PPIE design goal. In that ultimate equitable conversation solutions-search situation several streams of parallel activity

apply that will eventually converge at the design goal point. Chapter 2 referred to one facet of this as the sharing of a common language between two parties from different language cultures. Ontology construction offers an efficient solution to support this ‘Lingua Franca’.

4.8.3 Establishing an Aboriginal English healthcare Lingua Franca ontology

Tackling the second sub-objective involves concentration on finding available pragmatic AE expression in the form of healthcare discourse for inclusion in the bi-directional PPAC ontology. Whereas the T2DM guidelines are an orderly structured source, the process of transition of usable schema from clinical terminology to a PPIE lingua franca marriage of AE and SAE is confronted with much less structure and with an abiding non-taxonomic influence. To secure an application in a manner that will serve the purpose of increased cross-cultural cognition and equitable engagement with and between Aboriginal English patients and their healthcare practitioners much attention must be given to semantics. Within the semantic domain intricacies arise from variables such as implicature, metaphors, euphemisms and the complication of the uniqueness of each PPIE.

Reflecting understanding of the influence and status of health literacy as covered in Chapters 2 and 3, it is proposed that in the professional clinical aspect of the dialogue, the prospective ontology constructs can only rely upon mapping SAE diabetes guidelines to a newly created AE ontology. This intermediate matching and mapping process is required for ease of translational transition so that the parties to the dialogue eventually both share the same understanding. Inversely, the AE dialogue ontology, mapped to SAE clinical reporting, will be used to inform and advise various concerned local and remote healthcare practitioners/entities. This advice and information may include patient and family AE-generated responses, while preserving clinical meaning and healthcare value. In sum, the process objective is semantic interoperability. It is therefore vital that semantic translation accuracy is anticipated and protected throughout the design process. Semantics alone however are not the only challenge. Any ontology serving this function will require interoperability with a syntactic layer capable of dutifully representing the context of the cross-cultural dialogue.

The two contributory domains are viewed as constituencies containing key upper level markers as openings to solutions pathways. The solutions-driven concept maps for the two principal domains of Aboriginal English Home Talk, to be extended in context to ‘Health Talk’; and Type 2 Diabetes Mellitus (T2DM) are shown in figures 15 and 16 respectively. These concept maps have been produced as a late stage revised starting point of the ontology construction process. They represent a distillation from much larger sets developed earlier in this research and work intended to reduce tangential clutter, to finetune and make more viable the solutions pathways. These illustrations also introduce the entry gateway for building the merged ontology, identifying key areas for defining semantics, attributes and their reasoned relationships to help pragmatically bridge domain disparity and achieve the cross-mapping objective.

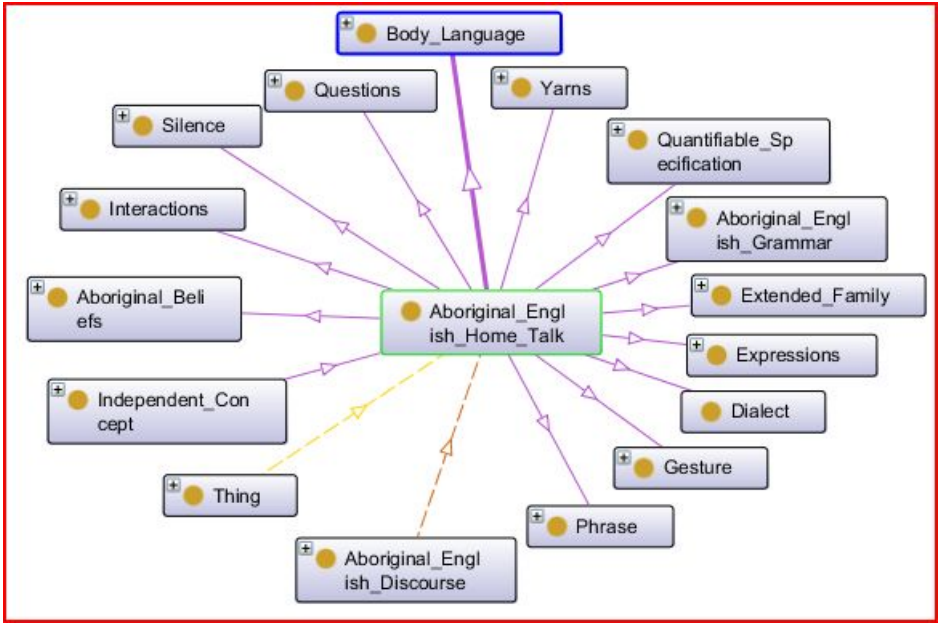


Figure 15: Aboriginal English solutions constituency concept map

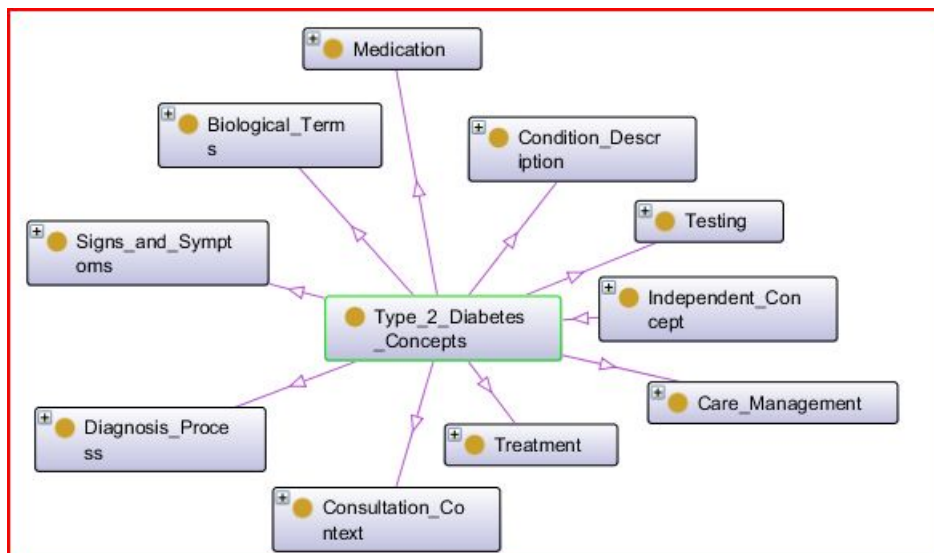


Figure 16: T2DM care solutions constituency concept map

4.9 Non-taxonomic data

Ontology development is largely based upon taxonomic structures. Taxonomy is an academic discipline of ancient origin for defining groups by name with related rankings and characteristics. Originally devised to categorize biological organisms, taxonomy has been adopted to apply to classification of almost any entity, tangible or intangible, including and most particularly in this research, concepts and the relationships between them. Among computer science researchers this is accomplished through ontology.

It has been essential to examine the output of others who have worked toward unravelling the non-taxonomic modelling issues. Few authors if any address the exact or closely related independent ontology domain sufficient to share enough data and achieve concise clarity from work already done.

Maedche and Staab recognized that defining non-taxonomic relationships consumes much of the time in the ontology engineering process[88]. Using a generalized association rule algorithm, the authors introduced a new approach for mining non-taxonomic relations from text building. The main focus of this work was time-saving and identifying prospects for automatic discovery from domain data and domain-specific natural language texts in particular. Some of the ‘menu’ headings described by these authors, while evidently relying upon organized data sources, are

useful signposts to possible methods that may in part be adapted and used in a manual abstraction process:

Shallow Text Processing; Generic German mining process

Tokenizer – Text scanning to identify boundaries of words and complex expressions;

Lexicon – Source containing 120,000 stem entries and more than 12,000 categorization frames;

Lexical Analysis – morphological analysis; name recognition; domain-specific information retrieval; and part-of-speech tagging.

Weichselbraun et.al agree that ‘identification and labelling of non-hierarchical relations are among the most challenging tasks in ontology learning’[89]. They attempt an automated bottom-up approach in which verb vectors are first extracted from semantic relations identified in the domain text, then aggregated by computing centroids for known relation types, storing these in a knowledge base (KB). In their research the authors emphasize the growing importance of identifying semantic relations. They comment on the work of others to this end, in which WordNet sense keys and tailored Google queries are used, in the latter case to obtain a large set of verbs, prepositions and conjunctions that were found in sentences that included a target pair of nominals, i.e. words that share features with nouns and adjectives. In their experiments, Weichselbraun et.al drew upon news media sites, using a suite of web mining tools to crawl directories.

Sanchez and Moreno write of learning non-taxonomic relationships from web documents, observing that the discovery of non-taxonomic relationships is often neglected despite its fundamental value in domain knowledge construction[40]. Advocating automated ontology learning they state that reliance on domain modellers and engineers is overwhelming due to size, complexity and dynamicity of a specific domain. Their viewpoint is expressed thus:

From a formal point of view, an ontology boils down to an object model represented by a set of concepts or classes C , which are taxonomically related by the transitive IS-A relation $H _ C \cdot C$

*and non-taxonomically related by named object relations $R * _ C$
· C · String. Even though many approaches for ontology learning
have appeared during the last decade most of them mostly focus
on the automatic acquisition of C and H and often neglect the
importance of non-taxonomic interlinkage between concepts [40]*

These authors justify the Web as a valid learning repository but they point out that complex text processing tools are not practical for accessing the knowledge within such a large data source. They warn of misinterpretation of text and natural language ambiguity risks from simplistic shallow analyses. Their argument is that an efficient analytical process can be performed if information from each resource is reduced to a minimum, whereby the nearest context of a queried concept will be evaluated. They refer to the product of such exercises as ‘text nuggets’, allowing relevant results from analysis without an exhaustive review of the entire text.

Whereas the foregoing published work on building non-taxonomic relationships in ontology provides direction for Web and other digital format text mining, it has limitations for identification and collation of relational concept data from non-electronic sources. The articles cited however are of value as guides to important priorities when constructing new and perhaps novel conceptual relations. Serra and Girardi add some illumination to this process while also concurring with the other authors on the time and cost impact of manual ontology construction by domain experts and knowledge engineers[90]. They write of two fundamentals in ontology learning, the first being the availability of prior knowledge. In this instance my work meets their qualification option that the T2DM AE ontologies each transform data into the first version ontology. The second fundamental is the source type, i.e. unstructured, semi-structured or structured sources.

In the cross-cultural health and PPIE scenario where the appropriate Aboriginal English dialect is undocumented and unpublished in any sizeable form, conceptual relationships must be formalised from scratch. The T2DM guidelines ontology stems from an unstructured source with the capacity to link to semi-structured sources such as dictionaries and thesauri that can help to simplify bio-clinical

terminology. The Diabetes Australia/RACGP T2DM guidelines are presented as a natural language Standard English text document available online and in print.

The tentative translation transition from medico-technical words and explanatory sentences to the required lingua franca for the Aboriginal English speaking patient interaction with formal English speaking practitioner passes through several stages. These have no direct specific precedent in published research on Aboriginal English. Anticipating this I have discounted the possibility of employing software tools for data mining in search of taxonomic and non-taxonomic relations. I rely instead upon analysis of a varied volume of accredited Aboriginal English education materials; the Aboriginal nurse focus group transcript, and personal advice (not cited) offered by members of the Aboriginal community in south west Australia.

Abiteboul has been heavily cited in the discussion about querying semi-structured data in electronic form[91]. His initial view is that semi-structured data is neither raw data nor very strictly typed as in conventional database systems, but he regards this as too imprecise. He advises that there is a need for semi-structured data and that this arises naturally in the data integration process. Documents that come as plain text require ad-hoc analysis to extract the structure; but the structure will remain partial.

Initially the T2DM guidelines source were treated as structured but as this is not a database schema per se, a revised view is that in the raw natural language non-electronic data context it is better regarded as semi-structured. This conclusion therefore permits some freedom when allowing for the need to create relationships that depend upon sharing the Aboriginal worldview of both type 2 diabetes and of the healthcare service delivery domain. This worldview influence extends to health care self-management concepts that are currently evolving and are both explicitly and implicitly present in the formal T2DM guidelines; but presently have no contextual or functional equivalent in AE data sources. The ontology engineering design process is intended to bring a more exacting structure to the self management aspect.

Serra and Girardi cited earlier propose a process making use of natural language processing (NLP) and data mining to extract non-taxonomic binary relationships between two ontology classes from English text. Their technique depends on retrieval of verbs which indicate a relationship in a sentence and which suggest where in the ontology hierarchy this relationship should reside. Three phases take the process through extraction of candidate relationships, analysis of the hierarchy postulation, and manual selection. In the first phase, text is into split sentences on the premise that relationships are identified within the sentence. Sentences are then searched to identify a minimum of two terms that will represent useable ontology concepts. The authors appear to encourage manual input in the next stage of extraction, suggesting the use of a generalization/specialization level defined by the user, with an expanded hierarchy allowing freedom to use synonyms with potential for hyponyms (words of more specific meaning than simple synonyms) and heteronyms (two or more words with the same spelling but different pronunciations and meanings, e.g. 'bow'). In Aboriginal English a hyponym for something regarded as 'good' might be 'deadly' which is an expression attaching strong appreciation of some valued object or activity. Such distinctions are important for this ontology work as the term 'deadly' has serious literal implications if heard by non-Aboriginal health care workers unfamiliar with this very common cultural expression.

A lexical analysis on the selected sentences next aims to identify those verb forms that indicate non-taxonomic relationships. Finally from the sentence retrieval this technique generates tuples comprising two concepts and a verb establishing the relationship between them. The authors point to two possible outcomes. Firstly sentences with terms representing ontology concepts at a maximum distance from each other with a verbal form among them. From Serra and Girardi's paper the tuple form is shown as <concept 1, verb form, concept 2>. The other may use sentences with the contract form "", illustrated by the jurisprudence example "Court's decision", in which case the tuple generated is <concept 1, has, concept 2>. This alerts the user that a decision is needed about the relationship label, as it may not be an aggregation, suggesting that "has" may not be the best choice. In the context of citing the court's decision the suggestion is that a preferable relationship (verb)

might be “take”. In the solutions search the lexical analysis as described is a vital contributor to the ontology construction.

4.10 Assistive Communications Technology (ACT) systems options

This section revisits the early to mid stage research into options for systemizing a solutions model that will efficiently mitigate if not negate the several different problem factors contributing to the overall issue of inequitable PPIE communications; and the consequences to Aboriginal patient wellbeing outcomes. There is a risk in searching for and trying to build the ideal collective and integrated solution. Every problem element and the respective solutions options create a need for collection and analysis of diverse and voluminous detail that inherently justifies several rather than a single doctoral research project. Notwithstanding this comment, for the ultimate acceptance of new ICT application it is also important to foresee as far as is practicable the most promising user preferences and system value associations. The expansion of a system and its functionality should not knowingly or unwittingly be blocked through inadequate framework accommodations.

4.10.1 The integrated ACT architecture solutions view

Central to the PPAC application is the user’s computing capability. Figure 17 depicts the *mid-stage* framework conceptualization of the system architecture. This diagram representation anticipates the presence of an integrated communications and Point of Care Testing (PoCT) information processing device similar to that found in some patient homes and aged care facilities. Equivalent options for this role and subsequently more relevant to my PPAC framework includes applications on smart phones, touch screen tablets and personal computers. This schema presupposes the capability for digital communication over broadband communications but also the fall-back contingency of plug-and-play through physical connection upload and download. The comprehensive scope of this earlier conceptualization however was subsequently modified so that some aspects of the more futuristic, albeit realistic and achievable, communications solutions have been deferred in favour of the practical realities of this specific research and patient user environment. This particular illustration is most concerned with explaining conceptually the rural and remote patient use of the PPAC system application.

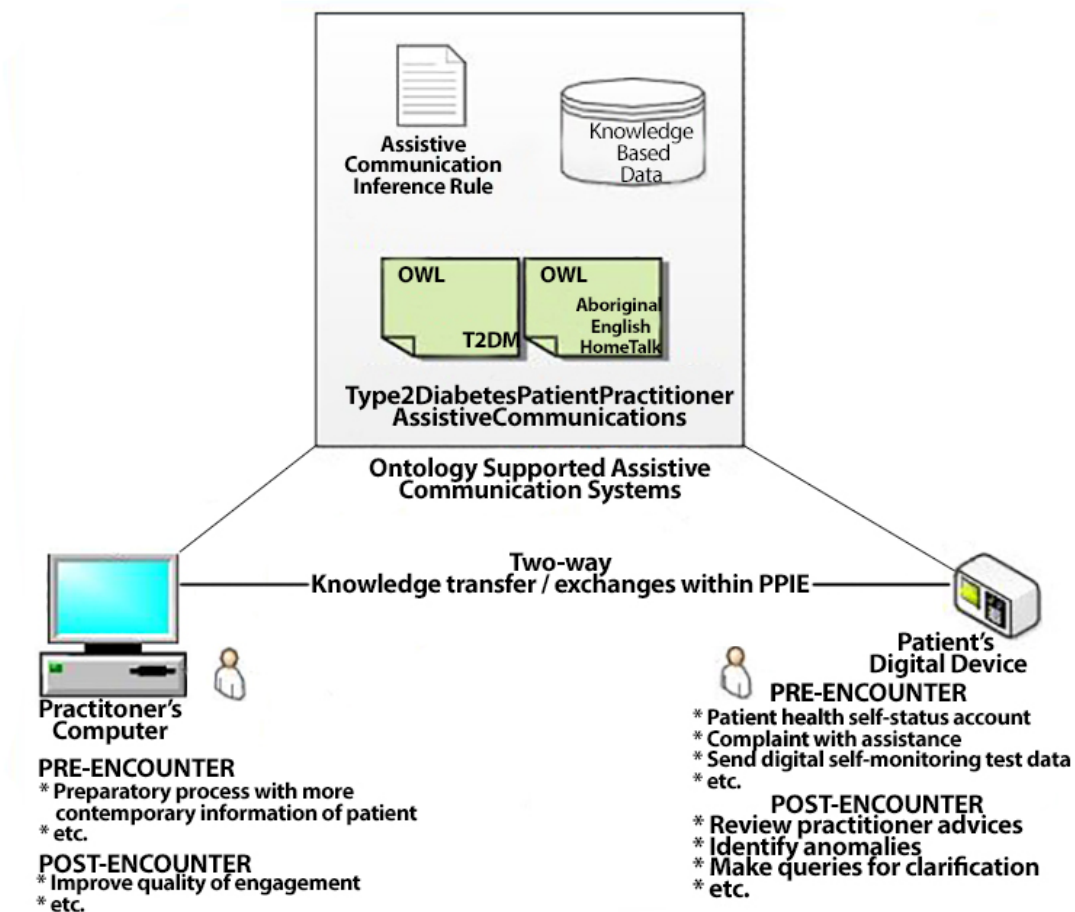


Figure 17: Mid-stage PPAC concept framework architecture

As shown in the diagram, the data collected, processed and transmitted by through and from the patient's device are intended to be part of the interactive communications processes allowing the clinic (nursing station) to receive and record information about the patient's health related condition. The context relevance and cross-cultural communications efficacy of this information are facilitated by the ontology supported assistive communications systems.

These systems consist of four elements.

- Knowledge based data is maintained in a repository and typically will provide user tutorial support; a store of retrievable contemporary information for response to domain specific queries; pictorial illustrations and links to related references including glossaries. Data held will be both human and machine-readable.

- The two ontology (OWL) files support T2DM guidelines and Aboriginal English bi-directional communication with pragmatic user-appropriate (Standard Australian English or Aboriginal English) syntax and semantic construction of data drawn from the knowledge base.
- The Assistive Communication Inference Rule is the fourth element, denoting the ability through ontology disciplines to automatically generate new relationships, based upon existing relationships provided for in the explicit ontology design.

4.11 Related healthcare ICT work

A broad range of ambitious technological approaches for augmenting communication with patients exist, mostly in conceptual or prototype trial form. Some influence in the research describing differing pathways toward patient community empowerment and knowledge transfer. These include a lexical database called Medical WordNet [92], an intelligent interactive system delivering individualized patient information [93], and a considerable volume of work on computer simulated health care interactions employing relational agents, emanating from Timothy Bickmore and various co-authors.

Common among these and similar sources is the inferred expectation that these are operating among a highly literate English-speaking population. As a counter to this, the MedSLT speech-to-speech translation platform was developed for use by physicians to treat patients regardless of the language used by the patient [94]. While speech recognition is easier to use, the authors found that accuracy of such systems varies between 30% and 50% making it inappropriate for use in a clinical setting. Approaches using social media are highly dynamic and present society with experiences, opportunities and end-user preferences that affect health care communications, for example as peer-to-peer support [95]. But these market force developments are so volatile as to elude meaningful early term impact and trend analysis. ICT is viewed by other researchers as a means to help overcome healthcare disparities through communications enhancement. Automation prospects include the use of medical dialogue management systems [96]; and multi-layered conversational intelligent agent systems [97].

4.11.1 Ontology-based solutions for healthcare communications systems

Ontology development is a relatively new discipline with research and publishing activity constantly offering evolutionary advice and lessons on analysis, methods, models, and structure together with emerging sets of rules, process steps and evaluation aspects. One of the challenges confronting the help search for ontology design is the extreme range of difference in scope functionality and ultimate purpose of ontology construction. This is especially acute when a domain user perspective is driving the research; when the specific bi-domain relationship mapping has not been attempted before; and when the necessary enhanced domain expertise is being developed simultaneous to conceptual ontology learning. It has been necessary to continually review ontology article sources to establish the rules and disciplines that can be borrowed and adapted to best effect. Some philosophical and/or practical design aspect from each of the cited sources in subsequent paragraphs has contributed to the solutions framework mindset.

4.11.2 Sharing semantics

Agents need to share terms and the meanings of those terms used in the ontology. Whereas Noy et.al describe[98] seamless conversations between agents as ‘the Holy Grail of Semantic Web Research’ there is a considerable and varied mix of leading-edge research across many fields emanating from this goal, placing disparate demands upon ontology construction. The sharing of semantics between agents is attained through ontologies, where explicit terms are used in an unambiguous form interpreted as such by humans and by machines. Although common ontologies are available for extension to specific domains and applications, the ground work for specialist domains must first facilitate reasoned inferences so that new facts emerge automatically; and the re-user does not have to share exactly the same ontologies in order to accomplish the intended tasks. Noy makes the point that reusing ontologies is hard and that ‘the Semantic Web makes it likely that people will reuse portions of ontologies incorrectly or inconsistently’.

For the purpose of this thesis, the search process has sought out ontologies that could be reused, modifiable for the purpose of mapping or tagging with the new T2DM and AE ontology work. One of the several solution search challenges is the creation of

sufficient fluidity in the function and relational aspects of the ontologies. The embedded discipline of existing clinical guideline compliance for example infers a chrono-linear step by step checklist process, while recognising variables that will create deviations and diversions. Effectively the AE PPIE model must anticipate and accommodate many more diversionary influences. From my research I have concluded that these are likely to contrast with past institutionalised practices and preferences of healthcare practitioners.

Framework developers help to illuminate the pathway to clinical semantics having introduced a Web-based architecture, the Digital Electronic Guideline Library (DeGeL). This facilitates gradual conversion of clinical guidelines from text to a formal representation in chosen target guideline ontology [99]. One commercial source web article discusses interoperability of various devices for different functions that make up an integrated diabetes monitoring system. The medical and technical westernized language bias of the concept description parameters however fails to address the issue of design challenges posed by variant informatics applications, the extremes of operating environments and cultural communications diversity [100].

4.11.3 PPIE enhancements

Doctor-patient dialogue inadequacies are receiving much attention from researchers developing ontologies to support health care systems. Leslie Barrett has proposed a point-of-service addition to an existing ontology of medical terms for doctor-patient communications, contained as a module in an Arab-English bi-directional machine translation lexicon. This extends beyond those commonly found descriptive symptom and treatment words in the dialogue, making connections using related verb groups such as drink, hurt, inhale [14].

Bailin and Lehmann, emphasizing the issue of bi-directional miscommunication, propose a clinical tool in which an agent-based system could infer the most recent ontologies for clinician and patient [101].

A study in South Korea has suggested a method for better diagnosis interaction between patient and doctor in a home healthcare setting, using Web Ontology Language (OWL) and Resource Description Framework (RDF), as a preliminary for Web-based Semantic interoperability [33].

In a New Zealand study focused on hypertension management outcomes, researchers have *'developed an ontology driven framework to enhance and facilitate important temporal querying requirements in general practice medicine'* [102].

Heimbürger, inferring the vastness of health and care terminologies, makes the point that a domain does not have to be the complete knowledge of the particular topic, but that part of it of interest to the ontology creator [103].

4.11.4 General healthcare ontologies

In the 'general' healthcare arena, ontology papers reporting stages of development are increasing in number. Buchanan [93] introduces an intelligent interactive system for delivering individualised information to patients; B. Celler [104] writes of emerging technologies in health – telehealth services for the management of chronic disease at home and in the community; Chalortham, et.al [20] offer a paper describing ontology development for a Type II Diabetes Mellitus (T2DM) clinical support system; and Ganendran et.al have published a proposed ontology-driven multi-agent approach for healthcare [28]. As discussed by Inui et.al while advancing an argument for interactional analysis in PPIEs, both pre-encounter and post encounter states are vital parts of the cycle of health care consultation, the latter in the context of PPIE outcomes [105]. Ontology construction is devised not as a substitute or intervention within the time-defined patient-practitioner meeting, but as an all-encompassing two-way knowledge transfer support system. This reflects the proposed mode of enveloping pre and post encounters while centring on the PPIE.

4.11.5 Information and communications ontologies

Burger and Simperl in the effort to prepare the way for ontology development opportunities introduced a method for measuring the benefits of ontologies based on a multiple gap model for user information satisfaction analysis [106]. Farrar et.al

[25] are working toward the creation of a linguistic community of practice by beginning work on a General Ontology for Linguistic Description (GOLD) [25] This is part of a larger effort ‘to create domain-specific ontologies connected to an upper ontology known as SUMO (see <http://ontology.teknowledge.com>)’. Claiming GOLD as the first ontology being designed specifically for linguistic description on the Semantic Web the authors are organizing linguistically related concepts into four major domains: expressions, grammar, data constructs, and metaconcepts.

Bilidas et.al have introduced ELEON, an editor allowing enrichment of OWL (Web ontology language) ontologies with linguistic and user-related annotations [107]. Enriched ontologies are used by natural language generation (NLG) engines to generate textual descriptions of objects represented in the ontologies in the selected language for the user's model. ELEON provides a well-defined interface for use by different NLG engines. In work on cross-cultural domains Bilidas et.al assist the ontology building process with advice on enriching OWL ontologies with linguistic and user-related annotations. Carstens identifies unresolved problems concerning the extent to which culture influences ICT usability, asserting the need to develop a model of cultural barriers to human-computer interaction (HCI) [108]. She declares that today’s technology and the different cultures that interact with ICT, a model of ICT and the human-computer interaction HCI barriers produced by it should be identified ‘to better help designers of ICT avoid technology pitfalls’.

4.12 Ontologies in the solutions research context

While recognizing that there is no exact solutions formula yet in existence that substantially contributes to the goal of this research, my solutions search process has encompassed ontology research contributions in order to try and discover portions of work activity that can be merged into a new formulation or ‘bolted on’ to the evolving framework. Examination of the work of others without an immediate partial adoption outcome does not necessarily denote absolute or permanent rejection of these sources. It has in large part served as a guide to help foresee and mitigate solutions design error; and to place emphasis on universal compatibility for future systems. The sharing and re-use philosophy for W3C (OWL) ontologies and the

powerful potential of the Semantic web give good reason for recording and archiving sources that may offer solutions support refinements over time.

Ontologies focused on health care are prolific in number and scope, yet are relatively limited in their impact on such a large multifaceted domain. A selection of journal articles were reviewed in this field ranging in objectives and ultimate purpose. These papers elaborate on ontology planning and potential for health and healthcare improvement and education, medical information management, clinical guidelines, patient Web-enablement, health care interpreter support and chronic disease management; and much more [33, 109-114].

4.12.1 Cross-cultural communications ontologies

While such work as stated in the previous paragraph offers a broad span of lessons for framework developers, interest in diabetes management and cross-cultural communications demands concentration on work that has a more specific relationship with this research. Moreover, based upon the search process it was found that little attention is devoted to communications ontologies serving the needs of LEP, socioeconomic and culturally disadvantaged healthcare communities enduring persistent healthcare and health disparities. None that address PPIE related cross-cultural cognition and communications barrier mitigation for Aboriginal patients could be identified from the search process..

4.12.2 Ontology representation of Type 2 Diabetes management

A number of researchers have worked on developing diabetes ontology. Chalortham et al. developed a diabetes mellitus ontology which covers risk assessment, diagnosis and complication, treatment, and follow-up[20]. The diabetes mellitus ontology was developed based on the Thailand Diabetes Mellitus Clinical Practice Guideline 2008 and suggestions by medical domain experts. Buranarach et al. introduced the synopsis of chronic disease healthcare framework in which the importance of ontology for healthcare knowledge management system was pointed out [58].

Lin and Sakamoto developed Glucose Metabolism Disorder ontology which was classified into diabetes mellitus, diabetes complication, hyperglycaemia,

hyperrinsulinism, etc. [59]. The ontology was also linked to Geographical Regions ontology and Genetic Susceptibility Factor ontology to describe genetic susceptibility factors of Diabetes Mellitus.

Ganendran et al. developed ontology based multi-agent systems in which diabetes management was applied as a case study involving three agents i.e. specialist agent, patient agent, and web agent [28]. Shahar et al. developed Knowledge Based Temporal Abstraction (KBTA) focusing on shared knowledge representation and reuse[43].

Currently, no T2DM ontology has been developed based on Australian recognised professional healthcare standard guidelines. There is also no evidence in the literature of any current effort, other than the work subject of this thesis, to facilitate a cross cultural biopsychosocial pragmatic ACT system to help Aboriginal patients in the PPIE setting context. Similarly I have not been able to identify ACT investment in solutions to support culturally and linguistically diverse immigrants whose health care communications and understanding of self-management is equally challenged. There is however considerable promise from budding ACT vehicles capable of optimizing ontologies, found in all forms of desktop computing, tablets, smart mobile phones and telehealth systems. The appeal of all such capabilities is the mitigation of the barrier of physical distance.

4.13 Solutions synthesis from ethnorelative communications research

Observations of PPIE communications issues included work with an Aboriginal focus group, interactions with members of the Aboriginal health care community, and critical review of a substantial literature of comprehensively constructed educational studies into Aboriginal English [70, 115-125]. These educational and training materials provide a strong contribution for the acculturation process that the PPAC system application must accommodate as an educational asset for the practitioner and general health care service provider community. They are less pertinent in the Aboriginal English speaker solutions design and Aboriginal patient user sense, as they offer little lexical enrichment of the AE health and health care vocabulary and pragmatic PPIE engagement. The gradual (but rarely literal)

translation, mapping and semantic merging of AE research teaching and learning literature content will for this work rely substantially on the ability of and outcome from simplification of the RACGP T2DM care GLs; and thereafter through identification of explicit and implicit relationships which transform this merger into a workable lingua franca.

In Chapter 1 (Kleine-Cosack) [126]; and Chapter 2 (Hobbs, and Ortony) [127] from the research literature illuminated the role of emotions in intercultural engagement, including human-machine interactions. De Maesschalck et.al explored emotional expressions through video observations in PPIEs [128]. Their findings confirmed the higher value of psychosocial versus bio-medically oriented encounters and of accommodating emotion in PPIEs. Emotion, beliefs and spirituality sit within the remit for deeper critical cognitive framework solutions design in order to achieve reciprocal end-user functionality. The objective is to find, blend and prepare those concepts in order to engineer interactive PPAC queries and response to cope effectively with those human behavioural characteristics, preferences and traits. Dance, whose communications concepts work is previously referenced in Chapter 1, with the selective relevance listing in Table 2, contends that a family of concepts ‘should also facilitate the treatment of communication in a systems Fashion’. His view is that members of the family of communications concepts may include “attitudes,” “opinions,” and “beliefs”. He states that scholarly pursuits are better systematized through a move towards reducing professional dissonance, eliminating conceptual inconsistencies and contradictions[129].

4.14 Solutions profile summary

This chapter declares solutions objectives and illuminates both the locale and abstraction rationale for solutions design contributions. The core outcome from this has centred on using cultural analysis to achieve

- Cultural competence
- Mitigation of ACT design bias
- Adoption of Aboriginal user worldview profiles
- Accommodation of health literacy and semantics design factor influence
- Changes in PPIE habitual processes
- Simplification of clinical practice guidelines, and
- Development of cross cultural participant ontologies for T2DM care.

Table 6 provides a listing of principal problem factors, solution pathways, the benefits sought and the constraints that to a varying extent will place limits on the communications problem resolution research effort.

Problem factor	Solution pathway	Benefit	Constraints
Abstraction of T2DM GL+ data for conceptual mapping with AE is manually and time intensive without benefit of adequate prior development and documentation	Extending medico language research beyond the foundation (RACGP) GLs, increase GL scope with multi-source collation of descriptive annotations in readiness for further concept abstraction	Extends potential for shared patient practitioner communications while protecting GL integrity	Clinical Practice GLs (CPGs) and their use by professionals are not designed as patient communications tools
Clinical language major barrier to patient communications cognition and merged concept mapping	Incremental simplification of annotations and of conceptual semantics and subclass analysis; aided by qualitative gap analysis of barriers from literature and focus group sources	Simplified SAE semantics induces and complements culturally appropriate interview and focus group opportunities	Very limited availability of CPG related lay-translation information sources and systems
Analyses of PPIEs hampered by absence of research relationships with Aboriginal communities	Develop and use a research strategy based on known (evidence based research) best practice	Time, cost and operational efficiency risks are mitigated. Data enrichment collection opportunity is elevated.	Unpredictable, high risk potential for protracted project cycle(s). Dominated by scratch start relationship building versus established working connections
SAE grammatical data constructs incompatible with AE pragmatic healthcare data constructs	Utilize AE educational research and Aboriginal interviews/focus groups, intensifying culturally competent semantically rich mapping and reasoning	Increased opportunity to grow the AE lexicon and develop the first AE health talk repository	Limited access to cooperative AE/SAE bi-dialectal health care conversant volunteers within a manageable project timeframe
ACT and ontology development methodology represent only viable choice (limited efficiency alternatives)	Accept ontology supported PPAC goal as the most promising option. Use ubiquitous uptake of mobile phones and known Aboriginal acceptance	Shared, re-usable and user expandable system	Regional internet access and affordability coupled with technology resistance of older community members; unpredictable Aboriginal ICT

	patterns to promote engagement		acceptance risk.
Exponential growth of mass consumer health care knowledge and use of digital devices threatens to exacerbate socioeconomic 'digital divide'	Design focused on AE-friendly multi-functional application that will explicitly and implicitly incorporate health care and health literacy education and cultural competence capabilities	Increased prospect of improvements in patient self-management of health	Pace, content and 'digital divide' growth dimensions and impact of digital media are unknown
Principal problem is inequitable communications in Aboriginal health care	Framework development to integrate all of the above and facilitate shared system (ontologies, PoCT) compatibility	Disciplined specification of PPAC ontology system	Time and labour intensive factors affecting PPAC development, quality and user market critical mass adoption

Table 6: Communications research problem resolutions benefits and constraints profile

Having identified and qualified problem solution concepts and key relationships between them, the effort now moves toward the refining the conceptual framework, presenting an overview of the research and development model aimed at achieving design goals.

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Chapter 5: Patient Practitioner Assistive Communications (PPAC) Conceptual Framework

This research in simple words is dedicated to communications in healthcare. The human to human relationships; human and machine interactions; and the relationships between intelligent machine agents facilitating those interactions represent information systems management and knowledge transfer tools. The Mosby Medical Dictionary defines ‘conceptual framework’ as:

*A group of concepts that are broadly defined and systematically organized to provide a focus, a rationale, and a tool for the integration and interpretation of information. Usually expressed abstractly through word models, a conceptual framework is the conceptual basis for many theories, such as **communication theory** and **general systems theory**. [1]*

5.1: Introduction - conceptual framework overview

From the sources of research data, including the literature review, it is concluded that there is a significant and harmful communications deficit in the patient-practitioner interview encounter (PPIE) when rural and remote living Aboriginal type 2 diabetes patients seek professional diagnosis, treatment and care. The chosen design pathway is to concentrate the conceptual framework development on assistive communications for the management of chronic disease, viz. Type 2 Diabetes Mellitus (T2DM). This choice for ACT development arises not only because T2DM is omnipresent in Australia’s Aboriginal communities; it presents countless communications and management complexities which are perceived as justifiable opportunities for significant research and solutions development. These opportunities open up future prospects for a broader applications and user population applying the same conceptual framework.

Previous chapters entered into the general discussion of the background and purpose of this research, and subsequently described the many problematic facets of health care service delivery and disparities. The main focus is the solutions search, a design process to develop an interactive communications systems framework.

Ultimately this will lead to a computer application to be used and continuously developed within both the PPIE setting. Ease of access and use will serve the shared T2DM management goals through the lesser-constrained opportune moments of access by patient and practitioner users outside of the PPIE appointment regimen.

The conceptual framework description for building the PPAC system begins with the research methodology approach; and provides an outline overview of the whole scheme. It references principles identified to achieve data and query functionality, schema data sources, and system user preference profiling. These general outline descriptions prepare the ground for the greater design detail contained in subsequent chapters.

5.2 Application objectives and significance

The impact intended from this research in the ICT/ACT context is as follows:

- Education of both patients and health care professionals to achieve ICT supported self-management and timely interventions for T2DM patients close to their local home environment.
- Facilitation of more effective bi-directional practitioner-patient dialogue. Prior projects have not provided culture biased ontologies to support care protocols including ICT interface relationships. This ecosystem enriches and empowers the Indigenous patient contribution to the dialogue, thus enabling better communication and understanding between all parties.
- Applications and capability growth via enhanced content and device scalability. It will become feasible to re-engineer for supporting chronic disease populations other than T2DM patients; and for emergency medical response requirements.

5.3 Design Goals

Goals progressing toward the PPAC system are

- the establishment and mapping of compatible, semantically sound and concise relationships within the AE and T2D schema individual and merged domain concept classes, with due emphasis on facilitating cognitive consonance for patient communities

- the development of syntactically and semantically workable pragmatic and paralinguistic SAE–AE synergies for type 2 diabetes health care communications concepts
- the identification and characterization of PPIE communications barriers and consequential solution-oriented instantiation of ontology concepts to counter these barriers

5.4 Science and Engineering Methodology

The crossover and mix of social science concepts with technology concepts demand interdisciplinary research. Described simplistically the PPIE communications problem arises in the social and health science arenas, while solution research grapples with science and engineering theories and development opportunities to work within the former. The research problems, once perceived as representing opportunities as opposed to the societal health care delivery problems stated earlier, have justified a close examination of technological solution options. This has been achieved through voluminous diverse and interconnected literature sources, together with real-world cultural interactions and subsequent analysis. The critical conceptual elements and desirable outcomes have emerged from this activity.

5.4.1 Three levels

Galliers[2] proposed three levels of engineering research. This theme has been adopted and adapted, keeping the main titles thus:

- Conceptual level: Creating new ideas
- Perceptual level: Formulating a new method
- Practical level: Carrying out framework testing and validation in preparation for real-world field testing

Figure 18 provides an illustration of the research structure with a concentration on human behavioural design factors that are central to this work. Constraints and knowledge encountered in the course of the research cycle, predominantly of a human behavioural character, have circumscribed the outcome, i.e. contemplation of building a prototype PPAC model has been forestalled in favour of strengthening framework articulation. These constraints and new knowledge factors and their

diversionary influence are explained below in the course of describing the research steps and methods I have applied.

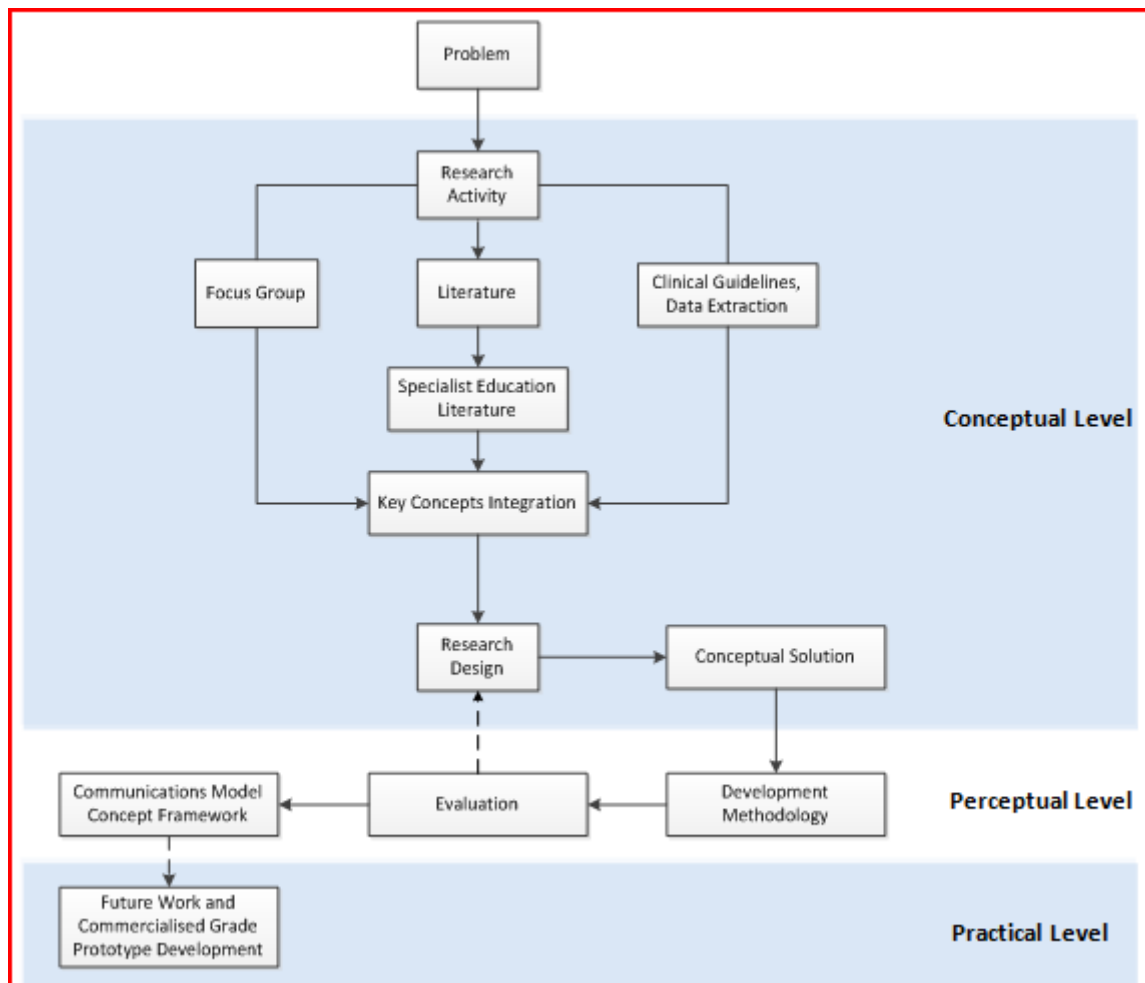


Figure 18: Engineering based phased-research structure

Conceptual

The creation of new ideas was stimulated by a review of Western Australia’s health care service delivery logistics challenges. The focus then narrowed to identification of the seriously adverse chronic disease incidence affecting the Aboriginal population and specifically to type 2 diabetes. A problem cause and effect analysis highlighted the PPIE communications failings and the litany of contributing barrier factors. The Aboriginal English dialect surfaced as a dynamic medium for potential development of an equitable acculturation support tool, having a substantial Western Australia-led foundation of leading educational and linguistics research published over several decades. This introductory research activity identified and correlated

primary research sources and objectives. The Aboriginal-only volunteer focus group was conceived as the most promising direct route to the cause and effect behavioural data. Data extraction, from T2DM clinical care GLs; from specialist Aboriginal English education literature; and from the focus group activity presaged key concept integration for the more incisive research design process that will secure the solutions model framework for the communications problem. Within and as an extension of the focus group contribution, I initially planned to explore potential for and then conduct one-on-one interviews with members of the regional Aboriginal community. This part of the activity was however abandoned for reasons described in Chapter 6.

Perceptual

At the perceptual level with the advantage of awareness and knowledge of ICT applications; and with research into assistive technology concepts; it was possible to envisage a method of building a framework that would combine the human behavioural assistance needs within the PPIE environment; together with the perpetually evolving communications technology software and hardware options. From this I arrived at a point where the terms ‘Assistive Communications (AC)’ and ‘Assistive Communications Technology (ACT)’ took primacy in my research.

Practical

At the practical level and long before the ability to carry out framework testing and validation in preparation for real-world field testing, it was necessary to step back to more fundamental human exercises in data collection, analysis and a gradual, deliberate and slow framework design process. In the Chapter 3 problem definition discussion, Tomiyama et al.[3] on Design Theory and Methodology (DTM) is referenced as one of the several design method options in which there is a need to collect facts through observation. The point was made then that there are several components and sub-elements to find, observe, assemble and integrate. Citing Shah[4], Tomiyama refers to Creativity-based design and Combination-based design, each of which is considered as a source of method guidance. In the creativity-design case, Shah breaks this out into two forms, intuitive and systematic. The philosophical similarity of the intuitive form to invention tends to move the work away from that

approach. Yet intuitive approaches, the flow of ideas, removal of mental blocks; and increased promotion of creativity, with exposure of designers to new knowledge and consequential stimulation of the imagination are all features of the engagement in this research. On the other hand systematic methods apply design knowledge more rationally and systematically. These methodologies follow the important assumption that existing building blocks and rules work together to achieve a disciplined process and output from a new design solution.

Because this work moves back and forth across the social science, health science and information systems design thresholds and domain combinations, other complementary design research author contributions are brought into this creative methodology arrangement. Hevner’s [5] work on the conjugation of design-science and behavioral-science is relevant to the foregoing scenario, as is the work of Venkatesh et.al [6] who recently published an article providing substantive advice on bridging the qualitative-quantitative research divide, focusing on and developing guidelines for mixed methods research in information systems. This is employed in the validation work reported in Chapter 8. The conceptual beginnings of a relationship between empirical and archival research material can be illustrated and distinguished in a qualitative-quantitative context, using core data shown in Table 5.

Qualitative	Quantitative
<ul style="list-style-type: none"> • Behavioral • Cognition • Communications barrier characteristics • Cultural • Healthcare service processes • Lifeworld/Worldview • PPIE • Pragmatics • T2DM patient status • Technology Acceptance 	<ul style="list-style-type: none"> • Collective community T2DM disease and Health Literacy status • Communications barrier problem frequency • Comorbidity rates • Hospitalizations • Indigenous v. Non-Indigenous Patient wellbeing ratios • Regional Healthcare resources/relativity • Regional ICT coverage and access • T2DM care-related patterns

Table 7: Qualitative and Quantitative comparison of research segments

5.5 Specific PPAC framework development methodology

The conceptual level involves

- The collection filtering and analysis of relevant primary (AEHT and T2D Concept) domain data from archival and focus group sources
- Identification of key useable semantics and syntax characteristics within domain data
- Identification of relationships between concepts, both intra and inter domain
- Accommodation as necessary of extra-domain data and concepts and their functional relationships, e.g. portal preparation for future interactive system development including device interfaces, telehealth, PoCT and re-use/sharing of other ontologies
- Confirmation of the process that will support the preferred technological medium, i.e. the choice of ontology construction to support ubiquitous digital communications device applications

The **Perceptual** level involves

- Identification and adoption of a newly formulated combination of manual, automatic and semi automatic processes and tools that represent a new development method in the context of supporting the stepped research objectives and the specific framework goal
- Combining of behavioral science and design science disciplines, with a qualitative bias
- Use of focus group observational analysis data; manual and semi-automatic ontology domain mapping and construction using a practical guide and the Protégé software tool; and automatic query and response capabilities for evaluation using Pellet reasoner, DL Query, SPARQL Query, and OntoGraf [7]
- Ontology construct support for the design of the assistive communications framework architecture

The **Practical** level involves

- Further query and response framework testing and validation in preparation for future work to include software and interface engineering and subsequent real-world field testing
- Preparing an outline of the disciplines, processes and objectives of the future work as a reliable guide toward producing a viable ACT end product

The PPAC framework development methodology is fleshed out in its more specific contributory corpus stepped process in Figure 19.

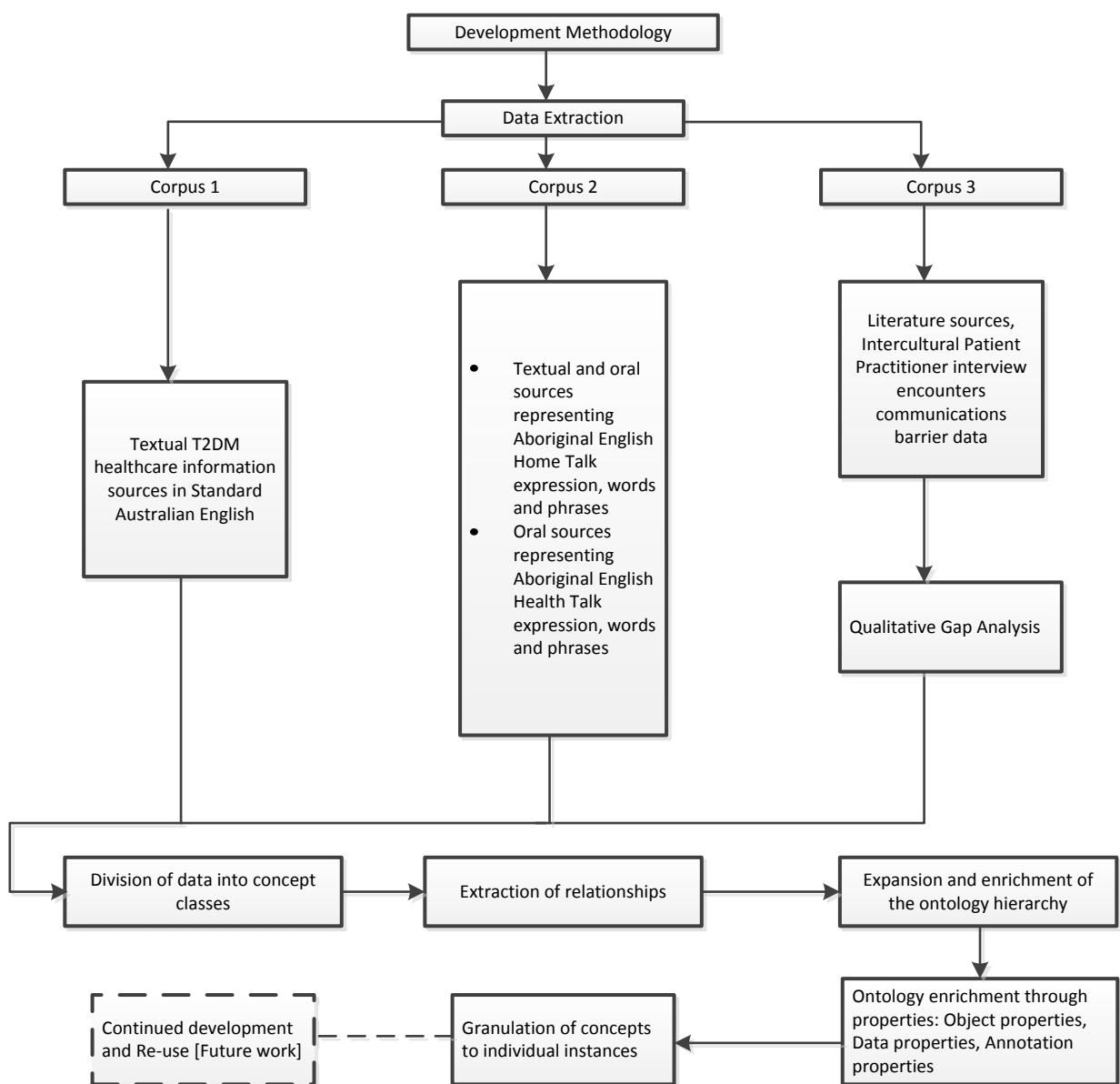


Figure 19: PPAC-specific framework development stepped process

5.6 Human user interaction with the PPAC system

An alternate view of the PPAC system architecture flowing on from Chapter 4 Figure 17: ‘Mid-stage PPAC concept framework architecture’ illustrates the PPAC ontology positioning schema, comprising two parts, i.e. the human entities and the Assistive Communications System. This is depicted in Figure 20.

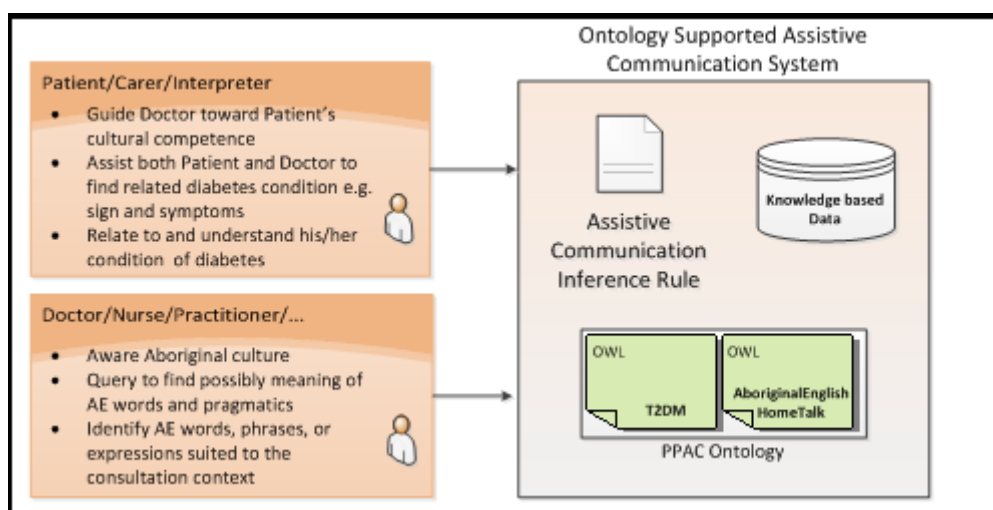


Figure 20: System Architecture of Type 2 Diabetes Patient Practitioner Assistive Communications

The context relevance and cross-cultural communications efficacy of information about the patient's health related condition are facilitated by the Ontology Supported Assistive Communications Systems. This version of the system conveys three elements, viewing the domain ontologies as merged into a single structure for the PPAC system. The digital PoCT device has been removed from the architecture for prioritization reasons reported earlier; but also because the PPAC conceptually must offer stand-alone communications capabilities that are not dependent on the presence of physical patient monitoring or testing devices. The framework design assumption is that compatible digital connectivity between the PPAC and PoCT systems will be available as an option subject to choice and circumstance affecting each user(s).

5.6.1 Pre-encounter, during-encounter, post-encounter PPIE process

The PPAC framework is designed to extend the temporal use scope and thereby the qualitative and quantitative contribution to PPIEs. Figure 21 amalgamates the PPIE process qualitative elements of the six process habit pavers in Chapter 4; while filling

in the contemporary model PPIE communications gaps shown in Figure 1 in Chapter 1. This flow diagram shows the Aboriginal patient T2DM management process beginning with the making of the appointment to see a practitioner. In time and with familiarity with the PPAC interface, the patient will initiate queries, retrieve responses and make entries before the appointment decision is reached. The most obvious example is the recording of signs and symptoms.

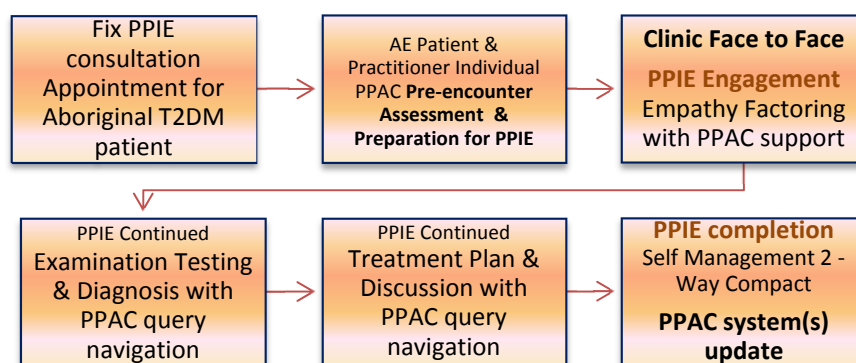


Figure 21: Process depicting pre-encounter and face to face Patient Practitioner Interview Encounter (PPIE)

Contemporaneous noting of symptomatic events will automatically record the timing of the data entry. ‘Walking’ through this process shows that both PPAC end users can undertake the assessment and preparation that will augment the face-to-face PPIE, offering potential gains in time optimization and patient status detail. Access to the PPAC system, sharing and exchange of culturally mapped syntax and semantic data; queried and retrieved via multimedia options; will help to facilitate the desirable level of equitable engagement. The easier management of T2DM terminology through AE ontology mapping is designed to be a continuous feature of each stage in the PPIE and to help prepare for post- encounter needs. Most especially this promotes the goodwill agreement to be reached between the patient and the practitioner for the former to adhere to professional advice, medication and overall self care to avoid T2DM complications.

The practitioner is also a partner in this Self Management Two-Way Compact, with the commitment to supporting the patient and partnering with the patient’s reliance on the PPAC through a communications system stakeholder philosophy. Upon completion of the face-to-face PPIE, both users are positioned to update their PPAC systems. The familiar updating practice by the practitioner using SAE and clinical

terminology can be used as a medium for transfer of care advice and compact detail to the patient's chosen PPAC application loaded device.

Figure 22 continues the process in post-encounter mode, when new information may come to light both in the clinical analysis processes and specialist interventions; and both the PPIE review and subsequent experiences of the patient. This will help to allay research based concern for the incompleteness of PPIEs as it will keep alive the option to record and revive unasked questions, correct previously undiscovered information inaccuracies and elevate the quality of the patient health record.

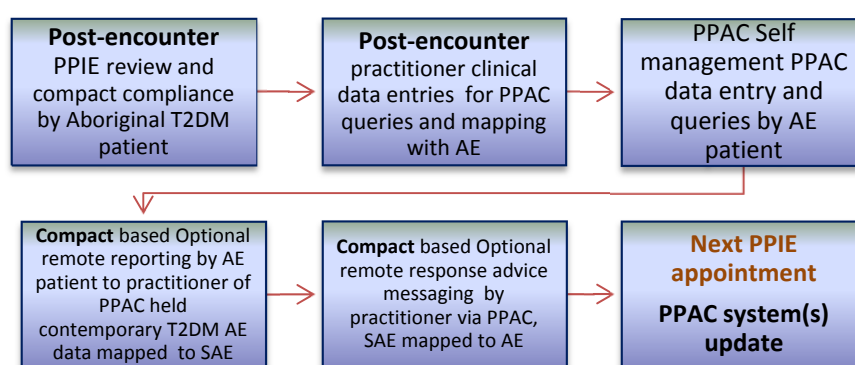


Figure 22: Process depicting post-encounter PPAC activity and optional communications flow, completing the loop back to the next PPIE appointment

The post-encounter PPAC access activity provides the opportunity for ongoing patient self management data to keep the practitioner aware of more recent patient history in T2DM relevant terms. It enables remote exchange of health and health care advice information; and earlier notice (compared with a conventional appointment process) of the need for more urgent medical intervention. The post-encounter communications gap-filling contribution creates a system of continuity of shared care and in the ideal circumstance, a constant T2DM-AE-PPIE communications loop.

5.6.2 Carers and Interpreters

Also shown in Figure 20 are the human entities in the PPIE. Besides the essential engagement between patient and practitioner, cross-cultural communications may require a third non-patient-practitioner party to assist with overcoming pragmatic language difficulties, including speech and hearing disabilities. A carer or interpreter may or may not be qualified or appropriately equipped with health care domain-specific knowledge to overcome misunderstandings. Conditional access may be permitted to the Assistive Communications System so that the carer or interpreter (a) is able to help with the query and search process during the PPIE to identify the best matches of Aboriginal expression with T2DM clinical guideline terminology; and (b) will be capable in both pre-encounter and post-encounter patient contact activities to assist patient T2DM self-management through a more reliable recall and/or clarification of health care provider advice, treatment and care monitoring priorities.

5.7 Functionality

The Aboriginal English (AE) concepts including home talk and health talk are mainly for access to and use by the General Practitioner (GP) or allied practitioners so that they can query AE words and pragmatics; and in the continuing education context, work toward understanding Aboriginal culture. The diabetes concepts are mainly for Aboriginal patients and carers to relate to and understand his/her condition of diabetes. For example for Aboriginal patients the ontology can relate hyperglycaemia with AE expression of ‘I need my sugar chopped’. The GP and allied practitioners know these diabetic concepts; the Aboriginal patients know the AE words and expressions. Therefore I conceptualise concepts for those who do not or may not possess this knowledge.

When the GP and allied practitioner attempt to follow clinical processes, within the history-taking effort there is a need to identify a patient’s prevailing signs and symptoms to enable diagnosis, and to justify a treatment and care plan. This information may not be volunteered or easily and reliably secured. The patient may have been previously diagnosed and a history of T2DM is known to exist; or may be asymptomatic and attending for reasons other than a diabetes related complaint. For my purposes the PPAC ontology is predominantly concerned with patients who have

already been diagnosed as suffering from T2DM. Notwithstanding this, health antecedence may not always be communicated clearly when a patient and practitioner meet for the first time.

5.8 Engagement and semantics

The general principles underpinning PPIE pragmatic interactions using domain ontology concepts and relationships coactively are two-fold; engagement and semantics. The goal is to surmount cultural-source schema barriers and achieve shared understanding. Without engagement between low and high context language users, semantics are elusive at best. Without semantic cognition (semantically driven verbal and nonverbal behaviour) coactive engagement is close to impossible. Engagement through shared semantic cognition invariably relies upon contextualisation. In the Chapter 7 ontology development and Chapter 8 research validation discussions, I show queries from a GP who wishes to find out what certain AE words might be taken to mean in Standard Australian English (SAE). Also shown are queries from Aboriginal patients who may (for example) want to find the related diabetes condition.

5.8.1 Aboriginal patient receptivity to knowledge acquisition

I do not assume indifference on the part of either query source; nor do I attribute prior lack of knowledge to disinterest in learning. No evidence has been found to suggest that Aboriginal English speakers are unwilling to learn or incapable of recognizing the more techno-clinical terms used by practitioners with the help of ACT. On the contrary there is evidence that Aboriginal and other ethnic minority patients wish to know and learn more about their healthcare so that they understand the rationale of diagnosis, treatment and care [8-11]

5.9 Chapter framework research summary

This Chapter has taken the solutions theme and design goals together through methodologies that establish the overarching Patient Practitioner Communications (PPAC) framework. The collection qualification and integration of research data conceptually and perceptually is described in Chapter 6. Chapter 7 is the precursor for the practical application.

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Chapter 6: Framework schema source synthesis

This chapter concentrates on the collection and collation processes undertaken to create the ontology structure, properties, relationships and individual instances; and to build in the acculturative reasoning supporting the functional capabilities of the foundation PPAC.

6.1 Chronology of primary concept data collection

This section recounts the stages of collecting the building blocks for the ontology construction as depicted in Figure 19. In summary these search and study activities in order embrace:

- Textual type 2 diabetes (T2DM) Australian clinical care guidelines and several other accredited sources of diagnosis, treatment and care process guidance
- Aboriginal English Home Talk (AEHT) educational research literature providing AE oral and non-oral forms of expression (non health care)
- Oral source work (Aboriginal focus group ‘yarning’) dedicated to identification and advice on developing an Aboriginal English ‘Health Talk’ schema
- A qualitative gap analysis (QGA) of a large volume of research literature disclosing frequency and characteristics of communications barriers in Patient Practitioner Interview Encounters (PPIEs)
- PPIE case study scenario projection based upon the foregoing
- Synchronistic concept development and ontology construction with ongoing collection and analysis; and subsequent refinement of the hierarchy with enrichment of inter and intra domain concepts and relationships

The research work summarized above was a sometimes erratic activity rather than a linear sequence of enquiry, necessitating much double checking of the veracity of data and contextual semantics that would validate concepts, and changing both data entry content, its attributed value and emphasis. For this reason in the following explanation it is necessary to divert slightly from the above bullet-point order so that related research output is covered in a particular background context.

My T2DM and AE research and data collection activities occurred simultaneously. Of particular value were the exceptional expertise, generous time and literature access afforded by members of the WA Department of Education. Linguists, researchers and educators specialise in helping to develop secondary level school programs for two-way acceptance, teaching and learning for Aboriginal English speaking students. Historically these students have been disadvantaged by the exclusive and pervasive Anglo-culture teaching practices in Australia's primary and secondary schools.

From the T2DM care GLs analysis it became possible to identify the same cultural dominance, while accepting that the GLs source is intended for use by healthcare professionals. It is however important to use such a source as a means of ensuring discipline and accuracy for the communications acculturation ICT processes that would follow. This then was linked to research literature focused on communications in primary care consultations, i.e. the PPIE experience. The concentration in this endeavour gave optimum attention to identification and qualification of barriers to equitable intercultural PPIE communication.

130 literature sources were examined and a qualitative gap analysis (QGA) conducted of the communications barriers observed, reported and/or postulated from evidence based research. This data collection process was followed by a manual analysis effort to identify the most pertinent framework model concepts and relationships for the ontology construction work. Before completing a satisfactory listing of the concepts and domain ontology structures which I intended to develop, several iterations were necessary. The foregoing summary of research activity prefaces my return to the sub-objectives sequence as selection and qualification of framework domain schema concepts for integration in PPAC design are primarily dictated by human user factors. For example AE and QGA dimensions influence the Aboriginal patient perspective I am adopting in the T2DM ontology contributions.

6.2 Type 2 Diabetes Schema source work

The 2011/2012 RACGP diabetes care GLs document has been dissected and evaluated for its process data and communications value content, accepting that it is professionally accredited having been compiled under the direction of an editorial panel, with contributions from several professional health and healthcare bodies and individual practitioners, general and allied.

6.2.1 Guidelines ontology schema source

The guideline document is intended for front line primary care. Having started with a study of editions published in 2009 and 2010 for the benefit of this thesis it works from the 17th (2011-2012) edition, which was published in July of 2011. At an advanced stage of this research updating to the 2012-2013 edition was rejected, in part because the RACGP was (temporarily) no longer a joint publisher with Diabetes Australia; and much time had been invested associating the GLs with the RACGP name as opposed to the full joint publisher name. As a precaution an enquiry was made of RACGP and on 12 March 2013 an email response was received from Stephan Groombridge Program Manager, Quality Care Clinical Improvement Unit RACGP stating as follows:

The RACGP did not review the 2012/13 edition and it is not endorsed by us. This is because we are moving to a new updated format for 2013/14, which will bring the handbook in line with other RACGP guidelines (in particular with better referencing and recommendation and evidence grades). The 2013/14 edition, due in December 2013, will again be jointly published.

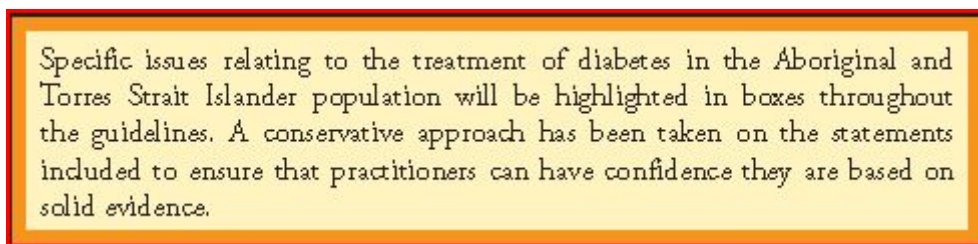
As a further precautionary measure, it was confirmed that all of the contributing professional bodies and individuals other than RACGP continue to contribute to these GLs. Moreover the issue is more one of compliance with institutional guidelines formatting than on any other, noting that RACGP will resume joint publication with Diabetes Australia in December 2013, at which time it is expected that the latter will benefit from the dedicated revamped version from the work of the RACGP.

The 17th edition copy consists of 92 pages, broken down into the following headings in the numbered order shown:

1. Diagnosis.
2. Assessment.
3. The team approach.
4. Initial management.
5. Health care for diabetes.
6. Medication.
7. Sick days.
8. Hyperglycaemic emergencies.
9. Factors complicating management.
10. Diabetes and reproductive health.
11. Driving (impaired driving ability).
12. Travel (forward planning risk management).

A section titled ‘Goals for management’ subsequently appears on the back page.

The guidelines modestly acknowledge the special care considerations for Aboriginal patients by including a total of eighteen highlighted advisory boxes at selected places within the text. The function of these is introduced as shown at Figure 23.

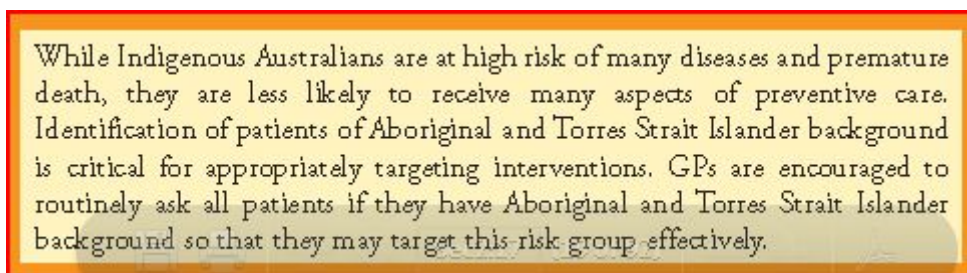


Specific issues relating to the treatment of diabetes in the Aboriginal and Torres Strait Islander population will be highlighted in boxes throughout the guidelines. A conservative approach has been taken on the statements included to ensure that practitioners can have confidence they are based on solid evidence.

Figure 23: T2DM care guidelines Aboriginal highlight advice

From the AE health care related research and particularly the QGA of communications barriers this work has applied a qualitative critique to these guidelines to determine their contributory worth for a process of transition in the building of a cross-cultural assistive communications system model. The text is relatively inflexible for that purpose not only because it is a clinically worded professional care aide, but also because it does not adequately address the special

adversities for Aboriginal patients arising from cultural communications competence concerns; and it fails to make an educational contribution in that respect. Figure 24 is an example of an advice which demonstrates the dominant feature of Aboriginal highlight box content, i.e. it is *about* the Aboriginal patient; but not about how the practitioner should (a) be aware of the high risk of misunderstanding, or (b) should prepare (train) to be culturally competent.



While Indigenous Australians are at high risk of many diseases and premature death, they are less likely to receive many aspects of preventive care. Identification of patients of Aboriginal and Torres Strait Islander background is critical for appropriately targeting interventions. GPs are encouraged to routinely ask all patients if they have Aboriginal and Torres Strait Islander background so that they may target this risk group effectively.

Figure 24: Page 17, RACGP GLs Aboriginal highlight advice

An immediate conflict becomes obvious based upon MY research on PPIE interactions with Aboriginal patients. The unqualified words ‘routinely ask all patients’ will often present the problem of resistance by regional Aboriginal patients to direct and probing questions.

It remains important however to honour the implicit discipline of such documents so that the practitioner as an applications end-user has a familiar lexical track to follow when engaging a novel communications system. The challenge has been to extract conceptual data from these guidelines and to formulate a semantically appropriate and credible AE healthcare lexicon that through two-way ontology mapping can be employed in reverse, according to the needs of the user.

6.2.2 Other clinical advice sources

The search was expanded to collect data from other published guidance on T2DM care health care consultation processes and terminology simplification. I attended an Aboriginal enrolled nurse diabetes care four-day training course 8-11 June 2010 at Marr Mooditj training college as a guest student and was given all of the course materials. In addition several other publications were read and information from them noted and preserved for the purpose of construction of the T2DM ontology in a

manner that would protect data integrity and system relevance. The combined product from all of these publications is the generation of multi-level concept class annotations, discussed later in this Chapter.

Additional sources (titles) to those already mentioned and included in this part of the study are:

Diabetes and Your Skin (WebMD)[1]

Johns Hopkins Diabetes Guide[2]

Medical Language Instant Translator (Chabner)[3]

Medical Terminology for Dummies (Henderson and Dorsey)[4]

Type 2 diabetes An Essential Guide for the Newly Diagnosed (Becker)[5]

Type 2 Diabetes (MIMS Australia)[6]

Type 2 Diabetes Mellitus Clinical Presentation (Khardori)[7]

6.3 Concept maps

While the schema collection activity was underway, the first concept maps were prepared, at first creating two ontology domains named ‘Community Health’ and ‘Aboriginal English’. These proved to be too cumbersome as they were far-reaching in scope and created the risk of dilution of the essential strength of the framework. As an example included here is a copy of the early version, the Pragmatics subclass portion, of the AE concept map, at Figure 25.

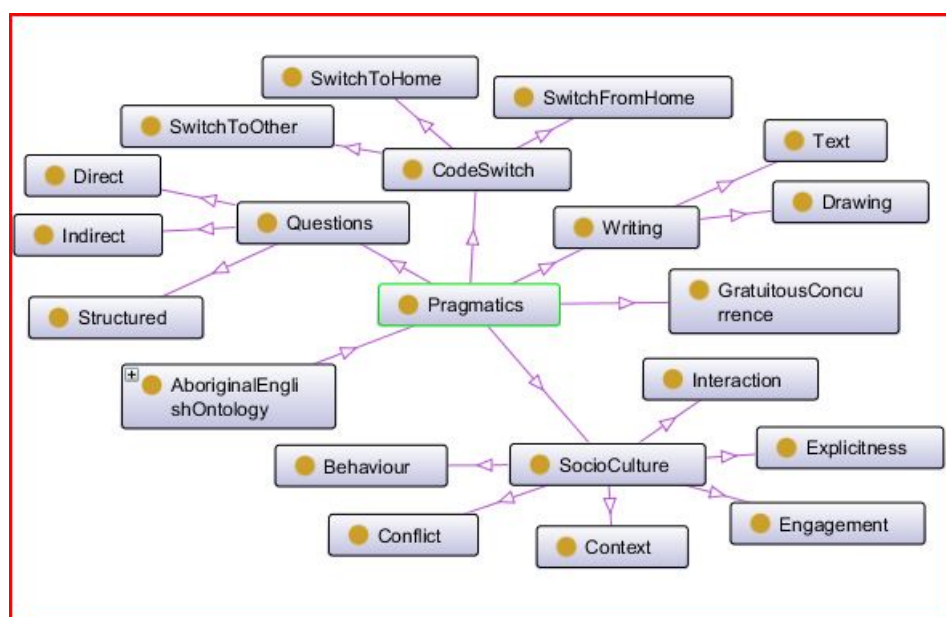


Figure 25: Early (superseded) AE pragmatics concept map

The framework value-diluting effect of entering into too much detail is demonstrated here, for example with concept properties and instances describing code-switching. The need perceived was to build variables into the system to accommodate what had been learned about these phenomena in the Aboriginal communities. A simple example offered in conversations is that of an Aboriginal student who would have to reluctantly and often with difficulty converse with teachers in SAE while in class at school; but in the school yard or on the walk home would code-switch to a form of adolescent Aboriginal English enjoyed by and shared within a peer group; and then a further code switch would occur when the student arrived at the family home.

By closer examination of this concept map and from the benefit of expert advice, along with a two day AE bi-dialectal education workshop, it was realised that the most productive focus for health care dialogue would be in the realm of AE 'Home Talk' as opposed to the variable circumstances of code-switching. The tendency to over-reach applied to both initial domains, and these were then abandoned in favour of new concept maps and ontology constructs.

Understanding of the ontology building and application support principles was a learning process necessary to ensure that data collection analysis and abstractions from the two major domains would prove to be sufficiently robust to provide a workable framework. Effectively this amounted to constantly testing while constructing concept relationships and still searching for credible AE healthcare pragmatics and paralinguistic[8] forms with which to populate and cross-map the two ontologies.

6.4 Abstraction of Aboriginal English schema and other related data

In the course of this research a number of shifts have occurred resulting in changed perceptions about applications, mostly due to what has been discovered or learned about Aboriginal and other ethnic group communication and clinical encounters in the health care service environment. A multiplicity of applications and of desirable deliverables and outcomes, and the constant change in technological capabilities dictates that it will be unwise to specify, as opposed to contemplate, the finite detail of the end user application. The scope of the anticipated applications domain however can be specified, i.e. assistive T2DM related communications for

practitioners, for patients, for patient carers, for patients' families, for health care interpreters and for emergency paramedics.

6.4.1 Revised approach

There is no literature describing relevant pragmatic healthcare dialectal expression using Aboriginal English Home Talk (AEHT). Such references as anatomical descriptions and self-descriptive biophysical characteristics, signs, symptoms and conditions generally appear in hardcopy or DVD media published by health care provider organisations, and then only in basic Standard English, along with graphical representations that attempt to convey a cultural connection with Aboriginal art. These media are constrained by knowledge of and respect for cultural taboos. For example gender sensitivities referred to by Aboriginals as 'men's business' and 'women's business' make it prudent to avoid publishing material that may offend the practice of separation of intimate sexual discussion; a factor also pertinent within other minority communities.

The single event focus group as described in this Chapter took more than twelve months to arrange. It was learned from the focus group experience that much of AEHT for health care comprises cultural metaphors and euphemisms. Ethics-approved individual Aboriginal interviews attempted proved disappointing and unproductive because Aboriginal Health Workers (AHWS) and trainee nurses, most of whom live in urban communities, tended to automatically respond in Standard Australian English. They apparently experienced difficulty converting to AEHT when speaking with a non-Indigenous researcher. The reality of this scenario is more complex than will be described here. As explained to the author by Aboriginal mentors, there is a very resilient disconnection between Aboriginal and the Western dominated culture of Australia. It is a significant influence on unsatisfactory health care outcomes.

A modified emphasis on data collection without interviews came about through a combination of reasons. Because this research engages three distinct domains, i.e. health science, ethnography and ICT, the development of trusted relationships within the Aboriginal community is seriously time constrained, and even more so in the rural/remote context. It represents an early part of a much lengthier process and in

common with other facets of this work typifies a preparatory pathway for continuing system enhancement leading to productive cross-cultural communications.

The literature and professional/mentor advisor sources have shown that Aboriginal people have to a large extent become sceptical and wary of researchers, in part because they rarely see any short term benefit, and quite often perceive that there is no longer term feedback of any worth. Effectively the original plan to gather and collate for mapping an extensive unpublished dialectal set of AEHT words and phrases was not achievable within the required timeframe. This was compounded by the need to keep health care and ICT research current and valid, and to arrive at the principal purpose of delivering an Assistive Communications Technology framework.

6.4.2 Aboriginal English in healthcare field studies

Among the voluminous wide ranging literature sources digested were three PhD theses that closely relate to the communication/mediation issues that are the end point focus for this work (Martini[9], Seaton[10] Taylor[11]). All originated within Health Sciences. Only one of these dissertations contained ICT matter, and none contained references to AEHT although much was written about ethnicity. They were all authored by qualified non-Indigenous nurses working in Australia. The one that included ICT did not enter into any technical detail as it was largely a philosophical examination similar to a Humanities approach; dealing with the adoption of Telehealth systems in WA and specifically the absence of consultation with rural/regional communities. The relevance here is that all were immersed in rural and remote nursing; their writings demonstrate many of the engagement complexities and both explicitly and implicitly the need to spend a great deal of time with the communities.

Knowledge of AEHT and the effort to align mapping for PPIE dialogue must be accompanied by deeper appreciation of history, tradition and much more of the cultural uniqueness of the Aboriginal communities. This can only be developed at the pace of learning dictated by the patient community. This conclusion is borne out by many writers and is succinctly described by Burchill[12], an Aboriginal woman from

Northern Victoria writing of her experience after five years as a researcher and the opportunity to comment on unsatisfactory practices of non-Indigenous researchers.

6.4.3 Unpublished influences in communications framework design

The findings as touched upon above have a direct bearing on the framework-building research. While confronting research continuity obstacles discoveries about communications efficacy have been made that are not fully explained by others, within or without the literature. These have changed the research posture. Many of the author's Aboriginal encounters in Western Australia (WA) have resulted in and still retain the goodwill of Aboriginals who want to see progress in this arena. Predominantly but not exclusively these are individuals engaged in healthcare services work.

Whereas the ethics conditions for focus groups and interviews have been observed, it has been a less informal, more personal, friend-oriented interaction that has proved more revealing and more contextually informative. There persists in such exchanges both implicit and sometimes explicit for non-attribution of any statements made or advice offered by the Aboriginal mentor. But because there have been so many non-responses from Aboriginal people of varied social standing; including university academics and directors of public health care units; author questions have been posed about choice of method, the possible influence of personality traits, and whether as a non-Indigenous researcher I have failed to identify sufficient alternatives to achieve a different outcome. It should be acknowledged that these are people with whom this author already had personal dialogue and in many cases, exchanged email addresses and telephone numbers after initial meetings. The expectation that they will keep their promises and their interest has too often led to the opposite outcome and protracted time-consuming effort on my part.

With the aid of trusted and qualified advisors and literature sources it was concluded that the limited response causative factors are not a personal reflection on my method of approach. Nor are they a reason for improperly attributing or perpetuating negative perspectives of Australia's Aboriginal culture 'values systems'. To the contrary they are pertinent to the central issue confronting healthcare service and

specifically the PPIE setting; and thereby to the communications design goals of this work. They are those cultural disconnects, not just with non-Indigenous researchers, but with the system, with western linear processes, temporally disciplined and objective-driven research. There is a strong inference that the desirable continuation of this type of communications work will be most likely to succeed if Aboriginal researchers become directly and significantly committed and involved in a team stakeholder endeavour.

The so-named ‘disconnect’ between dominant and ethnic minority cultures is amply illustrated by the anthropological perspective of Australia’s Aboriginal peoples, believed to be the oldest continuous culture on earth[13]. A serious student of Australian history will discover that pervasive non-Indigenous stereotypical depictions of Aboriginal people, with predictable exceptions, are misinformed and unsafe within a healthcare solutions seeking scenario. These relate to such western oriented measurements of worth such as punctuality, work ethic, and social responsibilities, among many judgement biased observations.

6.4.4 Cultural estrangement complexity acknowledgement

The complexity of the cultural estrangement is not examined in this thesis. It is the existence of that complexity however that exhorts protection of the necessary acculturation in building assistive communications technology capability, systems and devices. The literature clearly shows that translation of language alone is not an adequate vehicle for achieving mutually cognitive success in cross-cultural health care dialogue. The lessons available from the Aboriginal experience that has resulted in the existence and usage of AEHT provide signposts for design pathways to meet the ACT challenges for PPIEs involving disadvantaged ethnic minority migrants. These patients include refugees whose prior and ongoing traumas can exacerbate difficulties in communication.

6.4.5 New media communications influence

The challenges and barriers encountered in the initial effort recounted above brought about certain realizations that have determined the revised course of the research. These include the realization that the seeds of the envisaged mode(s) of assistive

communications technology applications for PPIE already exist in the form of social networking ‘new media’ practice. Web sites, blogs, Facebook, Twitter and mobile telephone access sources are engaged by a multiplicity of cultures yet are dominated by the English language and the western culture.

There is evidence showing that migrant groups use online ethnic support via ‘new media’ to help them adapt to living within a new host culture[14]. In effect, dialectal exchanges of ethnic origin bring about an improved understanding of ways to engage in Australian life including healthcare, by sharing data and system knowledge transfer. This form of interaction brings with it new paradigms for PPIE methodology, healthcare education and training.

6.4.6 Aboriginal English schema source work

This research involved study and harvesting of conceptually helpful data from a very large volume of language and human dyadic communications research literature outside of the healthcare domain [14-52]. This is primarily a trawling and analysis process to capture and build a store of useable cues, clues and evidence to improve understanding and system integration of Aboriginal English pragmatic concepts. It is therefore centred on AE knowledge assimilation, but also includes literature in which researchers explore among many related fields the differing factors of cultural and psychological habits and traits, beliefs, emotion, and child education. All play a part in the success, indifference or failure of two-way human engagement. The human-machine computer technology relationship research literature is included with the same cross-cultural perspective, searching for signs of consonant patterns to enable ontology work that will support a workable assistive communications framework. The parent class hierarchy of the AE domain ontology is shown at Figure 26.

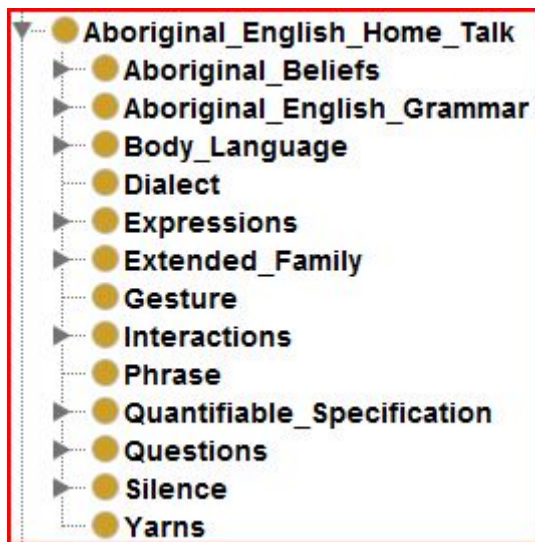


Figure 26: Aboriginal English Home Talk hierarchy

As a design caveat the essential need to anticipate AE to T2D concept mapping difficulties and the viable integration of multiple coactive facets of two otherwise unconnected domains requires a pre-design appreciation of differences in grammatical constructs. In other words, there is a need to be cautious when attempting to identify and agree forms of expression so that these do not alter the source (AE or T2D) meaning and relationship when cross-mapped. Becoming aware of the minutiae of grammatical conflict does not of itself offer an easy path to a set formula for language conversion. The dialectal grammar constructs, used contextually in a PPIE conversation, vary too greatly to support a literal direct translation, word for word, and/or phrase for phrase.

This study emphasizes that pending very extensive and time consuming future pragmatic and paralinguistic concept development, the framework should provide a vehicle for user understanding of cultural grammatical and cognitive differences; sufficient to help mitigate mistaken assumptions and expectations. This contention is mainly directed at the practitioner who invariably takes the initiative and has the power-primacy-based role in the PPIE.

In the AE data research and analysis early note has been taken of the dialectal constructs; in part to learn of mistakes to avoid and mostly in order to decide where and how to inject information into the framework to enhance user knowledge and

enrich the eventual application system. This approach was very important for bringing together the AE research literature data and concepts with the focus group output, as the inadequacy of a possible literal translation model was not immediately evident at the outset of this research. Moreover in spite of the search effort no AE health care dialectal vocabulary was available before the focus group session was held. A reasonable grasp of the implications helped the focus group process both in the preparatory negotiation and the actual event.

The pre-event consultations with the focus group host administration and moderator and the scripted wording of the introduction to the session were positively influenced by prior knowledge of the challenges to the non-Indigenous researcher of AE grammatical constructs and their contextual nuances. Appendix A contains the focus group preparation information. For the sake of underwriting the rationale of this grammar and focus group qualitative research methodology, included in this section is reference to some specific AE schema research findings and use in introductory ontology work.

6.4.7 AE grammar data sample

In early reviews of AE an infinite and intricate combination of semantic, syntactic and pragmatic challenges were discovered with many permutations of linguistic patterns. Table 8 provides a data sample, giving a variety of representational types that may influence the conversational modality within the PPIE.

Syntactic/Pragmatic role/relevance	AE representation	SAE comparison
Word	Camp	Home
Word	Mob	Group
Word	Lingo	Aboriginal language
Words/phrase	Sorry business	Ceremony associated with death
Words/phrase	Grow (a child) up	Raise (a child)
Word	Growl	Scold
Word	Gammon	Pretending, kidding
Word	Cheeky	Mischievous, aggressive, dangerous
Word	Solid	Fantastic
Phrase	To tongue for	To long for
Pronunciation	Enry's at	Henry's hat
Consonant pattern	Dere	There
Consonant pattern	Dat	That
Consonant Pattern	Bight	Fight
Word class change	Don't liar dad	Do not lie dad
Irregular verb use	We caught	We caught some

	snakes	snakes
Zero verb 'To be'	Dey poisonous	They are poisonous
Transitive Object marking	Dey catchem fish	They catch fish
Transitive Object marking	Then when em startem up dat motor	Then when they start the car engine
Quantification	An dere was a bi-i-g mob dere	There was a large group of (people etc) there
Tense	We was	We were
Redundancy marking	Ding	Thing
Question forms	What are you cutting dat, you cut dem small or sumpin?	Why are you cutting that? Are you cutting them into small pieces?
Plural marking	We seen lots of snake. I seen youse. We see monkeys.	We saw many snakes. I saw you. We saw some monkeys.

Table 8: Comparison of selected Aboriginal English (AE) pragmatic syntax and Standard Australian English (SAE). Selected sources: [32, 33, 36, 42]

The linguistic patterns mentioned above may vary regionally, notably in the use or non-use of consonants; and in the third one listed in the table, is the common word initial change so that AE pronunciation differs, with “b”, “p” = “v”, “f” in SAE. AE also commonly applies change to word class, in the instance shown the SAE noun becomes an AE verb. Irregular verbs are commonly formed via analogy with regular verb forms as shown with the word “caught” equating to the past tense “caught”.

The copula; e.g. *is*, *am*, is not required in AE. Transitive object marking applies to verbs that are sometimes marked for having an object (a noun to follow). Measurement of space and time is typically non-specific. Expression of quantity or proximity often involves use of sound effects, usually with elongation. All AE past tense words are frequently made to look like the first (person singular). Redundancy marking frequently occurs as a marker of previous or assumed information which is not repeated. “What” replaces “why” in many interrogative sentences. Plural marker “s” is not always used but may be used when there is no quantification. The second person pronoun may use the plural marker “s”.

6.5 Merging ontologies grammatically and contextually

One of the several challenges is the creation of sufficient flexibility in the function and relational aspects of the ontologies. The embedded discipline of existing clinical guideline compliance for instance infers a chrono-linear step by step checklist process, while recognising variables that will create deviations and diversions. Effectively the AE PPIE support model will anticipate and accommodate more diversionary influences, partly illustrated by the AE data sampling above and in contrast to past practices and preferences of healthcare practitioners.

Western logic does not satisfactorily match the Aboriginal worldview. This is amply illustrated by the findings of the QGA discussed later. This means that relationships between concepts in the ontology are influenced by variable patterns in which semantics and syntax are heavily dependent on surrounding context, as determined from the broader conversational content. AE expression does not reliably accord with and can defy the norms of English grammar.

Looking ahead to the ultimate design process for the PPAC, a preparatory tutorial in the form of a system walk through Wizard must set the scene, differently for the two cultures, i.e. Aboriginal patient and health care practitioner. This will elaborate on the QGA barriers and how these can be overcome. Included in the ontology is a concept class *Aboriginal_English_Grammar* and sub-class concepts that allow for gradual population of Aboriginal English every day home talk words. It is accepted that a considerable effort is required in future work to discover and document more Aboriginal English home talk words, phrases and other forms of expression as part of a general vocabulary. Table 9 shows Aboriginal home talk English ontology population and Table 10 shows Aboriginal English ontology population in the context of healthcare.

Table 9

Ontology class(es)	Data Property 'inAboriginalEnglish'	Data Property 'inStandardAustralianEnglish'	Annotation (if applicable)
Adjective	big mob	a large number	
Noun		a lot of	
Size			

Adjective Relativity	big mob time(s)	a long time many times	
Adjective	charged keppered up	drunk	
Adjective	cheeky	aggressive dangerous mischievous	
Adjective Spirituality	clear	free from any negative free from undesirable spiritual associations	
Adjective Spirituality	clever	spiritually powerful	
Adjective	cruel	very a lot	
Adjective Spirituality	dangerous	hazardous	due to possible spiritual power intervention
Adjective	djerupin	excited excitable	
Adjective	for liar	not serious pretending	
Adjective	hard English	English words difficult to understand	
Adjective	moorditj mooditj	good strong excellent the best	
Adjective	open	empty nothing penniless pathetic	
Adjective	real soft	quiet	
Adjective Verb Expressions	shame shame job too shame	profound embarrassment self-consciousness expression of sympathy	
Adjective	solid	fantastic	
Adjective	wicked deadly	Enjoyable Cool	
Adverb	dreclly	now	

Relativity		quite soon directly	
Noun	a bake	a roast meal	
Noun	a roast	a barbecue roast cooked meat an open fire	
Noun	bird feather	spiritual symbol	
Noun	boya	money	
Noun Blood- related_Family Community Non-related_Family	budda	brother	
Noun Verb	camp	home staying somewhere	
Noun Spirituality	debil	evil spirit	
Noun Adjective Verb	dinner out	eating of a meal outside	
Noun	emu	type of large bird a person with thin legs	
Noun	feed	food	
Noun	fellah fulla	man	
Noun Blood- related_Family Non-related_Family	grannies	grandchildren grandmothers	
Noun	horse	powerful a stud	used to recognize impressive capability in others

Noun Blood-related_Family Community Non-related_Family Mutual_Respect	huncle	uncle nephew	two-way use of same title
Noun Adjective	hungry mans	charming young men	
Noun	kepa	alcohol	
Noun	kulunga	child	
Noun	kwon	backside	
Noun	lingo	aboriginal language	indigenous traditional native language
Noun Plural_Marking	mans	men	
Noun	mob	family community group	
Noun	modiga	motor car	
Noun	monartj black cockatoo	uniformed policeman	pronounced 'monaach'
Noun Blood-related_Family Non-related_Family	mum	mother female who is not the biological mother	common practice in extended families is to apply mum to several people; as is the case with aunty and uncle
Noun	ole girl	elderly woman	term of respect
Noun Blood-related_Family	pop popeye poppy	Grandfather	
Noun Spirituality	rain	spiritual reference	in context of nature
Noun	song	message	possibly from a

			spiritual source
Noun Adjective	sorry business	death of an Aboriginal the ceremony associated with death	
Noun	wadjella wajala white fella	non-Aboriginal person	
Noun Plural_Marking	womans	women	
Noun	Yorga	woman	
Past_Perfect_Tense Past_Tense Present_Tense	bin	been have been am	
Verb	blonga blon bla	belongs to	
Verb	campin	staying overnight	
Verb	chargin on charging	drinking alcohol	
Verb	cheeking	teasing telling off	
Adverb	dere	there	pronounced 'dair'
Verb	finish up	die pass away	
Verb	gammon	joking kidding pretending	
Verb	go for	go hunting for	
Verb	grow (a child) up	raise (a child)	
Verb	growl	scold tell off	
Verb	hold	to spiritually own care for be responsible for	
Verb	jarring	swearing cursing	

		telling off	
Verb	kangarooin rooin	hunting for kangaroo	
Verb	learn	teach	
Verb	ney neh	stop listen	
Verb	pick up	choose collect pick up	
Verb	reckon	saying thinking	
Verb	schooling	going to school	
Verb	shelling	collecting shells	
Verb	smellin ourself	sleeping	
Verb Phrase Seeking_Agreement	unna inni	isn't it? it is, is it not?	
Sympathy	choo chew	sympathy	
Pronoun	dat	that	
Pronoun	dis	this	
Pronoun	dem	them those	
Pronoun Plural_Marking	youse	you	

Table 9: Aboriginal English ontology population

Table 10

Ontology class(es)	Data Property 'inAboriginalEnglish'	Data Property 'inStandardAustralianEnglish'	Annotation (if applicable)
Adjective Noun	black and gold	Cheap supermarket food.	Aboriginal people without adequate English proficiency unable to read food labels use

			‘Black and Gold’ brand packaging to identify inexpensive purchases.
Adjective Noun	bung eye coyee eyes	conjunctivitis	
Adjective Verb	crook feelin’ crook under the weather	generally in poor health feeling unwell	
Adjective	winyarn	bad poor weak	
Noun Feeling_Shame Gesture	bacon and eggs breakfast livener having a livenar	alcoholic drink consumed the morning after a night of excessive consumption of alcohol	
Noun	booras boogas boogadies	shoes	
Noun Adjective	bush tucker	traditional Aboriginal food	suited to healthy wellbeing of Aboriginal people.
Noun	coke bottle coke bottle lens goora bludgers second eyes	eye glasses spectacles	
Noun Adjective	deadly tucker	really good food for the Aboriginal person	
Noun Adjective Verb	giddy	insulin feeling weak tired fatigued	
Noun	gina djena	feet	sounds like “Jinna”
Noun	good stuff	alcoholic drinking	

Adjective	plumber kepa		
Noun	gooras	eyes	
Noun Adjective	sugar sugar sickness funny sugar	diabetes	
Verb	buzzing	tingling sensation feeling of ‘pins and needles’ in extremities	
Verb	flashies	numbness tingling in hands/fingers and/or feet/toes	
Verb	gettin blue	becoming drunk	

Table 10: Aboriginal English ontology population in context of healthcare

The tables present a somewhat disparate choice of words and phrases that at first sight appear to have little relevance for a PPIE. Viewing this through the biopsychosocial lens however, it is possible to learn how words can help to create context. For example, a practitioner treating a diabetic patient is interested to know about dietary practices of the patient. Speaking about food, the patient will use the word ‘feed’ as a noun, not necessarily as a verb. When speaking about a diet that includes sources such as flora and fauna, such as wild berries and kangaroo meat, the patient may refer to ‘bush tucker’. The complete description comprises these two words, and separately the words ‘bush’ and ‘tucker’ may not truly reflect what is being described. Moreover the phrase ‘deadly tucker’ does not mean poisonous food, but effectively the opposite, i.e. really good, enjoyable food for the Aboriginal person.

6.6 Belief systems data abstraction

One of the most delicate areas of PPIE discourse with the Aboriginal patient is the presence in the patient’s mind and worldview, of beliefs unfamiliar to the practitioner. This features strongly in the QGA and includes spirituality factors. It is always possible that the patient has been following traditional remedies and community consultations with respected Elders who have a holistic approach to

treatment and care, including what is sometimes referred to as ‘bush medicine’. A patient mentioning a song and ‘debil debil’ would be revealing a spiritual belief in a supernatural message and an evil spirit. Cultural competence, at the top of QGA findings list, is therefore a major objective in the development of the ontology, of enrichment of property annotations, and investment in user tutorial design. The possibility that discussion about alcohol consumption and visual impairment

6.7 The Focus Group

Twelve months of negotiation and trust-building resulted in a focus group of trainee enrolled nurse volunteers assembling at Marr Mooditj Training, Waterford, on Thursday 14 April 2011. This arrangement took place in compliance with Curtin University HREC ethics approval 72/2010. The facilitating documentation comprising the participant information sheet and the moderator preparation script is at Appendix A. The transcript from this focus group event is at Appendix B. The volunteers comprised seven female trainee nurses and three male trainee nurses. Two female Aboriginal staff acted as advisers/moderators. In attendance as observers were the author of this thesis and Dr. Jaipal Singh (PhD), Research Fellow PhD Curtin University.

All participants except the observers and moderator are de-identified. Signed consent forms including authority to audio/video record the session; together with a copy recording are held in a confidential restricted access file. No participants have elected to take up the option to view record copies. The session was a positive experience for all present and the trainee nurses proved to be enthusiastic contributors the majority of whom expressed support for the research objectives. The following section enters into key aspects of and includes excerpts from the focus group output which have played a constructive role in building the system framework.

6.7.1 Focus group data output and analysis

Two T2DM care related subject matters of import which carry implications for rural and remote Aboriginal patient communities received a good deal of focus group attention. These concern vision impairment; and the consumption of alcohol. This

increased my curiosity for a better understanding of both topics, separately and conjointly, in the Aboriginal context; and thereby the knowledge for a formal construction of concepts and relationships within the ontology-supported machine readable system. In later parts of this chapter and in Chapter 7 I continue with illustration of this construction work, inclusive of detailed alcohol and vision ontology concept relationships.

6.7.2 ‘Yarning’

The most common practice for exchange of information in Aboriginal community groups is known as ‘yarning’. This is made up of friendly storytelling narrative and a fluid cross-talking conversational activity that at times can make precise determination of content elusive. In the focus group setting any effort to impose a western culture style of control for the benefit of greater clarity would endanger the prospect of genuine unfettered productive engagement. In this focus group venue, an Aboriginal moderator’s prior familiarity established with the group was an important influence. She was the principal nursing course organizer and had daily contact with the participants.

Particular care was taken with the setting arrangements to ensure that the focus group was conducted in accord with best known practice established through a number of credible sources, including the advice of the experienced Aboriginal and non-Indigenous teaching staff at Marr Mooditj Training. Marr Mooditj hosted the session in a teaching area of the college building complex.

A primary objective from the focus group exercise was to secure single words and phrases that are recognized as commonly used in the Aboriginal English home talk environment and in the health care context. The student nurses identified their normal home locations but in the interests of de-identification of participants under ethics approved protocols, this data was not recorded. A little more than sixty percent were from urban locations; the others were from regional parts of Western Australia bordering and serving both rural and remote communities. The predominant Aboriginal community represented was the Nyungar group from the southwest; but it was evident from interactions that there was a shared understanding of the role of

Aboriginal English and of the variations arising from differences across state/regional Aboriginal groups. This occasionally arose through mention of a word that was not familiar to those of the Nyungar family. For example ‘livenar’ also spelt ‘livener’ in the focus group was explained as ‘a morning drink, to fix you up’. This is apparently a derivation from the old and now uncommonly used British slang word ‘Livener’ referring to an alcoholic drink[53]. The word may be used in varying context and in the focus group interpretation it implies that it is viewed as a ‘morning after fix’ following excessive prior consumption of alcohol. The British slang version however is pronounced with the ‘i’ as in ‘life’, whereas the Aboriginal English version as expressed in the focus group was pronounced with an ‘i’ as in ‘give’. The word is not in regular use among non-Indigenous Australians and from the focus group comment appears isolated to the rural and remote communities where alcohol abuse persists. I include this observation only in the context of T2DM comorbidity risk and relevance for ontology concepts. This simple example is an illustration of the dialectal adoption, adaptation and survival of words from the colonial history of Australia; and the continued use of words in an almost exclusive sense by the Indigenous community.

For the purpose of illustration here, I recount two specific topics from the focus group subsequently pursued in the framework construction exposition. These concern the T2DM care focus on consumption of alcohol and the relationship with vision impairment.

6.7.3 Focus group contribution on alcohol AE semantics

The proposed PPAC system offers advice for practitioners when asking questions of a sensitive nature. This account of the focus group output touches on the ontology construction, anticipating ontology querying and retrieval of results. This specifically surrounds a PPIE investigation into a patient’s alcohol consumption.

Independent class *Type_2_Diabetes_Concepts* subsumed *Care_Management* has the subclass property *Alcohol*. The function here is not to define alcohol, but to help with the PPIE in the context of assessment of the patient’s lifestyle, habits and risky behaviour. The latter concerns the excessive consumption of alcohol, which is known

to create a very high risk of T2DM comorbidities, including kidney damage or disease (*Condition_Description Nephropathy*) and vision impairment (*Condition_Description Retinopathy*).

As the subject matter is not comfortably or openly discussed by Aboriginal patients with their practitioners, the focus group explained that this research must recognize the metaphors and euphemisms which are employed to conceal what the patient may not be prepared to admit. These AE labels and phrases are sometimes conversational per group pieces that make light of, or even encourage humour about, excessive drinking of alcohol. Some terms as discussed below take on an ambiguous meaning, in that they are sometimes used to advocate further alcohol consumption on the morning or day after an evening or night of excess, in order to stabilize 'normal' physical and mental functioning. In western cultures the historical English metaphor for this is 'a hair of the dog'. The various steps leading to conclusions about excessive alcohol intake and the identified harm come under the *Diagnosis_Process* subclasses.

The focus group offered several expressions as typical of the Aboriginal English dialectal discourse about alcohol. The following is the complete sequence on this topic, with the most pertinent word phrase and explanatory concepts underlined:

Mix all the drinks too like beer, spirits, mixing different alcohols

Does um, opening up the question, does it bring about shame?

About drinking?

When you talk to the patient

The patient doesn't volunteer straight away that they drink too much, none of us do that do we

But If you raise the subject with your patient, are they gonna talk openly about it?

Some, some may say mind your open business

nah

Some do

It's not your life....

Depends on how much of their trust you got, if you been seeing them for a well

Yea charging last night, yea party animal

Charging?

Yea, like drinking

That's the phrase?

These are the golden words

coughing

Getting blue, yes

Good stuff

Plumber

Livenar

Yea, I'll just have a livener

Having a livenar

How the hell do you spell that?

A livenar?

Live - nar

I've heard chargin before, I haven't heard livenar

A livenar is a morning drink, to fix you up,

Ohhhh

Like 'oh I need a livenar, I got the shakes'

Yes, they think a livenar will spruce them up

So people would say hair of the dog would be a livenar?

Yea, exactly

Yep and then the people that know that, they can tell you been drinking and that,

then people know if they talking about then they having bacon and eggs, you having
bacon and eggs as well

Ohhh

It's flowing now

Look at ya, you mob are full of this stuff, ay

If you had a drink, they'll know that you're a drinker, if you had a livenar...they'll
have Bacon and eggs

Ohhh, wow

They'll have their breakfast

And then they'll be right for the day then

Yea, a livenar in the fridge, if they get up or...ya know

Yea, they'll do that sign, yea, need my drink

Like the hand signal

Yea

Be like where you going?

I'm going to charge

* inaudible speech *

Is it a fist or is it...?

It's like a bottle, a drink bottle

A gesture?

The hand signal

* inaudible speech *

Where you mob going to?

Going to down to....

inaudible speech

Laughing

I need money

That's a really good one, eh

I hope you don't see it in the waiting room

Laughing

Oh well you might do

Or they use their lips going...(physical drinking gesture similar to pursing of lips)

Oh yes

--- End of excerpt --

The above enabled improved comprehension of the Aboriginal cultural pragmatic nuances and preparation of the ontology formalism for PPAC system use in the T2DM PPIE.

6.7.4 Interpretations for ontology concept instantiation

Livenar (or livener): has the Aboriginal English meaning 'Alcoholic Drink Consumed the morning after a night of excessive consumption of alcohol'. It is a

descriptive noun. It is also known in English colloquial and metaphorical parlance as a 'hair of the dog' or 'a fixer upper'

Having a Livenar: Aboriginal English meaning the act of consuming Alcoholic Drink during the morning after a night of excessive consumption of alcohol.

Bacon and eggs (Similar to Livenar): Aboriginal English meaning *a mixture of alcoholic drinks consumed the morning after* a night of excessive consumption of alcohol (Euphemistic descriptive noun)

Breakfast: (Similar to Having a Livenar): has Aboriginal English meaning the act of consuming Alcoholic Drink during the morning after a night of excessive consumption of alcohol. (Euphemistic verb)

In isolation, the alcohol discussion does not add sufficient strength to the veracity of the intended framework. Put together system-wise with the associated T2DM and AE topics that can arise in a PPIE, the subject becomes more contextually meaningful. The choice was exercised to triangulate the T2D concepts of alcohol consumption and vision (impairment risk), with the AE context category class *Aboriginal_Beliefs*.

6.8 Cultural semantics extrapolation vision, alcohol, Aboriginal beliefs

This section initially concentrates on the two related issues which are important to diabetes Aboriginal patients, i.e. on vision and on consumption of alcohol. Permutations of concept relationships necessitate some reiterative explanations as finer granulation and semantics vary the context of instances. Frequency of alcohol intake and particularly binge drinking (excessive intake of alcoholic drinks in one continuous or protracted drinking event) will determine practitioner advice to the patient. The RACGP guidelines make reference to hazardous drinking being more prevalent among Indigenous males and females aged 35-44 years compared with the general population[54]. Honest and accurate self-accounting for consumption is confronted by several barriers, one of which is the feeling of shame; akin to embarrassment. If the practitioner is disadvantaged through ignorance, the PPIE process will be far from complete or effective in the sense of the longer term value of health care intervention.

Having offered background perspectives on alcohol consumption and Aboriginal T2DM patients and before proceeding to conceptualize it within the ontology; attention now turns to research on eye health in the Aboriginal communities; and to the relationships, biophysically and within the ontology concepts and relationship structure.

6.8.1 Aboriginal eye health and diabetes

The 2011 AIHW paper ‘Eye health in Aboriginal and Torres Strait Islander people’ summarises the findings of the 2008 National Indigenous Eye Health Survey (NIEHS) [Australian Institute of Health and Welfare, 2011]. The survey shows that over the age of 40 years, Aboriginal and Torres Strait Islander people have six times the rate of blindness of other Australians. Although diabetic retinopathy was not individually quantified 13% of Aboriginal and Torres Strait Islander people with diabetes had visual impairment, with diabetes being the cause of 13% of low vision and 9% of blindness. Among people with all types of diabetes, diabetic retinopathy was present in 30% of people; and was found in 6.3% of those who did not self-report the diagnosis of diabetes.

The further output of benefit to this research comes from interactive statements which help to illustrate acculturative characteristics within the Aboriginal health care sphere. Much of this coincides with and validates qualitative gap analysis findings in respect of communications barriers. Acculturative interpretation is a key ontology modelling process for mapping and merging these domains, enabling sense-making of concepts and relationships. The bulk of this is represented through annotation properties (discussed later); and it will be these properties that guide the future Aboriginal English health and home talk collection and collation work that will enrich the instantiation of terms that can be shared across domains.

6.9 Qualitative Gap Analysis

The focus group experience and contribution from members of a Nyungar trainee nurse community in south west Australia illuminated innumerable difficulties in building a dialectal lexicon. No Aboriginal English healthcare dictionary exists, and this deficit includes published documents that might otherwise justifiably contain

Aboriginal English linguistic or paralinguistic healthcare data. Accordingly I have turned to the literature to apply in search mode the knowledge gained from the focus group and from other informal encounters. From personal contact it was discovered that many Aboriginal people prefer social informality versus formalised ethics-bound approaches. The contextual schema search process criteria for the purpose of the conceptual framework ontology comprised 42 (forty two) AE pragmatics-oriented domain words and descriptions. These explicitly or implicitly identify PPIE barrier characteristics. They are listed in Table 11.

Asking questions	Grammar	Pausing
Body Language	Hand Signs	Quantification
Ceremony	Implicature	Semantics
Classification difference	Interpreter	Shame
Code-switching	Language	Silence
Conversation breakdown	Lifeworld	Sounds
Dance, Music, Art (cultural health relevance)	Listening behaviours	Space
Dialect	Miscommunication	Spiritual
Dreaming	Misunderstanding Deadlines	Stories and Yarns
Eye Contact	Oral Traditions	Syntax
Exclusion	Phonology	Time
Extended family	Physical proximity	Turn-taking
Facial Expression	Precision	Vagueness
Family	Prosody	Worldview

Table 11: QGA contextual schema barrier characteristics search keywords

In the analysis process search for and identification of PPIE barrier contextual pragmatics 146 keyword-selected literature sources were reviewed. Sixteen of these were rejected after review, as having insufficient relevance or applicable detail to offer meaningful data formalisms. The remainder were initially divided into

- General (non-intercultural) discussion of patient-practitioner interactions; and
- Cultural (intercultural) commentary on the same.

Source data is further divided into three groups, i.e. intercultural was split into Cultural (non-Indigenous) and Cultural (Indigenous only).

The benefit of the General category is that it takes account of behavioural and institutional influences that may present barriers in PPIEs without a cross-cultural dimension affecting the interactions. As the concept framework aims to capture a bi-directional patient-practitioner assistive communications (PPAC) system, an equitable treatment of participatory sources is important, i.e. to recognize and resolve miscommunication that can occur due to westernized health care provider causal factors, as opposed to the more obvious characteristics of intercultural PPIEs.

- One hundred and thirty (130) literature sources were reviewed.
- Ninety-six (73.8%) of the literature sources were peer-reviewed, consisting of 91 Journal articles; four books and one doctoral thesis.
- The remaining 'General' sources were made up of professional web articles and expert-source healthcare and cultural communications advisories and submissions.
- Fifty-eight (58) sources reviewed were in the General category.
- Seventy-two (72) were Cultural; and of these, thirty two (32) related specifically to Aboriginal PPIEs.

Data was identified under the following three column headings:

- Source Reference
- Setting and Participants
- Communications Barrier (Gap) Characteristics

In the Communications Barrier (Gap) Characteristics heading the data identified as pertinent for populating the ontology are determined using the criteria of those cultural and contextual pragmatics documented in the several Aboriginal English educational literature sources, applying such measures as (for example) time and space dimensions; asking questions; stories and yarns, etc. Effectively this qualitative evaluation also provides a quantitative indication of the need to overcome PPIE communications barriers, e.g. the repeated reference by different authors and researchers to consultation time constraints as a barrier.

This quantitative view is reinforced by observing a negative factor. I deliberately searched for contra-indicators of the persistent published message about disparities in

health care service performance endured by Aboriginal patients in rural and remote areas. In spite of extensive research I found no contradictory evidence to refute the conclusion that Australia's regional Aboriginal community patients are disadvantaged and underserved in the PPIE setting; and the same applies expressly to the inequitable communications dimension. In simple parlance, consistent confidence in and satisfaction with patient-practitioner communication in primary care does not appear to exist among country living Aboriginal patients; but if it does, then no credible publication providing evidence to that effect has been found.

6.9.1 Elicitation for framework contribution

The voluminous output included considerable detail to facilitate further analysis. This produced an original working table exceeding 100 pages and 30,000 words. Borgatti avers a rule of thumb for distinguishing cultural domains, stating that they are about perceptions rather than preferences. His techniques include eliciting attributes and relations that structure the domain [55]. Much of his work relies upon human 'respondents'. In this instance, specific subject matter literature and findings is treated as similar to a form of response. Subsequent analysis, in part drawing upon Borgatti's free-list and pile-sort techniques for eliciting items in a cultural domain firstly reduced the table to sixteen pages and 5,200 words. The next stage in this process narrowed the field of barrier characterization to seventeen sub groups. The final stage consolidated these into seven main attributes that are identified as overarching terms describing PPIE cross-cultural barrier communications, thereby providing semantic and syntax priorities for building the PPAC ontology.

The final working table is too long to include in the body of this thesis. A full QGA reference source is published at Appendix C. To provide more background to the QGA concept relevance collation method, single examples illustrating the more detailed mid-process table content for each of the categories, 'General'; 'Non-Aboriginal-cultural' and 'Aboriginal-cultural' are as follows:

General

Source: D. Angus, et.al [56]

Setting: Analysis of conversational behaviour in consultations, using an

automated computer visualization measurement technique.

Communications Barrier (Gap) Characteristics

Too much practitioner time ‘off-topic’ with rapport but at expense of developing health narrative, may represent poor task focus. Over-Use of check-lists can hinder health narrative development. Best conversations characterised by appropriate accommodation in approximation, interpretability, and discourse management. Patterns of interaction uncovered may explain why patients feel constrained by time or that doctors did not understand their needs.

Non-Aboriginal-cultural

Source: Australian Human Rights Commission [57]

Setting: Highlights of consultations interviews and public submissions with African-Australian community and stakeholders.

Communications Barrier (Gap) Characteristics

Culture shock. Breakdown of family ties. Language barriers. Health problems from food and diet changes. Lack of access to culturally appropriate health services. Inter-generational conflicts. Breakdown of traditional cultural lifestyle and values. Discrimination and racism. Children language brokers. Lack of knowledge: hygiene practices; sexual health; nutrition; importance of exercise. Practice of politely agreeing they understand doctors when they do not (gratuitous concurrence). Discrimination and stereotyped responses; lack of interpreter; reliance on family members resulting in wrong diagnosis; lack of awareness of health professionals; inadequate cultural skills; problems with translation and miscommunication.

Aboriginal-cultural

Source: J. Kelly et.al [58]

Setting: This study uses a framework derived from analysis of staff and patient interviews. It identifies five underlying factors that affect the needs and experiences of Aboriginal patients from ‘the country’(remoter parts) who come to Adelaide for care It is the *interaction* of all these underlying factors—being a country person in a city setting, experiencing a high burden of illness (and needing care across the hospital/nonhospital divide), perhaps not having English as a first language, perhaps being poor, and being Aboriginal in a mainstream system—that makes city hospital

care for country Aboriginal patients a unique challenge for them and their carers and staff. Note that not all Aboriginal country patients experience all of these factors equally or uniformly.

Communications Barrier (Gap) Characteristics

The Australian Indigenous Doctors' Association has developed a comprehensive model of health in five dimensions, for the purposes of assessing positive and negative health impacts building on existing definitions of Aboriginal and Torres Strait Islander health:

- Physical or biological—morbidity, mortality, chronic conditions, self-reported health
- Psychological or emotional—levels of stress, trans-generational and cumulative trauma, freedom from shame, discrimination, racism
- Social wellbeing—family and kinship systems, community cohesion; access to quality housing, education, employment, living conditions, support services; self-determination, participation, trust, social inclusion
- Spiritual—recognition and respect for Aboriginal people, worldviews, knowledge, values and aspirations (enacted in policy and programs); hope and despair
- Cultural integrity—levels of community control of health, education, land rights, police and fire protection.

In the intercultural non-Indigenous category, Kokanovic and Manderson explored the perceptions of Australian immigrants on their interactions with doctors for T2DM care [59]. Patients of Greek, Indian, Chinese and Pacific Islander origins living in Melbourne, were surveyed, disclosing a range of engagement barriers affecting both patients and practitioners.

In the Aboriginal literature category, Anderson et.al conducted a large interview study involving nine hospital renal units and 17 associated dialysis centres treating Australian Aboriginal early stage kidney disease (ESKD) patients. Among many barrier observations, Aboriginal patients were characterized as confused, frustrated

and poorly informed; accompanied by uncertainty about illness causation; and perceived exclusion from information [60].

Lastly, from the Aboriginal category Schoen et.al report the ‘startling age specific rate ratio for amputations in 25-49 year olds; of 41.25 for knee amputations and 27.5 for toe/foot amputations’ for Aboriginal compared with non-Aboriginal people[61]. They express alarm at the lack of free education resources for Aboriginal people on foot care. ‘Participants were unequivocal in their preference for real pictures of foot problems rather than cartoons’.

The findings from the QGA combine with the other schema source data reported in this Chapter, to facilitate ontology construction. The QGA findings however are also instrumental in another aspect of my research methodology, the development of simulated case studies.

From this evident cultural communications complexity and from study of those broader societal Web-based accessibility trend indicators, I conclude that

- reinforcing earlier comment, disadvantages affecting Aboriginal and ethnic minority communications in health care are likely to be exacerbated as the ‘digital divide’ of accessibility to interactive information sources widens; and
- investment in building taxonomic and relational data servicing pragmatic communications systems is a priority.

This prompted case study simulation of practical lessons that will suggest design implications for efficacious human-machine and human-machine-human healthcare interactions.

6.10 Patient-Practitioner Interview Encounters (PPIEs) analysis contribution

Table 12 displays the consolidated data from the penultimate and final QGA stages. Reference to the QGA work continues for its direct value in PPIE analysis. The QGA method discussed in 6.8 produced the results shown in Table 12. This output focuses on ontology design needs for PPAC framework ontology input for PPIEs involving Aboriginal English speaking T2DM patients. It emphasizes distinct values of cultural competence and biopsychosocial sensitivity as well as overcoming the

more obvious linguistic and paralinguistic obstacles encountered by Aboriginal patients and their practitioners in health care consultations.

Overarching Term for PPAC Ontologies Priority	Subgroups identified from Qualitative Gap Analysis (QGA)	Ontology contextualization. Communications barrier mitigation factoring
Cultural Competence (51)	Cultural Competence (39) Cultural Awareness (6) Cultural Safety (6)	Navigation and negotiation design for two-way cross-cultural cognitive consonance
Biopsychosocial (44)	Biopsychosocial (16) Emotion (11) Empathy (10) Practitioner dominance (7)	Emphasis of PPIE subclasses attributes/properties prompting inclusion of psychological and sociological as well as biomedical issues in the PPIE
Language (42)	Language/linguistics (21) Interpreters (11) Terminology/jargon (6) Storytelling (4)	System recognition of role of language barriers. PPIE syntax simplification; Aboriginal English dialectal accommodation; interpreter engagement advice.
Beliefs (40)	Beliefs (17) Lifeworld/Worldview (10) Concepts/taboo (9) Spirituality (4)	Extension of Cultural Competence. System recognition of role of Aboriginal holistic health including healthcare and death perceptions.
Education (28)	Education (19) Training/Retraining (9)	Extension of Cultural Competence, query and response FAQ type system knowledge transfer prompts. <u>Practitioners</u> : professional cross-cultural educational content. <u>Aboriginal Patient/Carer</u> : Using Aboriginal English pragmatic syntax and semantics to informalize and overcome T2DM and PPIE cognitive dissonance.

Family (25)	Family (15) Community (10)	Annotative inclusion of extended family and community terms and their relationship with individual member health/healthcare occurrences. Aboriginal family structures, names and contra-Western cultural constructs
Time (23)	Time – Cultural/temporal interpretation (6) PPIE Time Constraints (17)	Quantification and measurement guidance to engage/comprehend Aboriginal concept of time and timing of health ‘events’. Annotative advice on psychosocial impact of PPIE time limits affecting cross-cultural patients.

Table 12: Qualitative Gap Analysis (QGA) barrier characteristics

Barrier characteristics found in the QGA literature analysis were either specific or semantically inferred and confirmable through contextualization. Where specific terms were absent, participants were treated as active, passive or unsuspecting contributors to communications barriers. For example, ‘cultural competence’ was a very clear attribute though these words were not used, in articles describing PPIE type occurrences where health care providers were either ignorant of or indifferent to cross-cultural engagement for the wellbeing of an Aboriginal patient. If ‘cultural awareness’ or ‘cultural safety’ appeared in any QGA literature source, sufficiency of detail and context determined whether or not ‘cultural competence’ would be added to the classification.

6.10.1 Broader PPIE framework concept scoping

This work has relied upon evidence based research literature and mentor guidance to accumulate practical knowledge of both theoretical and actual practice in the PPIE. The literature review for this purpose included an analysis of findings from empirical research conducted in countries other than Australia. The objective of this global scoping exercise was to assess the extent of communications barrier awareness in the health care service provider industry; and to discover if applicable the existence of

measures being practised or developed to counter intercultural and disadvantaged patient communications difficulties.

Canada has a similar history and disadvantaged remote living Aboriginal population, and the similarities extend to disparities in health, healthcare access and communications [62-65]. In the QGA articles reporting Australian health care service practices and type 2 diabetes care affecting Aboriginal patients were linked in the barrier context through comparisons with accounts of PPIE conduct where cultural differences were not of consequence to the researcher; others that involved cultural differences between non-Indigenous patients and their practitioners. The studies of Australian Aboriginal PPIEs effectively compounded what was being found in the other groups, i.e. that PPIEs in great proportion are overly biased in favour of the western medical culture uni-directional mode of discourse dictated by the practitioner. The further methodology explanation shows how I have identified collated and strengthened the potential value of many less tangible traits that can help infuse the AE cultural contribution in the PPIE context.

Two important framework component factors of interest in this acculturative communications exercise are T2DM and ICT. In the non-intercultural category, Hayes and Aspray writing on health informatics of diabetes, refer to ‘the socially and institutionally sensitive use of information technology’ [66]; and Lustria and Brown in an accompanying book chapter cover ICTs for diabetes self-management and education (DSME) and ‘commonly focus group cited barriers’ to DSME [67].

6.11 Practitioner/provider role factor

There is a tendency in the literature to assign barrier causative factors in PPIE performance and outcomes to the practitioner/provider population [65, 68-74].

This posture acknowledges the widely perceived authoritative power-based medical culture and relative educational distance with patient communities, most especially those disadvantaged by socio-economic and ethnic status. The relationship between practitioner as the medical ‘expert’ and the lay patient is not equitable for good as well as negative reasons.

The difficulty presented for this research is that there is little Aboriginal patient-culture-generated research on the contributory value specifics to be nurtured and utilized from the patient source [75]. The reality of healthcare demand and supply however justifies caution with the risk of demonizing or overly blaming one group or unwittingly de-humanizing the heavily burdened medical profession and health care provider services. The purpose of this framework research is to build an assistive communications system to achieve a more equitable PPIE experience.

The clinical world from whence GLs emanate has not demonstrably contributed to acculturation of content for PPIEs with disadvantaged ethnic minority groups. Considerable work to that end remains based upon advocacy for this framework concept. In Chapter 8 as part of the system validation I provide more detailed illustrations of the output from my collations and analysis. The ontology excerpts used are focused on features of Aboriginal patient case scenarios opened up in Chapter 7, and are chosen as a consequence of what has been learned from the schema source work covered in this chapter.

6.12 Modelling for PPIEs as events and data triggers

Whereas the mid-term work was concerned with the PPIE in the context of interaction, further studies and the qualitative gap analysis (QGA) revealed that breaking this process into three phases, pre-encounter, during-encounter and post-encounter, actually aids in better communication and understanding for both patient and practitioner. This was described with Figures in Chapter 5. This is relevant for the PPAC system design, its eventual user interface and full interactive functionality, inclusive of the carer and interpreter roles. A fuller descriptive rationale for this approach follows.

6.12.1 Pre-encounter function

The pre-encounter enhances PPIE effectiveness through separate preparations by the patient and by the practitioner. Preparation for the patient is a mental exercise in rehearsing the intended patient health self-status account or complaint. The PPAC system provides for this through a digital assistant; which may also become an educational process and an opportunity to send digital self-monitoring test data. Data

enrichment can then elevate the practitioner's preparatory process with more contemporary information than merely the record of prior consultation. The difference is one of timing, in that practitioner preparation may be minutes before the PPIE and the patient's preparation is likely to be many hours or days before.

In the during-encounter stage, the practitioner will ideally collect information from the patient, clarify ambiguity in information, examine the patient, decide on action to be taken and present course of action to the patient. Completely achieving this ideal situation is in considerable doubt when cultural communications barriers affect the PPIE. The information collected during the pre-encounter stage will improve the prospect of greatly improving communication and knowledge transfer between patient and practitioner as both sides have a better understanding of the ailment. The final decision however rests with the practitioner on the nature of the ailment and action required to address it.

6.12.2 Post-encounter function

Acknowledging the fact that detail of the exchanges within the PPIE are not so easily or reliably recalled by the patient as opposed to almost instant data entry by the practitioner(s), a post-encounter facility to accommodate a patient review can add to that educational value. It can also facilitate improved quality of further practitioner engagement by allowing the patient to identify anomalies, raise queries for clarification and even influence the mode of engagement by the practitioner in future PPIEs. This may be achieved with or without the help of a carer/caregiver, depending upon the patient's personal circumstance. In this regard I am conscious of other, mental or physical, disadvantages such as hearing impairment or visual disability that can limit a patient's ease of system access and cognition. The ontology aids all three processes by providing a comprehensive set of standards and guidelines for patients and practitioners to follow as well as presenting it in a manner that is comprehensible to all users including carers and interpreters.

6.13 Preparatory mapping mindset

This section entertains the transition of T2DM care domain concepts into the lingua franca support role. As touched upon earlier, in cross-cultural healthcare discussion

and research, the literature variously cites cultural awareness, cultural safety and cultural competence, in some instances attributing definitions to semantically distinguish each label.

In educational domain ontology building Thakker et.al describe a work in progress, referring to cultural awareness as a key skill required in many settings. Using their semantic data browser in their existing technical infrastructure named I-CAW the authors have introduced a cultural prompt mechanism to raise cultural awareness [76] The eventual application will create an informal exploratory learning environment and will in time be of interest as potential for PPAC compatibility.

The inclination from this research and for the purpose of this thesis is to favour the term ‘cultural competence’ which properly denotes the effort toward meaningful engagement, as Betancourt states: ‘Culturally competent health care— broadly defined as services that are respectful of and responsive to the cultural and linguistic needs of patients’[77].

Incisive scrutiny suggests that optimal cultural competence must encapsulate both cultural awareness and cultural safety, the latter largely aimed at invoking provider consciousness and training to improve responsiveness to ‘the experience of the recipient of care’ [78]. Accordingly, SAE simplification of T2D concepts alone will not offer the desired improvement in PPIE communications and outcomes. A justifiable understanding of the AE specific cultural competence paradigm is the first requisite for devising satisfiable relationships and reasoning for concepts in the merged domain, ontology supported PPAC ecosystem.

6.14 Design goals

Identification of concepts and their precise relationships representing AE pragmatic and paralinguistic healthcare lingua franca characteristics is a primary goal. For a firm framework foundation the goal is to establish a clear and demonstrably provable/repeatable ontology supported capability to receive and respond to PPAC system user queries; by and for patients who rely upon and/or can benefit from Aboriginal English as their PPIE lingua franca source.

The preservation of clinical guideline integrity is a primary goal in this part of the process. Protecting the sequential order as well as the content of the GL protocols for T2D concepts structures is part of this design goal. The main goal at this source collation stage is to prepare the framework in readiness for perpetual mapping and merging T2D concepts with the AE ontology concepts.

A key design goal principle is that when the T2D/AE ontology cultural adaptation and mapping readiness is accomplished, a bottom-up user influence is brought to bear. This is deliberately counter to the top-down historical institutional culture of western medicine including primary care.

6.14.1 Components and hierarchy

From the Aboriginal English education research, focus group and mentor contact sources of knowledge; aligning with concepts in T2DM GLs and other healthcare research based work a composite set of semantically receptive domain concepts was engineered. These are aimed at employing the AE Home Talk ontology in a ‘Health Talk’ PPIE context. Figure 27 shows the Aboriginal English classes and subclasses structure from this effort.

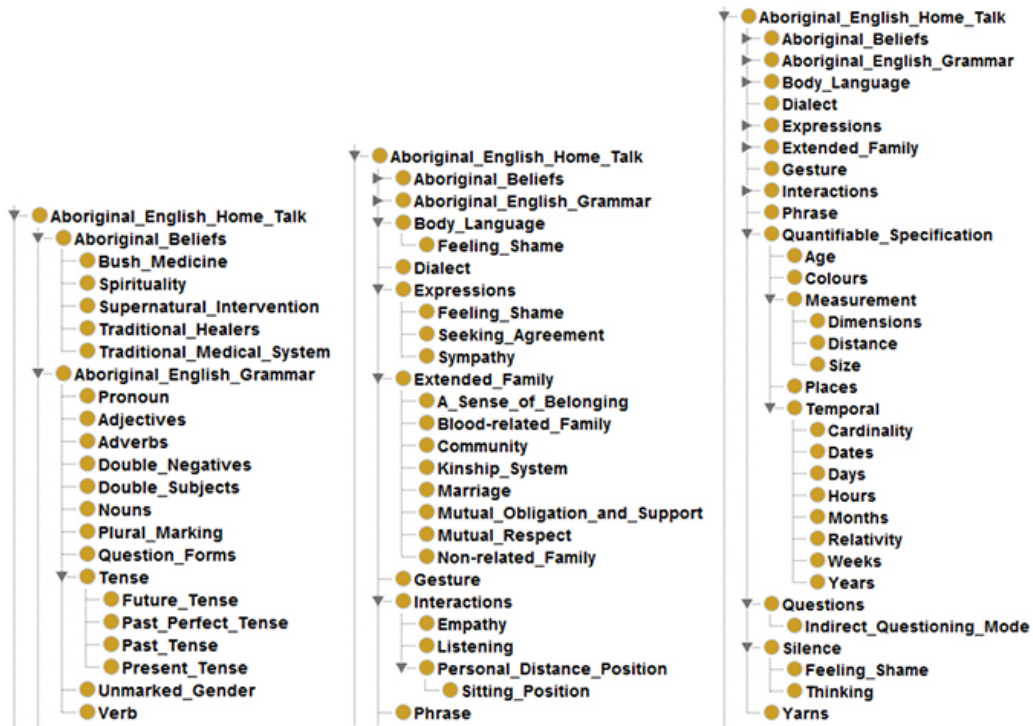


Figure 27: Aboriginal English classes and subclasses.

Use of the words ‘semantically receptive’ conveys readiness for merged domain mappings through concentration on opportunities for reasoned and dependable



Figure 28: Type 2 Diabetes concepts – classes and subclasses

concept relationship compatibility. I have constructed the T2D concept classes and subclasses as at Figure 28. This structure adheres to the RACGP GLs while enhancing classification data with other sources as described previously,

6.15 Annotations

Pre and post PPIE stages discussed above and ancillary forms of communicating health care information such as leaflets, prescriptions and prescription advice, and pathology reports; all can contain formal terminology that is difficult for patients to

understand and to justify provider confidence in their value and effect. At risk of repetition, the research perception is that there are many unsafe assumptions underpinning medical practice on the part of some providers, and a major one is that patients do not need to know what certain words mean. This works from the hypothesis, with the help of communications barrier analysis, that individual patient choice supersedes such assumptions and that better outcomes are achievable if knowledge transfer is not controlled on a power relationship basis.

Recognizing that a vital part of the pragmatic and paralinguistic translation effort to be achieved is the simplification of clinical terminology, the design work concentrates on building a repository with ontology data entries for each of the classes and subclasses listed at Figure 28, with a starting input of more than one hundred and thirty annotations. The Protégé ontology file provides access to this data. For explanatory purposes the concept examples of *Condition_Description* and *Signs_and_Symptoms* are provided to illustrate the formulation work. In the ‘specification of a conceptualization’ process this T2D schema concept work begins to factor in the search for compatibility through semantic mapping with the AE ontology.

The ontology annotations have been simplified from formal English clinical terminology but require further acculturation for the understanding of people who are customarily Aboriginal English speakers. The Australian Bureau of Statistics provides five skill levels for literacy in Australia, with Level 1 denoting people with very poor skills; and level 5 referring to people with very good skills [79]. No reference is made to Aboriginal English. The annotations shown are likely to be somewhere between Levels 3 and 4 in Standard Australian English terms. The Aboriginal English constructs in proficiency terms will be closer to levels 1 and 2 on the ABS English proficiency scale; but pragmatic cultural communications uniqueness factors place this outside of or rather as an offshoot of these metrics.

The simplest most accessible acculturative examples for matching of clinical terms with AE are those that apply labels to certain common and relatively simple signs and symptoms in T2DM, as observed by the Aboriginal patient. Examples are

- Nocturia (excessive urination at night)
- Polydipsia (excessive thirst)
- Polyphagia (eating too much; an excessive appetite for food) and
- Polyuria (passing large volumes of pale dilute urine)

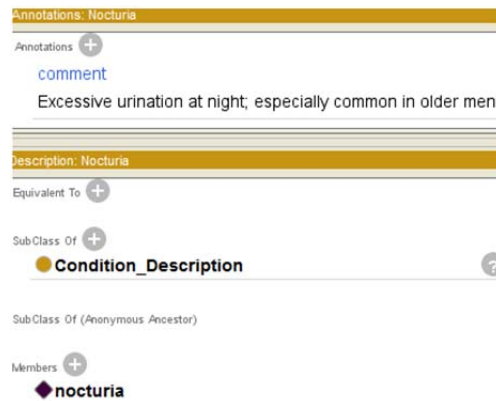


Figure 29: Annotation of Nocturia

The more elaborate, lengthy and technically-worded annotations present a strong time-consuming test for the AE acculturation mapping process. Considerable diligence is required to preserving integrity of clinical guidelines while adjusting to meet culturally distant and sometimes obscure, pragmatic and semantic needs of patients. The following discussion centres on the ontology annotation concept set of *Care_Management* as a practical demonstration of the procedural and behavioural nuances that are addressed within the framework as information and knowledge moves through semantic and syntactic conversion; from clinical vocabulary to the pragmatic dialectal form. This annotation research and classification is pivotal to subsequent identification of communications barrier characteristics. These barriers can be countered through the skilful design of culturally competent versions of clinical guideline annotations which will then provide the ontology with previously undocumented AE words, phrases and expressions.

6.15.1 *Care_Management* file annotation

Care_Management is a concept that refers to a set of evidence-based, integrated clinical care activities tailored to the individual patient, to ensure each patient has his

or her own coordinated plan of care and services. The care plan is developed collaboratively by the patient and care providers.

6.15.2 Risk_Control_Optimisation file annotation

Diabetes is an independent risk factor for both macro and microvascular disease.

Improved glycaemic control has been shown to reduce long term microvascular complications. Control of hypertension also reduces microvascular complications.

Reduction in macrovascular complications may depend on glycaemic control (shown for metformin) but clearly depends on modification of other risk factor such as smoking, hypertension and dyslipidaemia. Calculation of absolute risk will identify those people where especially active intervention and risk factor monitoring are indicated (absolute 10 year CVD risk >15%). The National Heart Foundation website provides a simple assessment tool (www.cvdcheck.org.au).

- All patients should be advised of the risks of smoking and offered assistance with smoking cessation.
- Assess cardiovascular risk and consider low dose aspirin for cardiovascular protection in high risk patients.

(Annotation text ends)

While Indigenous Australians are at high risk of many diseases and premature death, they are less likely to receive many aspects of preventive care. Identification of patients of Indigenous background is critical for appropriately targeting interventions. GPs are encouraged to routinely ask all patients if they have an Indigenous background so that they may target this risk group effectively.

In common with all T2D annotations the above require de-construction into essential content elements; then re-construction into AE semantic, syntactic and contextually modified equivalents. Some of the above sampled annotation includes information that will require different conceptual arrangements for the reverse flow contribution to cognition.

The annotations already represent advice in a form suited to the practitioner therefore the major effort goes into AE acculturation. For example, the final sentence above ‘GPs are encouraged’ etc., would be expressed in the appropriate AE form to advise

the patient PPAC system user, with explanatory reasons, that it is helpful to make sure that the doctor (practitioner) is aware that the patient is a member of the Aboriginal community or of Aboriginal descent. Fulfilling the need for high context, this advice in text and AE audible form will be designed to reassure the patient that because the Aboriginal community is exceptionally exposed to chronic disease illnesses special healthcare attention will be given. As will be noted from the discussion on Aboriginal English ‘Home Talk’ the T2D conversion, concept population and cross-domain mapping work for the PPAC system has been limited when compared with publicly available SAE versions of T2D. This is due to the significant absence of available documented AE health care forms of interactive expression pertinent within the PPIE setting.

In order to facilitate the ongoing schema collection, domain mappings and enrichment of the combined ontology data, via QGA the task is to set about identifying and qualifying those PPIE communications barrier characteristics that the system is intended to resolve. These have been instrumental in the T2D conceptual constructs and ontology relations design work.

6.16 Type 2 diabetes concept hierarchy

For the purpose of ontology domain identification the parent class of this ontology is labelled ‘Type 2 diabetes concepts’ and as such is referred to in the explanatory text in the abbreviated form ‘T2D’, as opposed to the broader scope of discussion using ‘T2DM’. Figure 30 shows the upper level ontology hierarchy constructed as a consequence of my research into the varied and merging dimensions that contribute to the future applications goal.

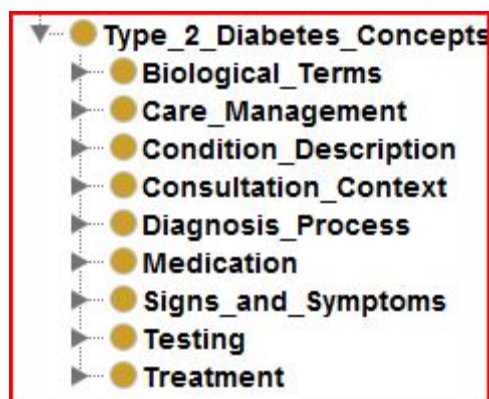


Figure 30: Type 2 diabetes concepts hierarchy

The nine upper levels subsume 123 subclasses including properties and instances, each of which is annotated in the Protégé ontology file. An illustration of the type and variety of annotative qualification posted in the ontology is given below as a sample. Included here with comment are some examples where Aboriginal patient interpretation and the acculturative communication transition is more and then less challenging for the PPAC design process. The subsequent hierarchical ontology screenshot listings of each of these chosen examples are included in order to elucidate the broad scope of the terminology corpus; and to emphasize the inherent demand for syntactic and semantic sense-making that will in turn necessitate systematic ontology reasoning capabilities within the eventual PPAC application.

6.16.1 Condition_Description

Condition_Description is defined/annotated as ‘*Written text or spoken words using recognized clinical terms that describe a health-condition*’. One next-level subclass selected for this discussion is ***Eruptive_Xanthomatosis***.

Comment: The annotation for *Eruptive_Xanthomatosis* carries complexity and clinical wording that present higher than average literacy and difficulty for conversion and use in a cross-cultural PPIE:

This condition may occur when triglycerides rise to extremely high levels. Severe resistance to insulin is associated with difficulty for the body to clear the fat from the blood. With extreme elevations in these blood fats, people are at risk for pancreatitis, an inflammation of the pancreas. Eruptive xanthomas appear as firm, yellow, waxy plaques (pea-like bumps) on the skin. The bumps -- which are surrounded by red halos and are itchy -- usually are found on the face and buttocks. They also can be seen on the back side of the arms and legs as well as in the creases of the extremities.

As a contrast, *Condition_Description* subclass ***Retinopathy*** can be more easily simplified in the conversion process:

Any non-inflammatory disease of the retina. Diabetes retinopathy is the negative effects on the eye that can be caused by diabetes mellitus, some of which may result in blindness.

The *Condition_Description* subclass as shown at Figure 31 is the largest of the T2D ontology subsets.



Figure 31: Condition_Description subclass

6.16.2 Signs_and_Symptoms

Signs_and_Symptoms are defined/annotated as: *Any indication of disease perceived or outwardly visible or internally experienced and reported by the patient; such indications of greatest significance to the health care provider that may help establish the identity of an illness.*

The selected *Signs_and_Symptoms* subsumed class is ***Sexual***. It is chosen here as an example to highlight the need for a concept to abide by an uncompromising discipline for ensuring that Aboriginal values are respected and inculcated in the system reasoning, providing protection for culturally appropriate responses to queries. This demands special care in the manner of dialectal system conversion.

Comment: The PPAC system should not allow a cross-over of very sensitive data that would cause serious offence if exposed to the wrong gender end-user. Exposure of the subject matter alone, i.e. without personal detail, can cause offence. In this entry, a precautionary approach by way of cross-reference is included. The *Sexual* annotation reads:

Erectile dysfunction (Aboriginal English: Men's Business) and Vaginal Dryness (Aboriginal English: Women's Business) are both symptoms/effects of T2DM. See Men's Business and Women's Business via Patient_and_Health_Professional_Interactions from Aboriginal_English_Health_Talk.

Continuing with another *Signs_and_Symptoms* subclass annotation I cite ***Vision***. Comment: A patient's ability to self-describe unsatisfactory eye conditions and convey the signs and symptoms is one of the less complicated actions in the PPIE. Annotation reads:

Altered, blurred, distorted or patchy vision that can't be corrected with prescription glasses. Problems with balance, reading, watching television and recognizing people; being overly sensitive to glare; difficulty seeing at night. See also Visual Acuity under Biological_Terms

The *Signs_and_Symptoms* subclass is shown at Figure 32.

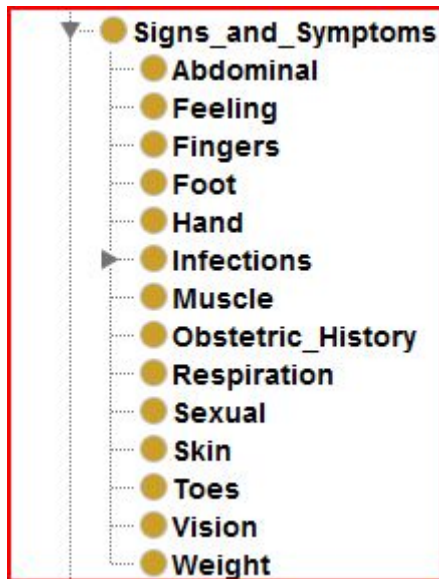


Figure 32: *Signs_and_Symptoms* subclass group

For the sake of clarity included here is the rationale for structuring T2D concept relationships working with and expanding from the classes discussed above. *Condition_Description* is generally the clinical wording used by practitioners describing a patient physiological condition used when that condition is confirmed by the various T2DM PPIE processes. It is not a term emanating from the patient. The patient however may use *Signs_and_Symptoms* words that lead to the professional conclusion that a condition exists as listed under *Condition_Description*.

If in *Diagnosis_Process*, *Patient_Condition_Assessment* and *Patient_History* an outcome is the finding that *Polydipisa*, and/or *Polyphagia* and/or *Polyuria* emerge as *Condition_Description* instances, the greater likelihood is that the communication process for this begins with the patient reporting in the context of *Signs_and_Symptoms*. The only difference in the occurrence is whether this information, i.e. excessive thirst, excessive consumption of food, and/or the excessive production of pale dilute urine, is offered first by the patient without solicitation in the PPIE consultation, or as a result of the more probing *Diagnosis_Process*. This extrinsic and intrinsic characterization of signs and symptoms is covered later in this Chapter as part of the PPIE case scenario projection and model refinement. The inference here is that these two events are chronological, i.e. the patient has the initial opportunity to tell the doctor why he/she is seeking medical advice; and the doctor or other clinician will subsequently pursue the opportunity to identify and qualify the patient health condition by drawing out signs

and symptoms. It is always possible that a patient may not recognize the significance nor easily admit to what will be regarded as one or more of the three conditions.

6.17 Diabetes related ontology work by others

There are researchers working towards diabetes ontology development with varied objectives and goals. The search and interest in their output has sought to ascertain whether there is synergic or closely related schema construction, or methodology that would be of value to this research.

Chalortham et al. developed diabetes mellitus ontology which covers risk assessment, diagnosis and complication, treatment, and follow-up [80]. Based on the ontology the reminding system was developed as part of type 2 diabetes mellitus clinical support system. The diabetes mellitus ontology was developed based on Thailand Diabetes Mellitus Clinical Practice Guideline 2008 and suggestion of medical experts.

Buranarach et al. introduced the synopsis of chronic disease healthcare framework in which the importance of ontology for healthcare knowledge management system was pointed out [81].

Lin and Sakamoto developed Glucose Metabolism Disorder ontology which was classified into diabetes mellitus, diabetes complication, hyperglycaemia, hyperrinsulinism, etc. [82]. The ontology was also linked to Geographical regions ontology and Genetic Susceptibility Factor ontology to describe the genetic susceptibility factors to Diabetes Mellitus.

Ganendran et al. developed ontology based multi-agent systems in which diabetes management was applied as a case study involving three agents i.e. specialist agent, patient agent, and web agent [83].

Shahar et al. developed Knowledge Based Temporal Abstraction (KBTA) focusing on shared knowledge representation and reuse [84].

The referenced work has been helpful by way of confirmation that there are diverse research and model building concentrations on finding contributory solutions for T2DM care problems. These may and in some cases will be integrated based upon future-identifiable synergies. The variety of T2DM centred research activity is not however exhaustive. I have not found any work that is directly focused on assistive communications for T2DM serving Aboriginal patients and/or ethnic minority immigrant communications acculturation. In addition there is no existing T2DM ontology that has been developed based on Australian recognised professional healthcare standard guidelines.

The sortation classification and collation of the Diabetes Australia RACGP T2DM Guidelines [54] data for use in ontology construction was conducted manually in the first instance. From the outset it was important to plan for mapping the guideline concept terms with AE concept terms; and to apply rules that will enable sorting of guideline concepts into a class structure that anticipates and accommodates end-user pragmatics. The steps in this development method are contained separately within the two major domains. By its nature, clinical guideline informational text data can be very complex and wordy. The rules for this structural conversion fundamentally draw upon parts of the Grice Maxims and on the work of Schwartz [85, 86]. The process:

- Applies a principle of adequacy with brevity and simplicity in the upper hierarchy classes
- Identifies and classifies, providing order according to functional relevance in the context of the integrated objective of mapping the two domains and serving future end-user applications
- Aims to avoid or mitigate the risk of ambiguity

6.18 Summary of PPAC ontology schema source research

This Chapter has covered the schema abstraction work for creating a foundation ontology that will be used to bring Standard Australian English textual abstractions of T2DM management into a useable patient and practitioner shared communication domain with Aboriginal English.

The following three chapters; ontology development, system validation and future work will cast a reflective look back at the potential offered by the AE Focus Group, T2D ontology annotations and QGA contributions.

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Chapter 7: Framework Ontology development

The PPAC design objective utilizing schema source output is to build a framework which provides assistive communication technology sense-making support for and about PPIEs. Each of the domains, data and behavioural factoring analysis conclusions outlined and counted as relevant and valuable in Chapter 6 are incorporated in the framework. This Chapter offers case scenario modelling justifications with user applications scope supported by software tools, data schema sources and qualitative analysis; knowledge of the role and use of web ontology language (OWL) and the architecture for building of a PPAC system.

7.1 Web ontology language (OWL)

Applications that need to process information systems content and not merely present data for reading by humans use the OWL Web Ontology Language. OWL provides superior machine interpretability of Web content than that supported by XML, RDF, and RDF Schema through greater expressive power and formal semantics.

The OWL ontology consists of Classes, Properties and Individuals. Using the Stanford University software tool named Protégé [1] this thesis occasionally refers to individuals as instances; and to properties as attributes. Individuals are the finer objects of interest in each domain; as is the case of individual instances arising from the combination of the two domains of interest. Individuals however may be identified by more than one name. This presents risks to reliability when looking for explicit meaning especially as the ontologies map different concept names which share the same meaning; and more so when the semantics of two different domain sources use an identical name which culturally or contextually does not match.

For example, a Standard English or Standard Australian English non-indigenous physician in non-clinical mode may have an exchange with an Aboriginal patient in which one or the other uses the word ‘deadly’ in a sentence. For the practitioner such an adjective may be used in preventive care advice, as a warning about lifestyle habits such as poor diet choice and excess consumption of alcohol. In Aboriginal

English the word ‘deadly’ means ‘enjoyable’ and by extension emphasis is on it being used positively to describe something as ‘very good’.

For individuals (instances of classes) in ontology it is essential to explicitly state that concepts with the same name are the same, or are different. Without this assertion, they are treated as if they might be the same or they might be different. The relations between two individuals are linked by properties. Properties are identified through binary relations even if multiple relations exist that link the same individuals.

7.2 Protégé Ontology software tool and process

In this work the greater part of ontology construction is compiled using Protégé which is a free, open-source platform providing a suite of tools to build domain models and knowledge-based applications. The Protégé software offers a set of knowledge-modelling structures for the creation, visualization, and manipulation of ontologies in various representation formats; and is utilized in semi-automatic mode, the data drawn manually from domain representation schema sources. Demonstration and tutorial models and published guidance from the Stanford University and Manchester University Protégé-OWL suite have included hierarchical representations for well-defined and simply-structured object ontologies [2].

Pizza and Wine ontologies have provided basic logic demonstrators for learning taxonomic construction. The work of domain or system experts and the wide choice and interest in developing functionality and objectives across a large diverse range of ultimate applications present researchers and developers with significantly greater complexity and difficulties.

The main building blocks of OWL are classes and initially the empty ontology presents us with one class, named ‘Thing’. The starter screenshot is shown at Figure 33. OWL comprises sets of classes or sets of objects; and ‘Thing’ represents the parent set containing all individuals; making these all subclasses of ‘Thing’. By adding classes, conceptualizations of the individuals within the domain of interest are defined.

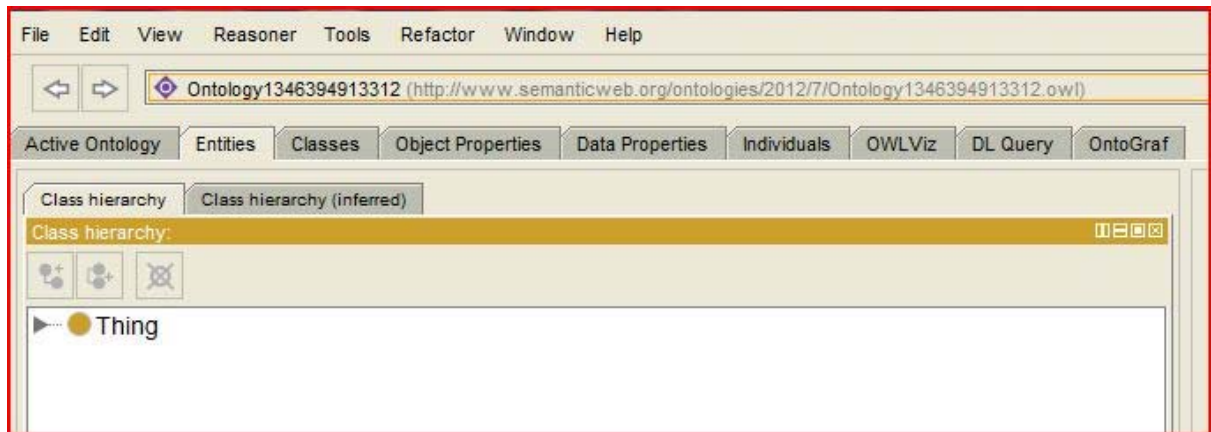


Figure 33: Opening/starter screen for Protégé 4.2 OWL ontology construction

The Class Hierarchy Pane (Figure 34) depicts three icons that facilitate additions to classes, sibling additions to subclasses and deletions (in order left to right). The figure shows the introduction of the upper class *Domain_Concept*. Fuller illustrations appear in later Chapters of this thesis.



Figure 34: Class Hierarchy Pane

7.2.1 Relationships

An important part of the process of building a valid ontology is the representation of relationships. These are represented through OWL Properties, with the two main categories Object Properties and Datatype Properties. The former represent relations between two individuals; the latter describe relationships between an individual and data values such as an XML Schema Datatype or Resource Description Framework (RDF) literal, which accommodates class values such as strings and integers using a lexical format. Each property type can be created by using the appropriate properties tab. Whereas the tutorial does not directly address the importance of semantics, the Protégé system avails the ontology builder of several features accessed through icons to work toward integrity of the ontology in respect of explicit dependable truths, including mitigation if not entire elimination of ambiguities.

One of the most powerful tools within the system is the reasoner. This allows

- consistency checking based on the requirement that a class must have instances
- testing of the validity of relationships
- resultant ability to compute ontology hierarchy inferences.

The Protégé 4 system accommodates several different OWL plug-in reasoners. To invoke the reasoner facility requires moving from the manually constructed ‘asserted hierarchy’ to automatically classify the ontology in terms of its ‘inferred hierarchy’. Once completed, this process will produce a new ‘Inferred class hierarchy’ screen window to accompany the existing ‘Asserted Class Hierarchy’ window.

Other construction disciplines and their executable components with the Protégé system are designed to manage and protect data and concept relationship accuracy. These include processes to qualify classes as disjoint, ensuring that an individual cannot be classified as being a member of more than one class when that is the factual objective.

In the case of links between object properties, it is necessary to recognize the existence of inverse properties, e.g. ‘*relatedConditions*’ is inverse of object property ‘*relatedConsequence*’. For example in the circumstance of this research into PPIE experience if a patient with cardiovascular disease consumes alcohol this places that patient at risk of complications. In context, a diabetic patient is already at greater risk compared with a non-diabetic through increased exposure to comorbidities, which include cardiovascular disease. The extent of alcohol consumption (amount consumed at one time, frequency of consumption) will determine the level of risk.

There is also however something of a contradiction involving reverse properties. Concerning glucose in the blood, the related condition for this can be hyperglycaemia (high blood sugar) or hypoglycaemia (low blood sugar). Therefore reverse properties apply here as two apparent opposite effects, both hyperglycaemia and hypoglycaemia can be the consequence of alcohol consumption. Additional construction processes cover functional, inverse functional, transitive, symmetric, asymmetric, reflexive and irreflexive properties, with varying degrees of relevance

according to the particular domain ontology under construction. Property existential and universal restrictions are each addressed in the tutorial. One of several examples of property restrictions offered is identifying the class of individuals with at least one *hasSibling* relationship. OWL restrictions have three categories: Quantifier restrictions; Cardinality restrictions; and hasValue restrictions.

7.2.2 Conventions for OWL Ontologies

Before the PPAC ontology for T2DM is presented, graphical notations are discussed in this section to facilitate the PPAC ontology modelling process. Table 13 shows a list of notations.




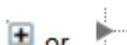



Notation	Terminology	Semantics
	Primitive Class	If something is a member of this class then it is necessary to
	Defined Class	If something fulfils the conditions then it must be a
	Subclass Relationship (pink colour)	Superclass-subclass hierarchy. Note that it has the same
	More Subclasses	More subclasses in a hierarchy.
	Object Property Relationship (different colours represent	Link two instances or classes together.
	Instance / Individual	Objects in the domain in which we are interested.
	Instance / Individual Relationship (blue colour)	Instances of the classes. Note that it has the same notation

Table 13: A list of Modelling Notations

In context, class, property, and instance / individual are written in italic style to distinguish from the text. In order to maintain consistency with names there are naming conventions for each ontology component. All class names start with a capital letter and have the remaining word(s) capitalised; and underscores are used to join words for example *Aboriginal_English_Home_Talk*. Property names or relationship names start with a lower case letter, have no spaces and have the remaining word(s) capitalised. Relationship names are prefixed with verb or adverb e.g. the words ‘has’, ‘in’, or ‘related’ for example *hasComplicationRisk*. This naming

convention is used to allow for the possibility to generate more human readable expressions for descriptions. Instance or individual names start with a lower case letter and have the remaining word(s) in lower case; and underscores are used to join words for example *vision_impairment*. In parts of the following sections, single words used in the context of query triggers are not italicised as they represent real-world human generated concept descriptions.

7.2.3 Annotation

Annotation properties are a valuable facet of OWL ontology. It is frequently necessary and even essential, to bring greater clarity to concept specification than is offered by the hierarchy and relationship structure alone. In this work I am dealing with an area of problematic communication and weakness in cognitive engagement. As a first step textual annotations can begin the process of information and knowledge enrichment through explanatory data designed to bridge an intricate cultural divide. Annotations are described as metadata or pieces of auditing or editorial information that can extend to a range of sources including web pages. In this work however, I recognize that many Aboriginal end-users of a PPAC based application will not be able to read textual data, and that I should therefore anticipate in my future planning the need for matching and convergent audio visual annotation options.

7.3 PPIE case scenario projection

With reliable research source material, QGA conclusions and the advice of mentors it was possible to put together case scenarios to project the presentation of a type 2 diabetes Aboriginal patient in circumstances where the patient-practitioner relationship and consultation are confronted with communications difficulties; and where the proposed solutions approach would be applied. Proceeding through each scenario the study enables anticipation with considerable vigilance of the potential for and nature of communications barriers that it aims to overcome. This is an incremental iteration process in which prognostic issues arise within the evolving Aboriginal PPIE story prompting the need to evaluate and secure ontological relationships and system reasoning. It starts with a very basic case study account and

moves on to more complex interactions as I map, develop and strengthen the ontology and thereby the PPAC framework.

7.3.1 Initial Case Study: Aboriginal Patient with Blurred Vision

First a simple case outline is provided to illustrate how the ontology can be used in the PPIE.

Diabetes patients with high blood sugar may suffer from blurred vision. This might be a temporary condition or a precursor to more serious conditions such as retinopathy, glaucoma or cataract. An Aboriginal patient may walk into a clinic once he/she notices his/her vision is blurred. Typically, the patient will say they have “bad eyes” when seeing the doctor or they might choose to say “Gooras Winyarn”. This was referenced by the focus group. In the Nyungar AE retention of and assimilation with original language words with English “Gooras” means “eyes” and “Winyarn” means “bad”. If the condition is serious, the patient would use the Aboriginal English word as it not only provides a description of the problem but also the severity of it, which is not captured in Standard Australian English.

Knowledge captured in the PPAC ontology (as shown in Figure 39) illustrates that the Nyungar Aboriginal words of gooras winyarn can be taken to mean blurred vision or altered vision. Literal translation between traditional or original Aboriginal words that now have a place within Aboriginal English pragmatics is limited and not always sufficiently explicit as to carry a specific meaning. Such words appear in phrases and accord with circumstance; and will therefore vary in context. It is not appropriate for instance, to assign a distinct Standard Australian English (SAE) meaning to ‘gooras winyarn’ unless the context is completely clear.

Another facet of PPIE for T2DM concerns the potentially excessive consumption of alcohol. In the communications context this was deliberated in detail by the focus group. The T2D concept structure therefore contributes relationships between signs and symptoms, including alcohol consumption and vision, in the PPAC ontology.

In the situation where a patient is anxious and/or has limited English proficiency, words such as those proffered by the focus group become key triggers to justify

ontological system queries. The practitioner will know from the annotation that together ‘gooras winyarn’ come close to meaning ‘eyes bad’, thereby informing the practitioner that an eye problem is suspected and will require investigation. The investigation may then include comparison with a prior PPIE record in addition to physical examination that will then better determine whether the condition is altered or blurred vision, or possibly both. Recognition of alcohol consumption related and possible causative factors for impaired vision may also assist the PPIE care process.

7.3.2 Alcohol and vision ontology constructs

To more fully illustrate the relationships emanating from the focus group examples of alcohol and vision health care issues, included here are classes and concepts as a preface to the ontology building discussion.

Alcohol: Alcohol consumption concerns the health care context intake of alcoholic beverages. Hence it is captured in class *Alcohol_Consumption* subsumed by class *Care_Management* subsumed by class *Type_2_Diabetes_Concepts*.

Cardiovascular complications from diabetes place consumers of alcohol at high risk of worsening health outcomes. Hence class *Alcohol_Consumption* has relationship named *relatedCondition* with class *Cardiovascular_Disease* subsumed by class *Condition_Description* subsumed by class *Type_2_Diabetes_Concepts*. Also class *Alcohol_Consumption* has relationship named *hasComplicationRisk* with class *High_Risk* subsumed by class *Complication_Risk* subsumed by class *Dependent_Concept*.

Due to sugar intake, blood glucose increases from alcohol consumption and this relates to hyperglycaemia condition; but the effect of sustained intake can lead to the opposite, i.e. hypoglycaemia condition. Hence class *Alcohol_Consumption* has relationship named *relatedCondition* with class *Hyperglycaemia* subsumed by class *Condition_Description* subsumed by class *Type_2_Diabetes_Concepts*.

Also class *Alcohol_Consumption* has relationship named *relatedCondition* with class *Hypoglycaemia* subsumed by class *Condition_Description* subsumed by class

Type_2_Diabetes_Concepts. Figure 35 shows how I capture these concepts in the ontology through class *Alcohol_Consumption* relationships and constraints. Figure 35 also shows the relationship annotation connected class *Alcohol_Consumption* with class *Hypoglycaemia* as an example.

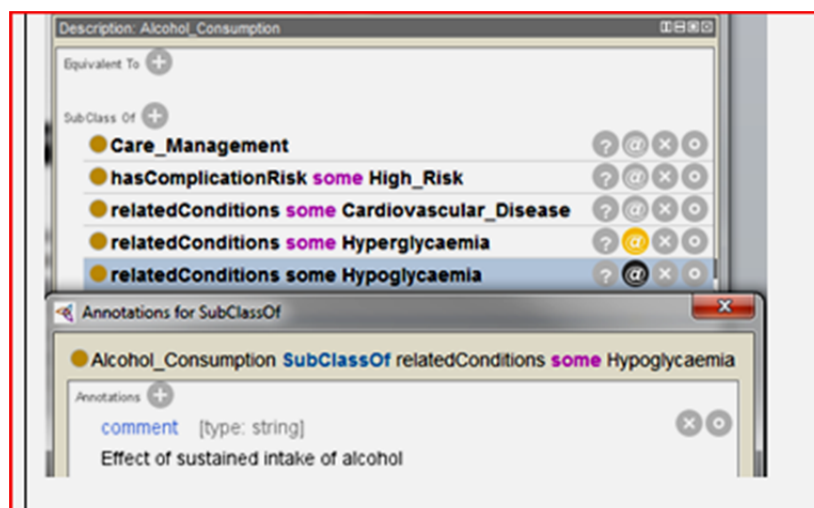


Figure 35: Relationships and Constraints of Class *Alcohol_Consumption*

Figure 36 shows class *Alcohol_Consumption* relationships and connected classes and their super classes in graph format.

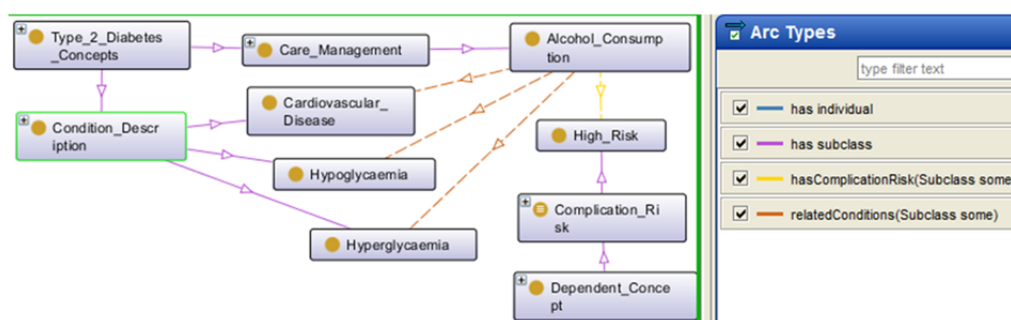


Figure 36: Relationships and Connected Classes of Class *Alcohol_Consumption* and their Super Classes in Graph Format

Vision: Instance *bad_eyes* has relationship named *relatedConditions* with instance *retinopathy* which is instance of class *Retinopathy* subsumed by class *Condition_Description* subsumed by class *Type_2_Diabetes_Concepts*. Instance *bad_eyes* has relationship named *relatedDiagnosisProcess* with instance *vision_impairment* which is instance of class *Patient_Condition_Assessment*

subsumed by class *Diagnosis_Process* subsumed by class *Type_2_Diabetes_Concepts*. Instance *bad_eyes* has relationship named *relatedTest* with instance *eye_testing* which is instance of class *Eye_Testing* subsumed by class *Testing* subsumed by class *Type_2_Diabetes_Concepts*. In other words, gooras winyarn or bad eyes relate to the diabetes testing of eye testing as shown in Figure 37.

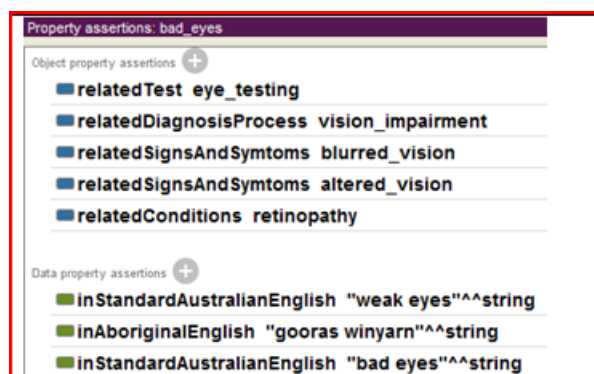


Figure 37: Phrase of Gooras Winyarn Captured in the PPAC Ontology as Instance Property Assertions

Class *Retina* which is sub class of class *Biological_Term* subsumed by class *Type_2_Diabetes_Concepts* and class *Retinopathy* have relationship named *hasObservationType* with class *Extrinsic_Observations* which is subclass of class *Signs_and_Symptoms_Observation_Type* subsumed by class *Dependent_Concept*. In other words, retina and retinopathy can be observed by the GP as illustrated in Figure 38.

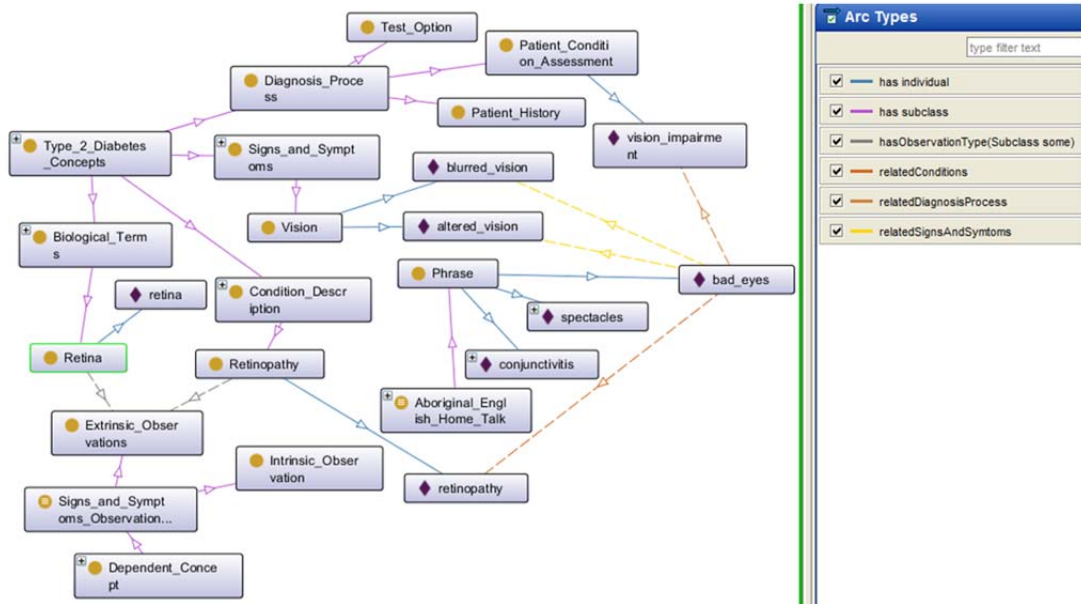


Figure 38: Ontology Relationships for Gooras Winyarn

The following AE phrases represent a limited regional set of descriptive concept instances as offered by the Aboriginal focus group activity. ‘Coyee eyes’ is an AE description of conjunctivitis, which is inflammation of the conjunctiva (the outermost layer of the eye and the inner surface of the eyelids). ‘Bung eye’ is similar to Coyee eyes. ‘Goora bludgers’ is AE for eye glasses/spectacles. ‘Coke bottle’ or ‘coke bottle lens’ are AE for eye glasses/spectacles. ‘Second eyes’ is AE for eye glasses/spectacles. These are captured and presented in Figure 39.

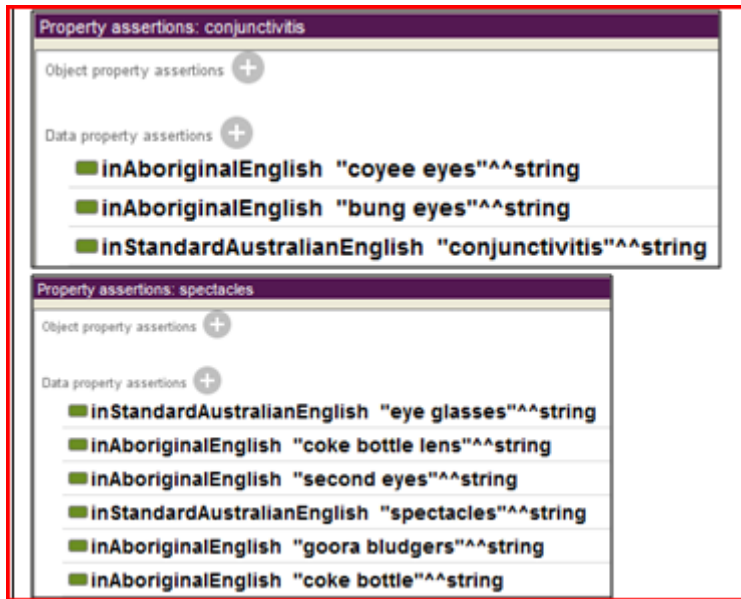


Figure 39: Vision Related Concepts i.e. Conjunctivitis and Spectacles Captured in PPAC Ontology

Revisiting the vision example, as can be seen in Figure 40, *gooras_winyarn* is an instance of class *Words* which is sub class of class *Aboriginal_English_Home_Talk*. Instance *Altered_Vision* which is same instance as *Blurred_Vision* is instance of class *Vision* i.e. sub class of class *Signs_and_Symptoms* i.e. sub class of class *Type_2_Diabetes_Concepts*. The instances are mapped through object properties in *AboriginalEnglishHomeTalk* and in *Type2DiabetesConcept*.

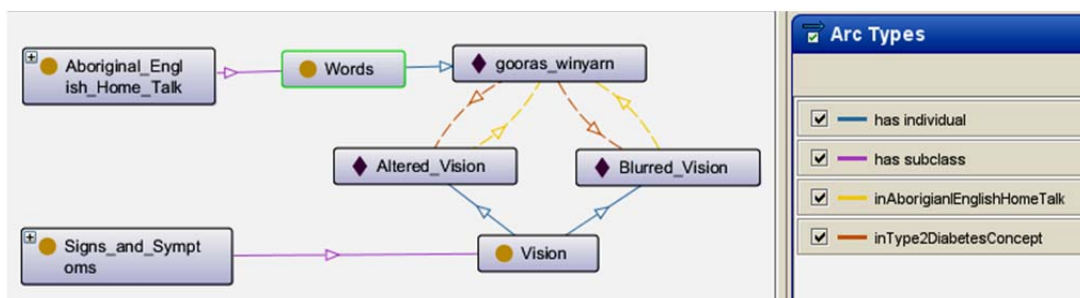


Figure 40: Object properties in *AboriginalEnglishHomeTalk* and in *Type2DiabetesConcept* mapped classes *Aboriginal_English_Home_Talk* and *Signs_and_Symptoms*

7.4 Refining the PPAC Ontology

There are refining concepts which will add meaning to other concepts. This forms class *Dependent_Concept* as shown in Figure 41.

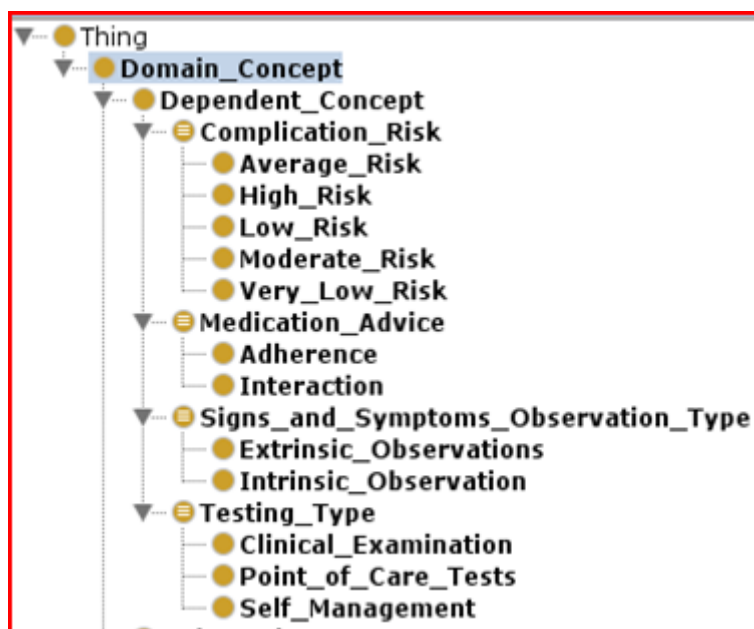


Figure 41: Class *Dependent_Concept* and its sub classes

Class *Complication_Risk* adds risk value to any sub class of class *Type_2_Diabetes_Concepts* through relation *hasComplicationRisk*. It can be restricted to particular risk; of average risk, high risk, low risk, moderate risk, or very low risk.

Class *Medication_Advice* adds value in term of medication advice of adherence and/or interaction to any classes under classes *Care_Management*, *Treatment*, and *Medication* through relation *hasMedicationAdvice*. Observation of particular signs and symptoms of a patient can be specific to extrinsic or intrinsic observation of the patient. This can be specified through relation *hasObservationType*. Figure 42 shows class *Testing_Type* adding value to class *Testing* through relation *hasTestingType* in term of types of testing i.e. clinical examination, point of care tests and self-management.

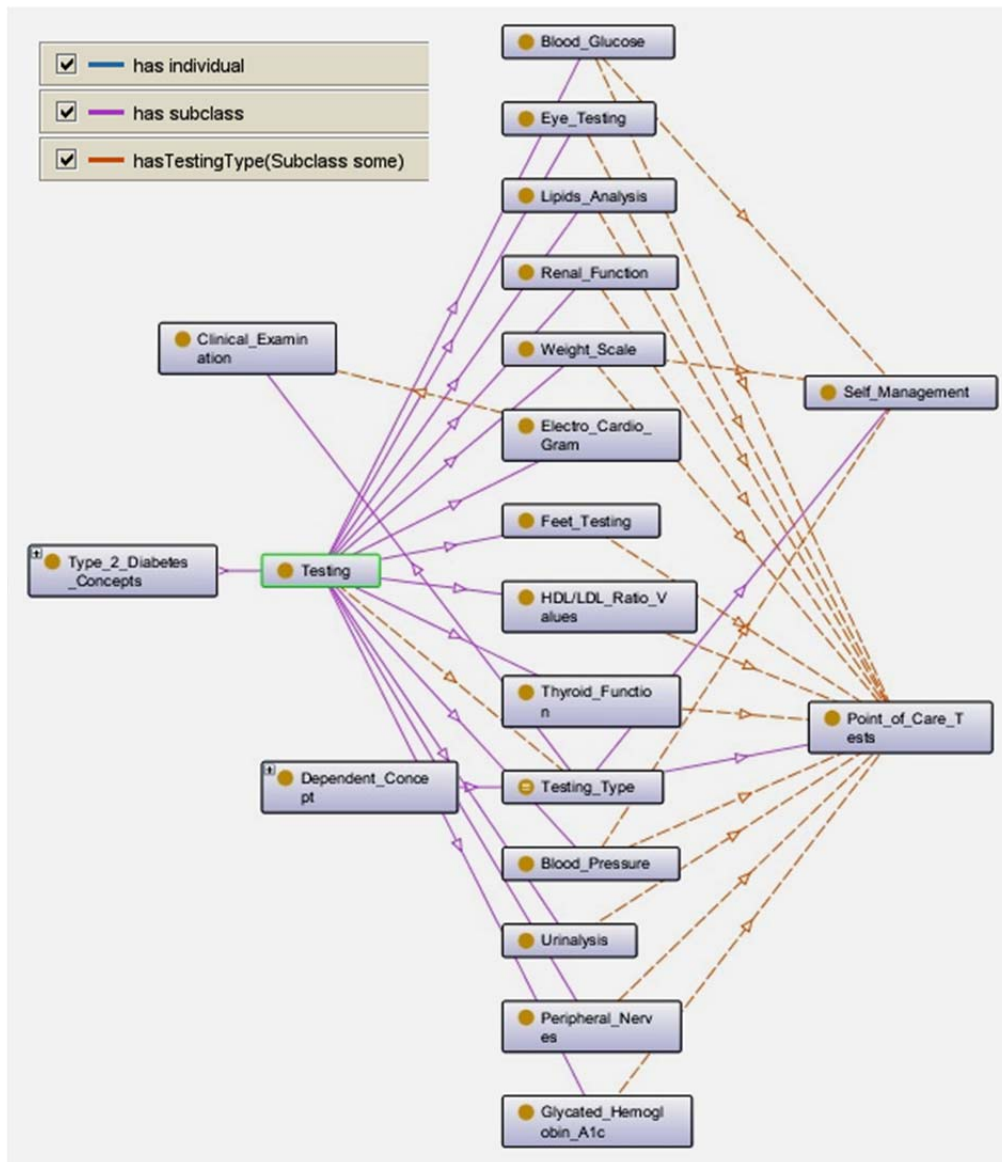


Figure 42: Class *Testing* relates to class *Testing_Type* through object property *hasTestingType*

7.5 Harvesting information from PPIE challenges

Based upon research findings and through the help of amplified PPIE situational iterations it is possible to determine how existing PPIE practices can be modified to better effect for the participants, applying the PPAC concept. Known and emerging problems in communication were purposefully introduced to the case study approach in order to provoke system challenges and design solutions. This can be illustrated conceptually by bringing together the known components of current practice with the

future capabilities offered by assistive technologies, supported by the AE and T2DM ontologies.

The scenario for this projection is a fairly common setting in rural health; the provision of primary health care service for regional Aboriginal English speaking patients through country location general practice clinic appointments. In context it must be remembered that many parts of regional Australia, and in particular for this purpose, Western Australia, have very few primary health care sites. Each site has variable resource capabilities and serves a widely scattered population in a physical ecosystem with a relatively weak and environmentally vulnerable infrastructure. As a consequence the relevant health care knowledge gap between patient and practitioner is greater than that applicable to patient-practitioner relationships in metro/urban locations.

Further complexity can arise in rural and remote areas from inadequate continuity in the patient-practitioner relationship, for an assortment of reasons including among many the mobility of patients who habitually traverse the Australian bush; attrition rates of health care provider staff and the presence of international medical graduates. In most instances, ICT access and usage by patients embedded in these lifestyle circumstances will be significantly less than health care providers and urban patient counterparts. The concept however envisages gradual change in this disparity, in part because patients suffering complications of T2DM receiving essential treatment and care in metropolitan and urban hospitals are becoming more exposed to ICT and specifically to the active use of mobile phones across extended Aboriginal family communities.

A summary of challenges is not complete, as these carry an element of unpredictability and are also implicit if not explicit within sub-domain attributes and specific individual instances. The phenomena known as ‘code-switching’ discussed in Chapter 1 and practised by Aboriginal patients is a particular challenge for practitioners as briefly discussed later in this Chapter.

A more expansive and exploratory case study scenario and its consequential value for PPAC ontology modelling is now presented.

7.6 Expanded case study scenario

A 28 year old Nyungar male ‘Vincent’ is in the care of a fifty-eight year old close community friend ‘Ted’ who while not blood related he refers to as ‘uncle’. Both have been living for an unknown period of time in bushland in and around the south west of Australia. Together they attend a country health clinic by appointment, and initially the older man enters the doctor’s office alone. He is surprised to discover that the GP, Dr. Rose, is a white European-born female. He tells her that he wants a male doctor to examine his ‘huncle’ but that the patient is refusing to come in from the waiting area due to embarrassment. The only person in the waiting room at that time she notes is Vincent who is visibly unwell and suffering dizziness but could not possibly be (in her view) Ted’s uncle.

The doctor is somewhat confused but realises there is a communications barrier. Her training should enable her to consider how to resolve this quandary. The option of querying an ontology supported PPAC system would help her to navigate through a search of consultation context subclasses and attributes to learn more specifically how she might handle this situation.

7.6.1 Extended Family

From the above scenario Dr Rose could query search for the word ‘huncle’ to find its possible meaning. Figure 41 shows the query used for finding the possible meanings of word huncle and the result provided from DL Query. Figure 42 shows the result in details in which it shows that word ‘huncle’ in AE can be taken to mean ‘uncle’ and also to mean ‘nephew’ in Standard English. Figure 43 shows that ‘uncle’ can be taken to mean ‘nephew’ as well. This refers to bi-directionality in the uncle and nephew relationship.

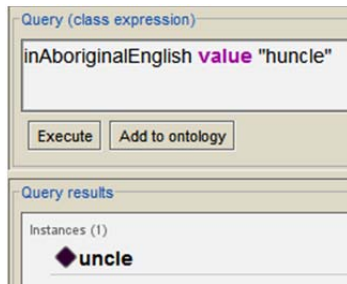


Figure 43: Query to find possible meanings of word ‘huncler’

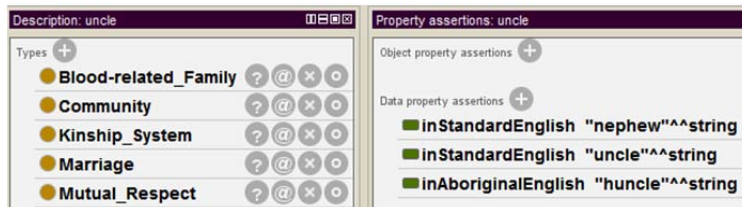


Figure 44: Query result in detail for individual uncle

As can be seen in Figure 44 it is also an individual of classes *Blood-related_Family*, *Community*, *Kinship_System*, *Marriage*, and *Mutual_Respect*.

Figure 45 shows subclasses of class *Extended_Family*. From this reference it shows that the notions of extended family and community as family in Aboriginal communities encompass the idea that children are not just the concern of the biological parents, but of the entire community. The raising, care, education and discipline of children are the responsibility of everyone - male, female, young and old. Also shown in Figure 45, ‘elder’, ‘friend’, and ‘neighbour’ are instances of class *Non-related_Family*. This reflects community as family.

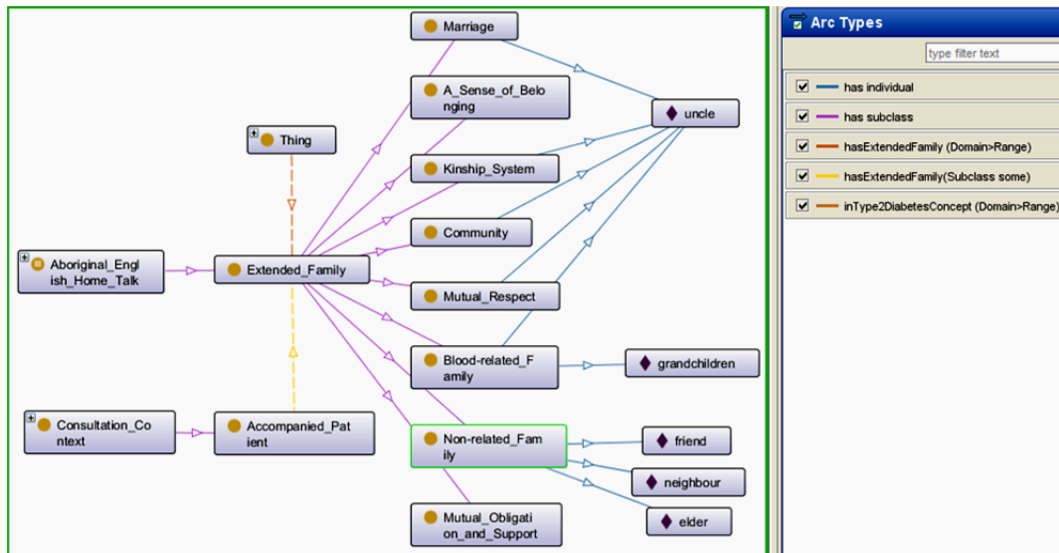


Figure 45: Ontology graph representation of the notions of extended family and community as family

Dr Rose can also navigate through the concepts. Looking into class *Consultation_Context* which has class *Accompanied_Patient* as subclass, there is relation called *hasExtendedFamily* which links to class *Extended_Family* (yellow dot line in Figure 43). With all these references, it then makes sense to infer that Vincent, accompanied by Ted, although being called his uncle may not be his blood related uncle. Hence from these references, Dr Rose will be able to assume that the Aboriginal patient and his carer are part of a community that would treat each as ‘uncle’ of the other.

Another term that can cause confusion like uncle is the term ‘grannies’ which is commonly used to refer to Aboriginal ‘grandchildren’. Figure 46 shows a query and its result from the word ‘grannies’. Figure 47 shows the result in detail in which it presents that grannies in AE can be taken to mean grandchildren in SE and it is an individual of class *Blood-related_Family*.

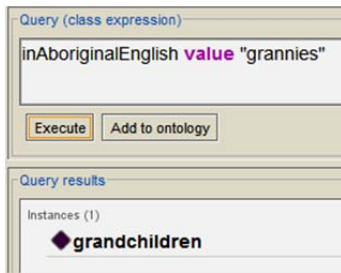


Figure 46: Query to find possible meanings of word ‘grannies’



Figure 47: Query result in detail for individual grandchildren

7.6.2 Men’s Business Gender Sensitive

In this scenario, it is apparently a ‘men’s business’ gender sensitive and possibly a ‘shame’ situation. Among other subclasses of class *Consultation_Context*, Class *Bio_Psycho_Social_Sensitive* has classes *Mens_Business* and *Womens_Business* as subclasses. It would be possible to confirm by looking at concept of class *Consultation_Context* in the PPAC ontology. Figure 48 shows class *Consultation_Context* and its subclasses and its relations.

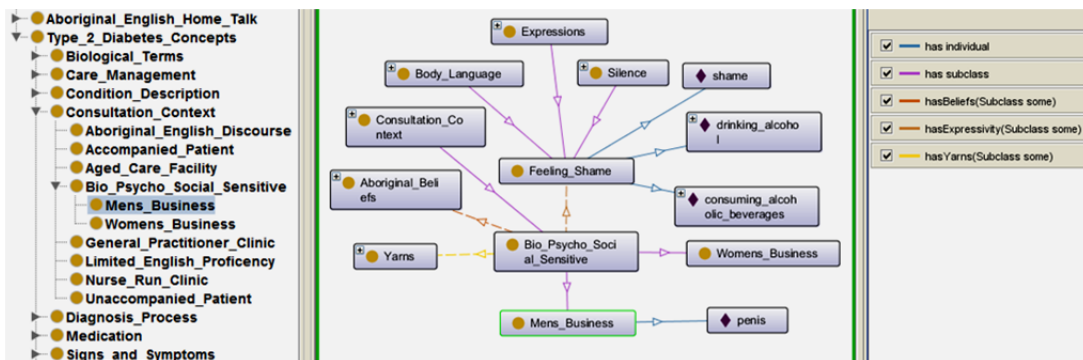


Figure 48: Class relations to show related concept of men’s business gender sensitive

Doctors can carefully seek further information based on professional knowledge and the T2DM guidelines ontology mapped to AE. Dr. Brown has reason to investigate

‘men’s business’. He can use both observational and system generated indicators of the likely gender sensitive issue. It may be prudent to avoid launching too quickly into the removal of clothing for a physical examination as the patient’s reaction is unpredictable without the benefit of further engagement and trust building. My approach is to use ontology annotation tags that will include clinical graphic depictions of a range of known conditions that can become evident as biological signs and symptoms. Many GPs have such visual media on their own system and/or fast access to accredited Web based health files serving the same illustrative purpose. This is a process mentioned by way of ontology annotation advice on Aboriginal English emotion in the context that making the patient feel that his condition is not unusual but important to treat, will help remove a barrier to physical examination.

It will be necessary to include colloquial Aboriginal English descriptions for genitalia in the ontology, e.g. ‘Ma ole fella’ is one Nyungar expression that refers to male genitals, and there are others more commonly found in the more earthy English slang. It is not likely for instance that formal anatomical words such as ‘penis’ or ‘testicles’ or ‘vagina’ will be used in Aboriginal English discourse; but it will be necessary over time to build the ontology so that T2DM maps with many AEHT alternatives. Figure 49 shows a query to find an AE word for penis in SE. Figure 50 shows the query response result in detail.

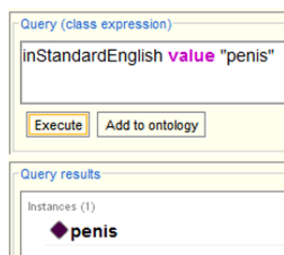


Figure 49: Query to find an AE word for penis in SE

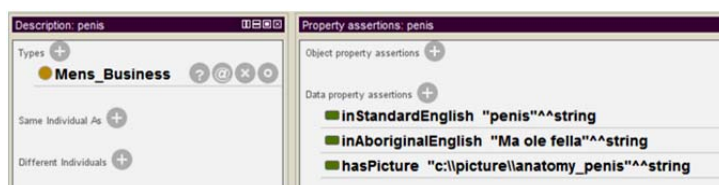


Figure 50: Query result for an AE word for penis in SE

Class *Bio_Phycho_Social_Sensitive* relates to class *Feeling_Shame* with relation *hasExpressivity*. Instance of class *Feeling_Shame* detail is shown in Figure 51.



Figure 51: Detail of individual shame of class *Feeling_Shame*

Class *Feeling_Shame* is subclass of classes *Body_Language*, *Silence* and *Expressions*. These convey that feeling shame is a kind of body language, expressions, and silence having signs of bowed head and turning away; and providing the precaution (the risk of) early unannounced departure of the patient from the meeting. Feeling shame can be shown or expressed in any consultation context. Men’s business is biopsychosocial sensitive in the consultation context.

From these references shown in the PPAC Ontology, this would tend to confirm that Dr Rose should call upon a male doctor colleague to conduct the PPIE. In the limited resource circumstance of most country clinics, General Practitioners are not locally resident but conduct such clinic work on fly-in fly out (FIFO) or drive-in drive out (DIDO) visiting schedules. It would be more likely in the circumstances described to rely upon a locally based male Aboriginal Health Worker or nurse to overcome this barrier. For illustration purposes it is assumed here the availability of a male doctor called ‘Dr. Brown’ and account for this by recognising that the Dr. Rose is a new arrival in training as a locum to cover for Dr. Brown while he is absent from the area.

7.6.3 AE and Aboriginal mode of measurement

Projecting further that Dr. Brown is treating another patient in a nearby home and will be back in thirty minutes, it is advisable for Dr. Rose to reassure the two men so that they do not prematurely leave the clinic and fail to complete a PPIE with Dr. Brown. In the PPAC ontology, different forms of media i.e. audio, video, and graphics are captured along with some concepts. These are in form of relations *hasAudio*, *hasVideo*, and *hasPicture* which links to the location where digital media files are kept. In the scenario, if Dr Rose navigates through AE concepts, quantifiable specification is captured to describe how the Aboriginal world view quantifies and qualifies things as temporal, which references time; and measurement; which also

express distance, dimensions and size in relational terms. Figure 52 shows class *Quantifiable_Specification* and its subclasses and instances.

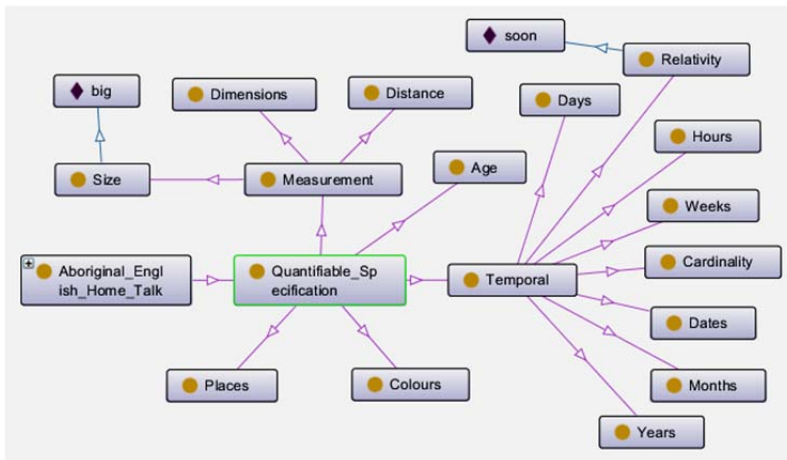


Figure 52: Class *Quantifiable_Specification* and its subclasses and instances

In the scenario, Dr Rose finds instance ‘soon’ and the recording of an Aboriginal English voice can be heard to say ‘soon’ in elongated form (‘so-o-o-on’) to represent Aboriginal English mode of measurement through vocal emphasis. Instance ‘soon’ has relation *hasAudio* with a string which shows where audio is located. Note that the elongated version of ‘soon’ represents a short time. The elongated version of ‘big’ (‘bi-i-i-g’) however represents a large size which is the opposite in terms of temporal (time) length measurement. Figure 53 shows annotations for relationship *hasAudio*.



Figure 53: Relationship *hasAudio* annotation

Note also that this audio concept-development is presently abstract only and although existing technologies can be used to deliver interactive speech systems suited to PPAC, this is a matter for future work.

7.6.4 Second stage of the same scenario

Dr. Brown, after being briefed by his female colleague, and with the advantage of access to a record of Vincent's prior medical history would be positioned to conclude, in advance of the PPIE with Vincent, that

- the patient is a diagnosed type 2 diabetic.
- Vincent has probably neglected his personal wellbeing as he appears to be in some distress; has not attended this clinic for a long time; and it is well established among medical professionals that T2DM, also known colloquially as 'the lifestyle disease', demands constant attention with daily care to ensure patient wellbeing.
- From the information provided by Ted on Vincent's behalf, his condition will possibly include some form of personally intimate information and may necessitate examination of male genitals, hence the 'men's business' inferences expressed by Ted.
- Ted represents a member of Vincent's extended family and subject to the doctor's professional judgement with the help of PPAC advice will be regarded in the PPIE as acting in the role of 'carer'. Carers of Aboriginal English speakers living in rural and remote areas fulfil multiple roles including moral support during interactions with health care practitioners.

Dr. Brown's assessment as just described denotes recognition of challenges to cultural competence and safety in securing the continued cooperation of the patient. Dr. Brown would have the opportunity to observe the two Aboriginal men in the waiting room. Assuming that he has not met Ted previously and has a vague recollection of Vincent as a patient from 18 months before, confirmed by his computer records, it is feasible to assess how the PPAC model will help to fill gaps in interpretation of Vincent's demeanour. A doctor with experience of consulting with Aboriginal patients in rural and remote areas may recognize the risk that the PPIE will end prematurely; behavioural signs may be witnessed but reasons and therefore prevention tactics may not be instantly evident. The men for example may be talking in a fairly agitated fashion but it is not possible to decipher exactly what is being said, the dialogue being rich with Aboriginal English home talk, accents and dialectal phonology (pronunciation, sounds).

7.6.5 Self-populating

Dr. Brown could, via this integrated ontology model concept, search for clues and cues. One challenge in this process is that conversations taking place between Ted, Vincent and the doctor will involve a contextually changed form of communication as previously referred to and known as ‘code-switching’. In ‘Ways of Being’ and in the AE context Ian Malcolm describes these phenomena as follows:

The speaker of Aboriginal English will often use Standard Australian English at work and when interacting within the broader community and Aboriginal English as soon as he/she is at home or within an Aboriginal community. This is called code switching. But for the speaker of Aboriginal English, this requires not just the changing of one’s speech (pronunciation and grammar) but also requires reference to a completely different set of meaning systems for each dialect situation [5]

Dr. Brown at times will be an observer trying to make sense of what is said between the two Aboriginal men. From his observation, Dr Brown could populate new instances into his own knowledge base which may be useful and can be reused by other GPs. In this particular scenario it is possible that Ted is a community Elder and is more self-confident than Vincent. Dr Brown would be able to learn from Ted any new words that might arise, with their meanings and populate into his ontology driven system as new instances of dialect, words, phrase, and expressions. Figure 54 shows class *Aboriginal_English_Home_Talk* and some of its subclasses in which the user could populate instances while the ontology is in use.

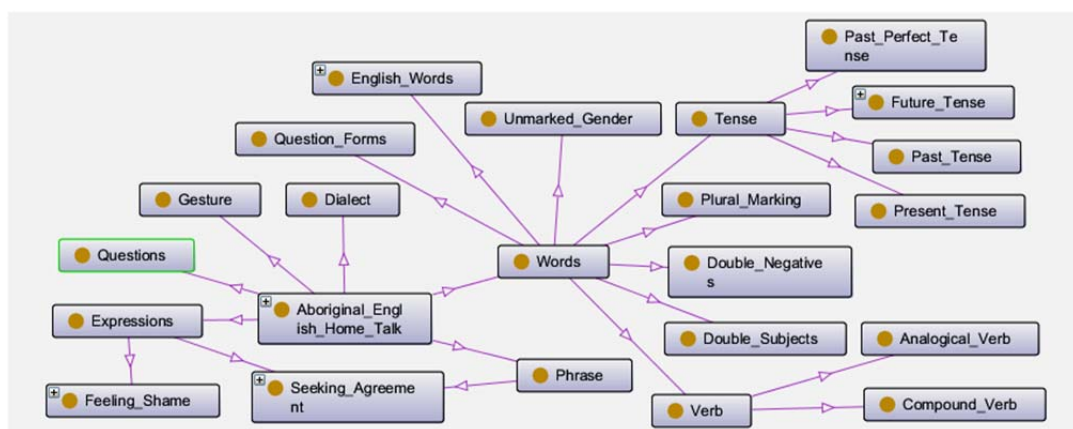


Figure 54: Class *Aboriginal_English_Home_Talk* and its subclasses

Interrogating the system to determine whether dialectal differences might affect the PPIE communication is justified as a precaution. If it appeared that Ted is from the north of Western Australia, whereas Vincent is from the south west, this may suggest a slowing of the PPIE conversations to limit miscommunication and misunderstanding. Dialectal advice options in the initial ontology constructions are, however, mostly limited to known Nyungar Aboriginal English names and expressions.

7.6.6 Patient and Health Professional Interaction

During the subsequent PPIE Dr. Brown may adopt a physical posture that he has learned from the PPAC ontology to offset cultural barriers that present difficulties for his patient and carer. The idea promoted here is that habitual routine PPIE is an unreliable mode for communication when there is reason to believe in advance that the patient may intrinsically endure a persona or perception of significant cultural disadvantage. In many Australian country care circumstances, the Aboriginal patient is pragmatically disposed toward the provider sitting alongside the patient as opposed to a face to face positioning. Moreover this helps to reduce another risk; that of offending the patient by using direct eye contact. The doctor would after consulting or confirming system advice choose to sit next to both men in the interview/examination room. Figure 55 shows advice on interaction captured in the ontology.

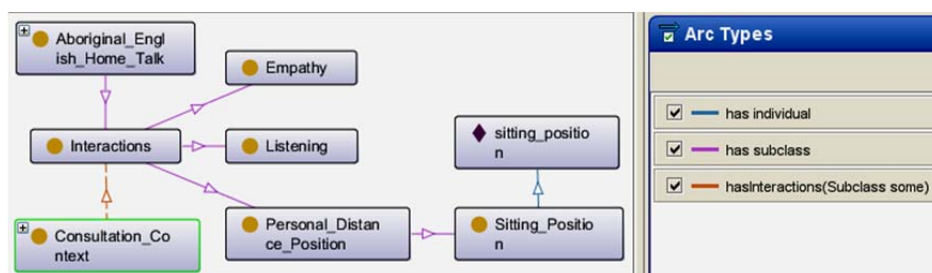


Figure 55: Capture of advice on interaction

From Figure 55, the ontology driven system would trigger the system to prompt practitioners of the importance of personal distance position, of listening, and of empathy. In particular on personal distance position, the system would be able to

further advise on appropriate seating positions with (for example) the suggestion of a short arc of three people alongside each other.

7.6.7 Asking Questions

In the course of the PPIE Dr. Brown will want to elicit some symptoms from Vincent, in part with the encouragement from Ted, who while not specifically acting as an interpreter, as a trusted member of Vincent's community can be regarded as Vincent's carer. One prevalent problem in the Aboriginal T2DM management domain is the consumption of alcohol. It is a subject matter replete with Aboriginal English euphemisms and metaphors with a fairly high risk of being missed by unfamiliar general practitioners. Patients generally as well as Aboriginal patients can be defensive when asked questions on this topic. Figure 56 shows this is annotated as a precaution in asking such questions.

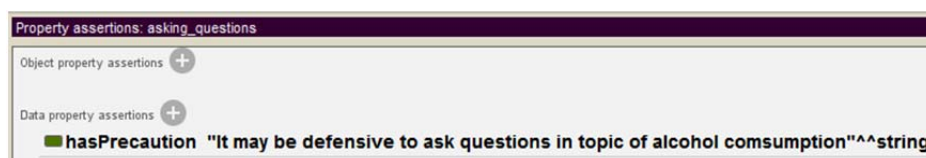


Figure 56: Data property *hasPrecaution* for instance *asking_questions*

From the focus group Aboriginal nurse trainee contributors, it is known that if the doctor hears words such as or close to 'e bin chargin' last night'; this is a reference to excessive drinking of alcohol. Physical gestures, for example, a patient curling his fingers as if holding a glass, lifting his hand toward his lips, may accompany such remarks. With limited conversation, perhaps using Ted the carer in the process, Dr. Brown may confirm the alcohol consumption factor by querying for 'bin' and 'chargin' as shown in Figure 57 and Figure 58 respectively.

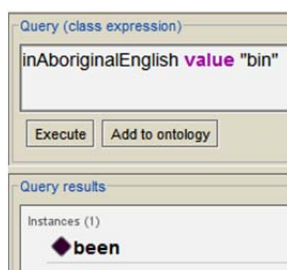


Figure 57: Query to find possible meanings of word 'bin'

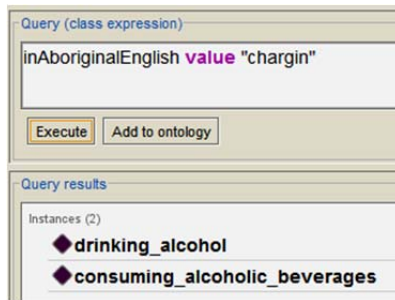


Figure 58: Query to find possible meanings of word ‘chargin’

The query results show further details of each instance as shown in Figure 59 and Figure 60 for ‘bin’ and ‘chargin’ respectively. The word ‘chargin’ from the results shown in Figure 60, is identified as a euphemism; for drinking alcohol and implicitly drinking excessive amounts. Several other metaphorical but semantically similar terms can also be captured.

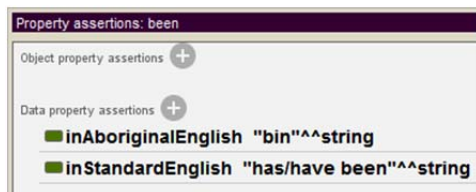


Figure 59: Query result for possible meanings of word ‘bin’

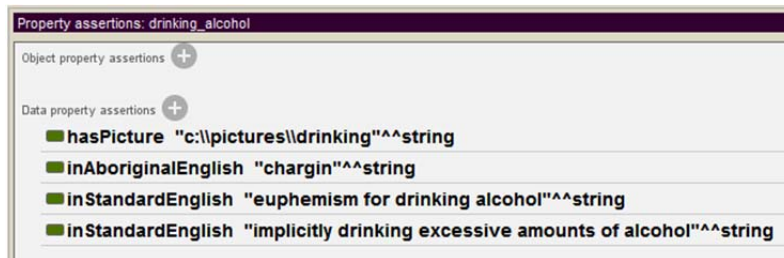


Figure 60: Query result for possible meanings of word ‘chargin’

Alternatively Dr Brown could also navigate through classes Words, Gesture, and Expressions. Figure 61 shows relationships in classes *Words*, *Gesture*, and *Expressions*.

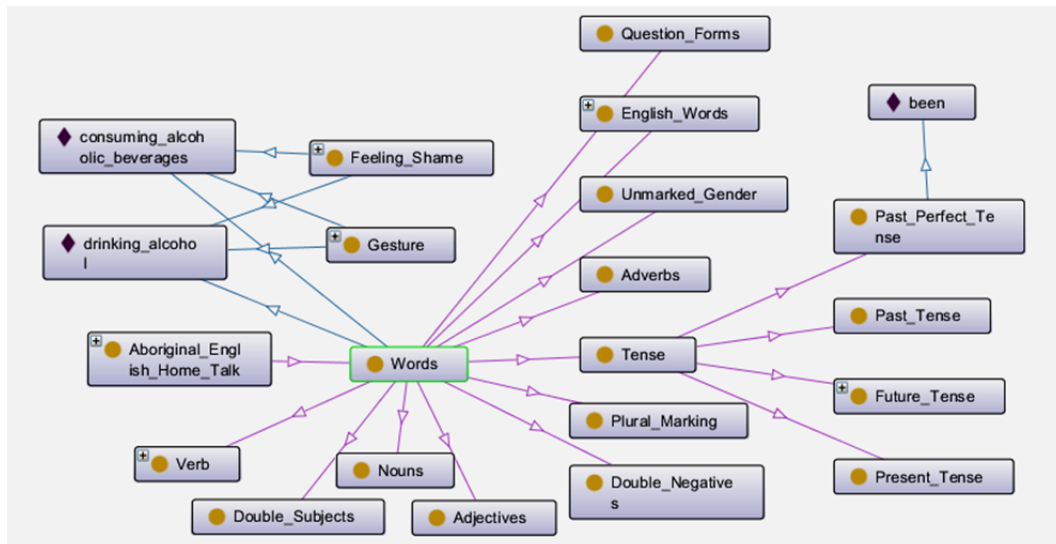


Figure 61: Relationships in classes *Words*, *Gesture*, and *Expressions*

Again from the focus group, it was learned that phrases identical or close to ‘*good breakfast, eggs and bacon*’ said in context are statements meaning that the subject has consumed a mix of alcoholic beverages. Practitioners can query for a word with “bacon” in a phrase as shown in Figure 62 in SPARQL. The query is posed at the top and results are shown below the query.

```
SPARQL query:
PREFIX rdf: <http://www.w3.org/1999/02/22-rdf-syntax-ns#>
PREFIX owl: <http://www.w3.org/2002/07/owl#>
PREFIX xsd: <http://www.w3.org/2001/XMLSchema#>
PREFIX rdfs: <http://www.w3.org/2000/01/rdf-schema#>
PREFIX ppac: <http://www.semanticweb.org/ontologies/2012/7/Ontology1346394913312.owl#>
SELECT ?Words ?AE
WHERE {
  ?Words ppac:inAboriginalEnglish ?AE.
  FILTER regex(?AE, "bacon")
}
```

Words	AE
consumption alcoholic beverages	"breakfast, eggs and bacon" <http://www.w3.org/2001/XMLSchema#string>

Figure 62: Query and its result in SPARQL to find possible meaning of word with ‘bacon’ in a phrase

Figure 63 shows the detail of the instance, in which the phrase in Aboriginal English of ‘breakfast, eggs, and bacon’ can be taken to mean consuming a mix of alcohol beverages.

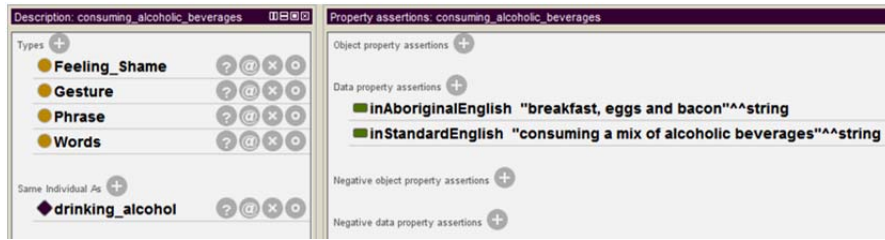


Figure 63: Detail instance of phrase in Aboriginal English ‘breakfast, eggs, and bacon’ (alcohol mix consumption inference)

Note that this instance is also an instance of classes *Feeling_Shame* and *Gesture*. This indicates that it relates to feeling shame and having gesture captured. In this case, a movement and use of arms, hands, fingers and head to convey a meaning of drinking is captured under class *Gesture* for drinking. Denoting shame, the PPIE communication could cause Vincent to bow his head if managed without care. Hence if Dr Brown looks further on feeling shame instance as can be seen in Figure 64, it can be confirmed that Vincent’s bowed head indicates that he feels shame.

Another sign that infers the Aboriginal patient is feeling shame is physically turning away from the practitioner. The practitioner should also be cautious of this as a presage to early unannounced departure by the patient. I return to the ‘alcohol’ dialectal and cross-cultural discourse in Chapter 8 as a helpful demonstration of the AEHT domain ontology development; using other T2D concepts and their relationships in the continuing context of the ‘Vincent and Dr. Brown’ case scenario.

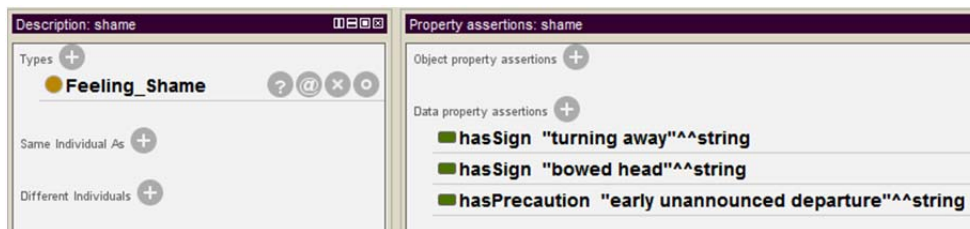


Figure 64: Data property of an instance of class *Feeling_Shame*

The design thinking for this is that although there is no intention or attempt to implicitly or explicitly interfere with the work of the qualified medical professional, the overall aim of the model is to help participants move toward a shared compact for improved patient wellbeing outcomes. To that end the ontologies cross-map AE and

T2DM guidelines to highlight differences in world views and thereby head off breakdowns in cognitively consonant communication.

From commonly used Aboriginal English expressions it is also possible to confirm that when the patient closes a statement with ‘unna’ this means ‘isn’t it so?’ or ‘isn’t that right?’ ‘Unna’ is therefore a single word that may be found by querying shown in Figure 65. Figure 66 shows the query result in detail in which it shows that it is an individual of class *Seeking_Agreement*.

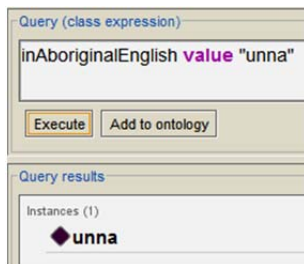


Figure 65: Query to find possible meanings of word ‘unna’



Figure 66: Query result for possible meanings of word ‘unna’

7.7 Summary of this chapter

This chapter has demonstrated the integrated product from the framework schema sources, conceptualization, relations and qualitative analysis design input in ontological terms. There is a degree of validation implicit within the foregoing method and structure explanations, flowing into the next chapter; it is anticipated as touched upon in Chapter 9 (Future work), that the domain schema development methodologies and system user prospects may be improved through changes and advances, most particularly within the practitioner health care delivery arena. The next chapter further explores the case scenario as a demonstration platform for evaluating the integrity of the PPAC ontology system.

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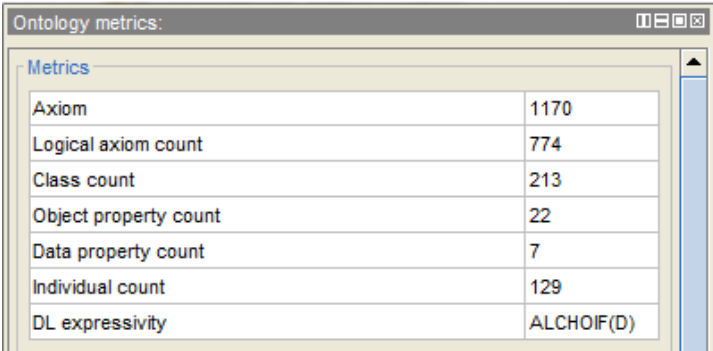
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Chapter 8: Validation of the PPAC concept framework

8.1 Introduction: Consolidation and background summary

The two major domain ontologies are linked together through ontology relations and constraints. I have steadily updated and extended the PPAC ontology development to include cultural aspects. The Aboriginal English Home Talk related concepts will gradually become more focused. The update is focused through scenarios and these contribute to future work planning as stated in Chapter 9.

Figures shown in this thesis are captured from Protégé using its capability of reasoning, querying, and graphical presentation to ease understanding on the update and focus. So far the PPAC ontology contains 213 classes, 22 object properties, 7 data properties, and 129 instances. Figure 67 shows the complete ontology metrics including axiom and logical axiom counts.



Ontology metrics:	
Axiom	1170
Logical axiom count	774
Class count	213
Object property count	22
Data property count	7
Individual count	129
DL expressivity	ALCHOIF(D)

Figure 67: Ontology metrics for PPAC ontology in Protégé

Ensuring ontology consistency is an important part of ontology development and testing. It is especially important when a shared ontology is necessary for meaningful communication. If a shared ontology is inconsistent, no reliable conclusion may be deduced. Consistency validation through a reasoner for PPAC ontology includes consistency checking, concept satisfiability, classification, and realization. These services are all the standard inference services traditionally provided by a reasoner e.g. Pellet, Racerpro, etc.

8.2 Process principles for validating the PPAC ontology

Mixed method research validation precepts as explored by Venkatesh et.al and introduced on pages 124 and 195 have been followed[1]. These involve separate consideration of validation principles applicable to qualitative and quantitative research. The greater proportion of the framework construction research is qualitative. Venkatesh declares that qualitative research does not, unlike quantitative research, have generally accepted or widely used guidelines or evaluation criteria. It is intended to add some strength to the Venkatesh argument that ‘a mixed methods nomenclature can be useful in order to differentiate mixed methods validation from quantitative and qualitative validation’.

The two primary validation issues for quantitative research highlighted by the literature review for the Venkatesh article are reliability and validity of measures. Yielding the same result repeatedly; and the objective truth from accurately represented findings; supports these issues. This is coupled with design validation, in which (citing Shadish et al.) internal validity is ‘the approximate truth about inferences regarding cause-effect or causal relationships in a scientific enquiry’[2].

Venkatesh spends a good deal of time discussing different author views and opinions about qualitative research validation before favouring the mixed methods inference quality conclusion of Teddlie and Tashakkori, who state that inference in mixed methods design is:

‘a researcher’s construction of the relationships among people, events, and variables as well as his or her construction of respondents’ perceptions, behaviour, and feelings and how these relate to each other in coherent and systematic manner’. [3]

Venkatesh et al. regard their mixed method research validation approach as consistent with Teddlie and Tashakkori, choosing to use the term *inference quality* to refer to validity; and *data quality* for reliability. Their guidelines for validation of mixed methods research, the principal aim of their publication, ‘are based on the notion of inference quality and its dimensions’.

Quantitatively the framework research subject of this thesis has relied upon carefully chosen and persistent concept input; from credible verifiable statistical data and data repositories of various functional type relatively or directly connected and/or contributing systematically to healthcare communications, epidemiology and the two main domains in my study, i.e. Type 2 diabetes and Aboriginal English. Fashioned here is a new or at least a largely unobserved and previously unpublished relationship between these domains. The third domain in an abstract sense is ICT, which in my framework provides the bridging vehicle for users in the PPIE environment.

In the following sections validation techniques are explained which

- apply the practical case scenario illustration to demonstrate the intended ontology performance and concept integrity
- show how PPAC user queries are designed to work; and
- describe steps and competency questions for testing the ontology.

8.3 Validation of Type 2 diabetes ontology hierarchical construct and annotations

As cited in Chapter 6 my annotations construction work embraced and selectively composed property and instance textual descriptions from several sources; in addition to the main Diabetes Australia/Royal Australian College of General Practitioners (RACGP) guidelines for type 2 diabetes management.

The annotations drafting from this process was reviewed in May 2013 by Dr Thomas Smalberger, B.Sc, M.Sc, D.Sc, M.B.Ch.B, FRACGP (Fellow, RACGP) a General Practitioner practising in the southern suburbs of metropolitan Perth. He conducted a clinical validation review of the draft work, providing additional contemporary practice knowledge and editing advice, which both modified and introduced new data content. The resulting professionally validated version of this work comprising a total of 132 (one hundred and thirty two) type 2 diabetes concepts annotations now resides in the Protégé PPAC ontology.

8.4 Validation of PPAC ontology for T2DM

The validation of the PPAC ontology for T2DM is twofold. Firstly this reasons logical consistency of the PPAC ontology for consistency validation. Secondly, I compose queries aimed at system retrieval/answering for usability validation of the PPAC ontology. For both parts the ontology reasoner is needed and I use Pellet which is one of the built-in reasoners of Protégé 4.2.

8.4.1 Consistency validation

Ensuring ontology is consistent is an important part of ontology development and testing. It is especially important when a shared ontology is necessary for meaningful communication. If a shared ontology is inconsistent, no reliable conclusion may be deduced.

Consistency validation through the reasoner for the PPAC ontology criteria includes

- Consistency checking,
- Concept satisfiability,
- Classification; and
- Realization.

These services are all the standard inference services traditionally provided by a reasoner e.g. Pellet[4]. The test is to ensure that PPAC ontology does not contain any contradictory facts. Logical consistency of the ontology is checked through Pellet and Racerpro. The PPAC ontology must also have concept satisfiability i.e. a class in PPAC ontology can have instances. If a class is unsatisfiable, then defining an instance of that class will cause the whole ontology to be inconsistent.

Within the validation criteria the PPAC ontology must have a complete class hierarchy (classification service). The class hierarchy can be used to answer queries which I cover in the next section, usability validation. The most specific class to which an instance belongs to must be found in the PPAC ontology (realization service).

In the systems code-switching is used to feed new information back into the systems so that the PPAC ontology will be able to self-populate additional instances. While conversation is taking place among GP and Aboriginal patient and carers or extended family, the GP could populate new instances from his/her observations into the

knowledge base which may be of value for reused by other practitioners. Hence additional instances will be populated while the PPAC ontology is in use. In this case, the additional instances will also need to be checked on whether they conform to the PPAC ontology through consistency checking of the instances with reference to the PPAC ontology.

8.4.2 Usability validation

By reasoning the PPAC ontology, facts can be derived that are not expressed explicitly in the ontology or in the knowledge base. It provides services to help users gain new knowledge. The system answers queries over PPAC ontology classes and instances; for example to find more general/specific classes or to retrieve instances matching a given query. It also uses query responses to validate the PPAC ontology usability.

In the natural language process of preparation for building queries into the Protégé knowledge acquisition system two statement sets are provided. These are designed to form queries for the purpose of PPAC ontology usability and also to reach shared semantic understanding.

The practitioner objective is:

- To identify T2DM SAE concept equivalents of patient AE words, phrases or expressions
- To identify AE words, phrases or expressions suited to the consultation context
- To semantically identify relevant AE properties

The patient-oriented objective is:

- To guide the practitioner toward cultural competence
- To find AE concept equivalents of T2DM words, phrases or expressions
- To guide the practitioner toward links with relevant AE PPAC concepts

The complexity of the task of identifying concept relations; and the design of the query process to secure explicit information in this combined domain ontology; arise from the many-faceted cultural competence gaps. The principal users/participants will often lack prior semantic knowledge of the technical and dialectal lexicon used by the other. This may mean that each does not automatically recognize and employ

those concepts that trigger and help to formulate queries. In my future work on application development, this will be anticipated and assistive tutorials will offer a wizard walk-through guide as a user-entry prelude to the PPAC ontology.

The case scenario(s) approach described in prior chapters is now employed to demonstrate the nature and therefore the testing of a query process in which rural/remote T2DM care concerns about alcohol consumption and vision surface in a PPIE.

8.4.3 Competency questions process steps

Query input and response output was previously referred to in Chapter 7, as part of the framework construction development; and in the process this described initial validation work.

The ontology validation process steps are:

- Compose plain language competency questions as anticipated user queries, while also creating an expectation of the answers required.
- Identify key words for framing the questions, and match these with concepts, relations and attributes for which the ontology has been designed.
- Frame the concept or relations query and enter it into the system.
- Retrieve the answer and check the veracity (correctness) of the concepts, relations and properties to ensure that these are properly defined at the right level.
- Act to correct any changes required to rectify accuracy and reliability flaws.

Two query languages are used in the validation work.

The DL Query tab, a standard Protégé 4 plug-in, provides a user-friendly feature for a classified ontology search. The query language (*class expression*) is based on the Manchester OWL DL syntax. It simply collects all information about a particular class, property, or individual, presenting it in the form of a single construct, called a frame. More intricate queries however will necessitate the use of SPARQL query language, which is much less user friendly but has greater capability for achieving granularity of detail from ontology instances.

The Simple Protocol and RDF Query Language (SPARQL) defines a standard query language and data access protocol for use with the Resource Description Framework (RDF) data model. SPARQL works for any data source that can be mapped to RDF. Protégé provides a query panel where query entries are made in the SPARQL syntax. Clicking on the Execute Query button generates query results which will be shown on the screen.

8.4.4 Competency question tests conducted on the PPAC ontology

Competency questions reflect the intent to induce an education experience and knowledge transfer in the circumstance of entry-level formative exposure to Aboriginal English acculturation in the PPIE. The user sample profile for a practitioner includes relative novices in the rural/remote community service sense, e.g. IMGs/OTDs, recent nurse graduates, urban-experience-biased practitioners and AHPs of all types, These are system test questions but typify the queries that these users can be trained to apply.

On behalf of the practitioner Question 1 is: ‘What is Aboriginal English Home Talk?’

The query is constructed using DL and choosing the concept which uses the key words in the question, as displayed at Figure 68. The combined screen result is also in Figure 67. Results show 13 sub classes and 115 instances (due to limited space all 115 instances cannot be shown). From the selection of instances shown below shows the instance brother details as example → in AE in which brother is called ‘budda’; brother is not only blood related family but may also include a non-related family member. Clicking on any of the query result subclasses will produce instances which in this case collectively suggest the broad scope of AEHT and the opportunity to acquire richer cultural engagement knowledge. Clicking o an instance will generate data and property assertions.

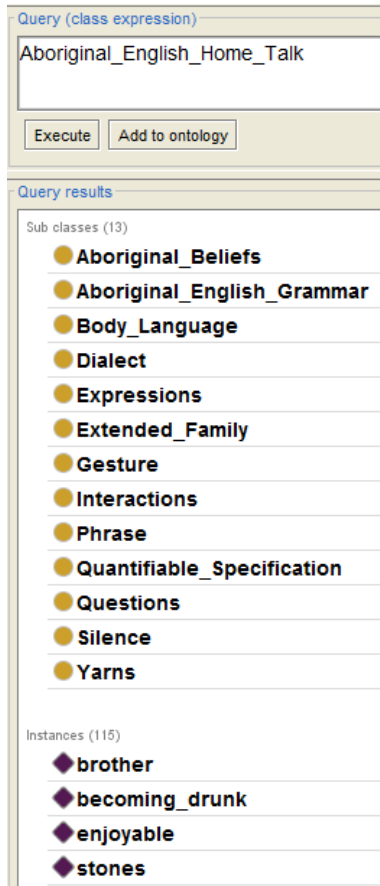


Figure 68: Aboriginal English (Home Talk) query entry and results

This example pursues the query explanation of the instance ‘brother’. It may provoke a user’s curiosity to know why ‘brother’ is of consequence for understanding AEHT. This eventually presents a sequence of ontology concept detail, with descriptions and property assertions as shown in Figure 69.

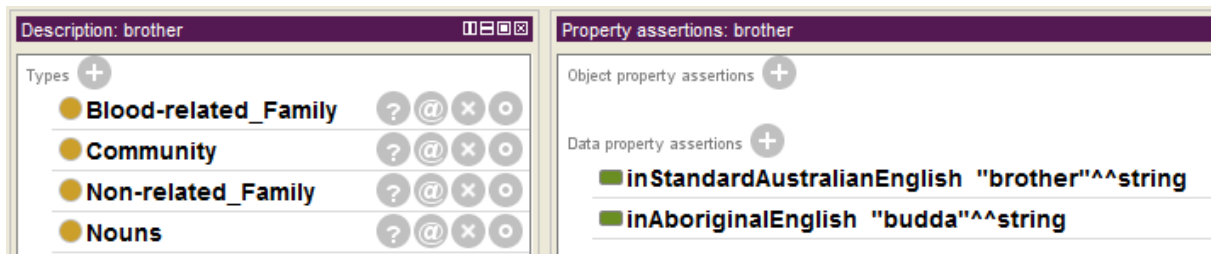


Figure 69: AEHT ‘Brother’ instance query result descriptions and assertions

Figure 70 below shows the Aboriginal English home talk annotation. In the training of practitioner users, this annotation merits primacy for further query work.

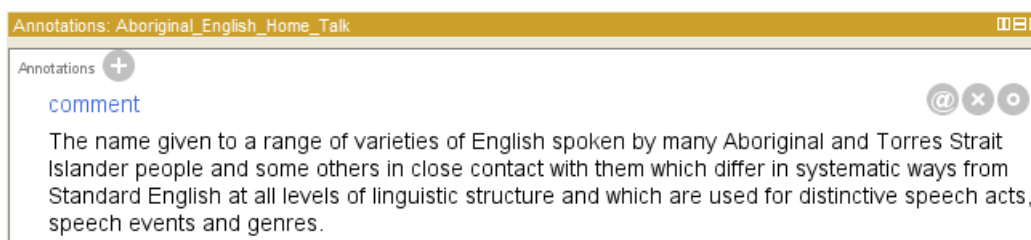


Figure 70: AEHT parent class annotation

Practitioner Question 2: What can I learn about Aboriginal beliefs? This subclass question is a natural extension of the first as it further invites professional learning. Figure 71 shows the query, query result and instances; again revealing a host of instances.



Figure 71: Aboriginal beliefs query and results

Each instance links to annotation, descriptions and property assertions.

Figure 72 below shows the instance ‘other country’ details as example → in AE; in the spirituality context and explanatory annotation showing the ‘other country’ belief in detail.

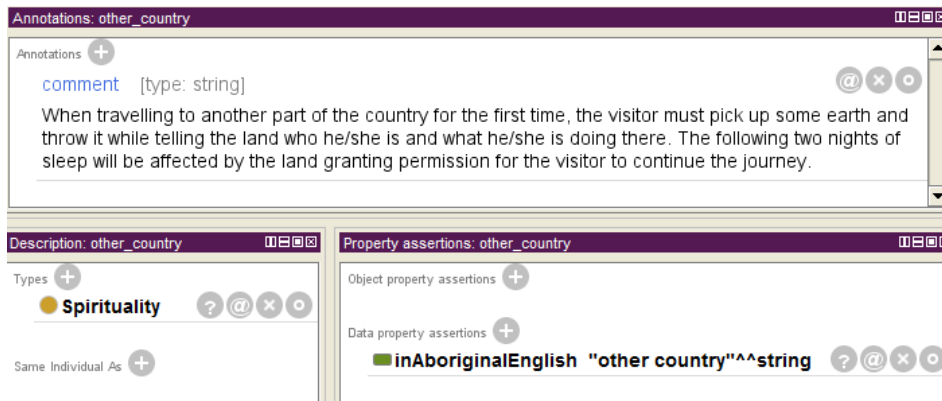


Figure 72: Annotation, description and property assertion for ‘other country’.

This step begins to pose questions for practitioner querying of AE patient behavioural pragmatics. Question 3 is: “How will I know/suspect that a patient is feeling shame?” A companion query is Question 4: “What is the known cause of ‘shame’ affecting an Aboriginal person?” In Figure 73 I query in DL by using the concept with key words ‘feeling shame’

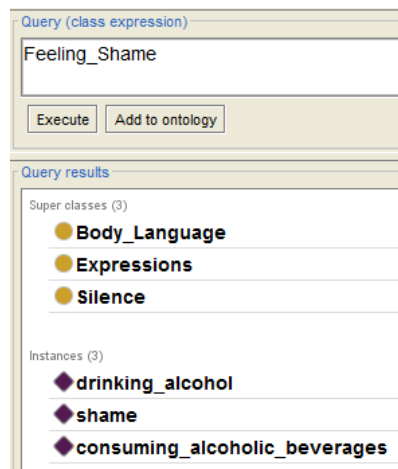


Figure 73: ‘Feeling shame’ query and results

It is noted that this query disclosed three super classes: body language, expression, and silence; with three instances. I next investigate the instance ‘shame’. Figure 74 shows the instance shame details, including links to three class descriptions and data property assertions enabling an answer which indicates ‘has signs of turning away, bowed head’ while also flagging (for the practitioner-user) the data property precaution of ‘early unannounced departure’.

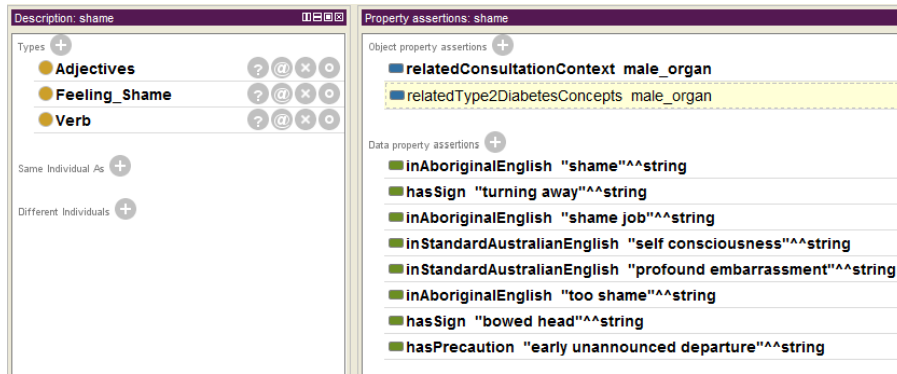


Figure 74: Description, object property and data property assertions for ‘shame’.

In the Figure 74 ontology query screen depiction for ‘shame’ the object property assertion includes the T2D classified concept ‘relatedConsultationContext male_organ’. In my Ted and Vincent case scenario I alluded to and explained the AE concept of gender sensitivity and how this can impact the PPIE.

Figure 75 shows details of membership of instance male_organ and relations with subclasses beliefs, yarns, expressivity and interactions to ‘shame’

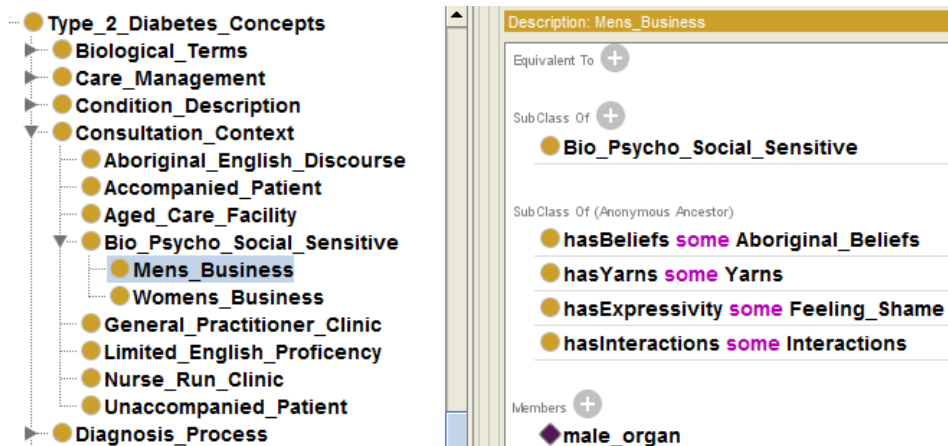


Figure 75: Hierarchy subclass Mens_Business description showing it as subclass of Bio-Psycho_Social_Sensitive; links with male_organ

Figure 76 shows the ‘feeling shame’ annotation contextualised for AE understanding.

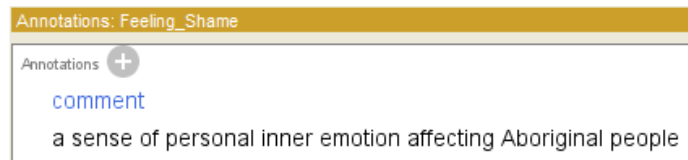


Figure 76: Feeling_Shame annotation

Returning to the earlier ‘shame’ query responses shown in Figure 73 there is reason to query the remaining two instances, i.e. the instance `drinking_alcohol`, and the instance `consuming_alcohol_beverages`. Figure 77 below shows the instance description and property assertions for `drinking_alcohol`; Figure 78 shows the matching details for `consuming_alcohol_beverages`.



Figure 77: ‘drinking_alcohol’ instance description and property assertions

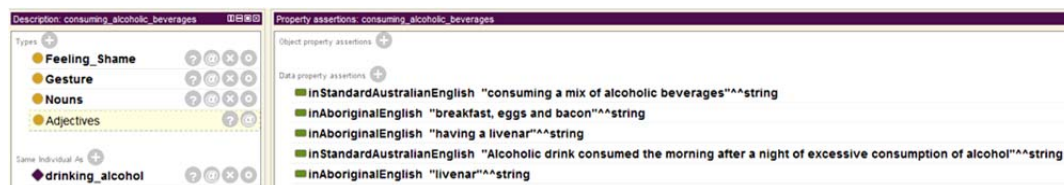


Figure 78: ‘consuming_alcohol_beverages’ instance description and property assertions

Question 5 for the practitioner user is “What should I know about my patient’s Aboriginal family and community background?” This more probing query construction requires the SPARQL query language to attract and secure more granular detail from the needed answers /instances (compared with DL). In the

Figure 79 SPARQL query searching for a class with ‘Family’ in it retrieves the class Extended_Family.

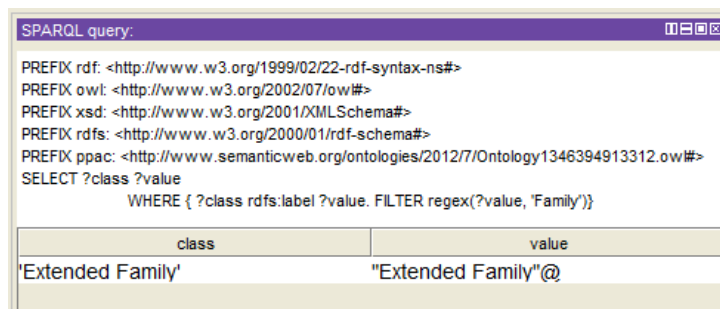


Figure 79: SPARQL query searching for a class with ‘Family’ in it retrieves the class Extended_Family

Figure 80 shows results from Extended_Family in detail

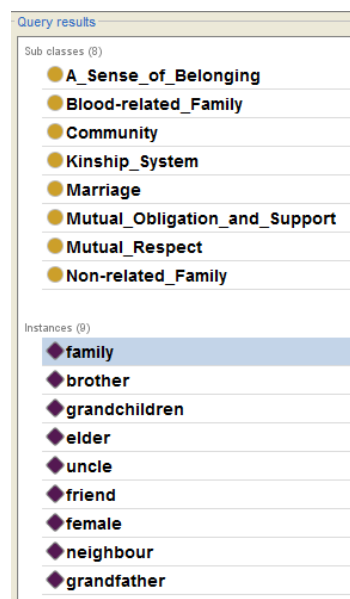


Figure 80: Extended_Family query results and instances

From the results shown in Figure 80 and clicking on selected instances I recover more detail. Top of the list of instances as a good example choice is ‘family’. Figure 81 shows the instance ‘family’ in detail

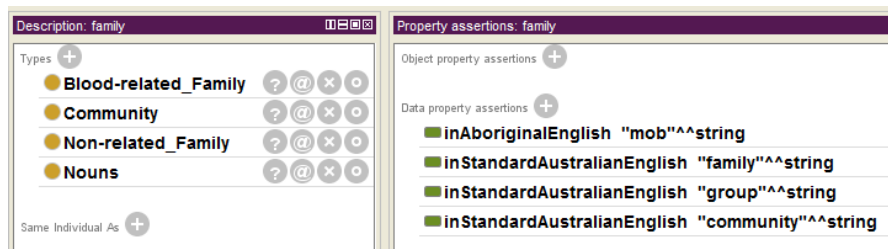


Figure 81: ‘family’ descriptions and property assertions

Question 6 for the practitioner user is “What words should I listen for to determine my patient’s alcohol consumption habits?” This is also a SPARQL query language task as it implicitly seeks information and knowledge of concept relationships that may not be obvious to a practitioner through the conventional PPIE process; and that may also be subject to communications barriers arising from ‘shame’ as referenced in prior descriptions of ‘alcohol’ related queries. Figure 82 shows the five instances which link to SAE sources offering deeper exploration and explanation.

SPARQL query:

```

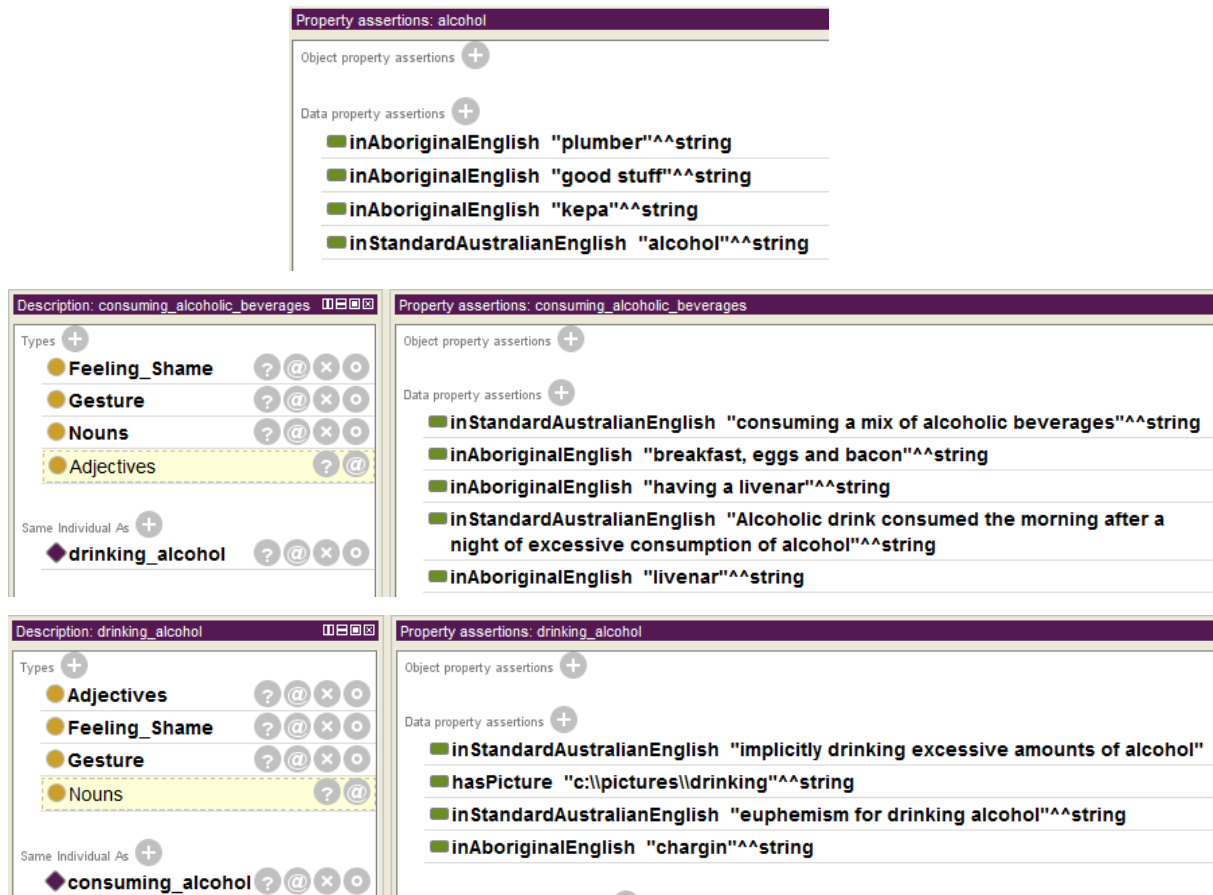
PREFIX rdf: <http://www.w3.org/1999/02/22-rdf-syntax-ns#>
PREFIX owl: <http://www.w3.org/2002/07/owl#>
PREFIX xsd: <http://www.w3.org/2001/XMLSchema#>
PREFIX rdfs: <http://www.w3.org/2000/01/rdf-schema#>
PREFIX ppac: <http://www.semanticweb.org/ontologies/2012/7/Ontology1346394913312.owl#>
SELECT ?instances ?SAE
WHERE { ?instances ppac:inStandardAustralianEnglish ?SAE. FILTER regex(?SAE, 'alcohol')}

```

instances	SAE
consuming alcoholic beverages	"Alcoholic drink consumed the morning after a night of excessive consumption of
consuming alcoholic beverages	"consuming a mix of alcoholic beverages""<http://www.w3.org/2001/XMLSchema#string>
drinking alcohol	"implicitly drinking excessive amounts of alcohol""<http://www.w3.org/2001/XMLSchema#string>
alcohol	"alcohol""<http://www.w3.org/2001/XMLSchema#string>
drinking alcohol	"euphemism for drinking alcohol""<http://www.w3.org/2001/XMLSchema#string>

Figure 82: Instances from SPARQL query for SAE words with ‘alcohol’ key word

Figures 83, 84 and 85 depict the sequence initially emanating from the query ‘alcohol’. Figure 83 provides four data property assertions. The description ‘consuming_alcohol_beverages’ locates four types. In Figure 84 ‘Adjectives’ is selected and returns data property assertions that disclose AE conversational metaphors and euphemisms. Figure 85 shows the screen results from the key word description and concept ‘drinking_alcohol’, linked to semantic equivalent individual ‘consuming_alcohol’. Selecting the description ‘Nouns’ produces data property assertions qualifying relationships



Figures 83, 84 and 85: ‘Alcohol’ descriptions and property semantics/assertions sequence

Shown in the above sequenced results above are the words the practitioner should listen for, i.e. chargin, livenar, having livenar, breakfast, eggs, and bacon, good stuff, kepa, plumber.

Posing as **Aboriginal user**, I am confronted with some difficulty because of the relative incompleteness of the AE healthcare-specific lexicon. It is possible however to satisfy several queries. Queries described here may be generated independently or with the aid of an AIHW who has some awareness of the communications barriers.

Aboriginal English speaking patient Question 1: Why does doctor talk about alcohol when I complain about my bad eyesight (gooras winyarn)? A companion Question 2: is “How serious is drinking a lot of alcohol? These joint queries are made in the context of T2DM care. From my case scenario the first intimation of an eyesight problem comes from the AE words ‘Gooras Winyarn’. The first query result is the instance ‘bad eyes’ as in Figure 86.

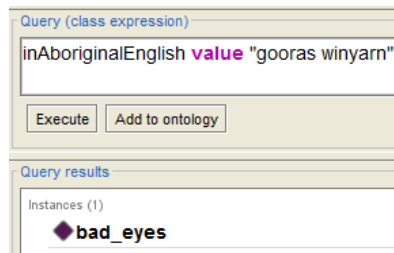


Figure 86: Query of class expression ‘Gooras Winyarn’.

Figure 87 shows results: signs and symptoms of altered vision; and blurred vision, eye testing, diagnosis process of vision impairment, condition of retinopathy.

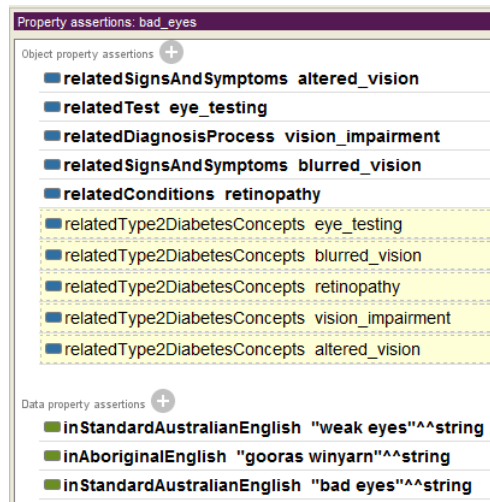


Figure 87: Property assertions for bad_eyes

If the Aboriginal user is interested in blurred vision, the query process shows as below in Figure 88 the details linked to property assertions for T2D concepts of alcohol intake. These reveal that it is has a relationship with alcohol consumption. Also the results below show related conditions of hyperglycaemia and hypoglycaemia with alcohol consumption.

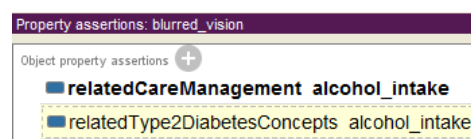
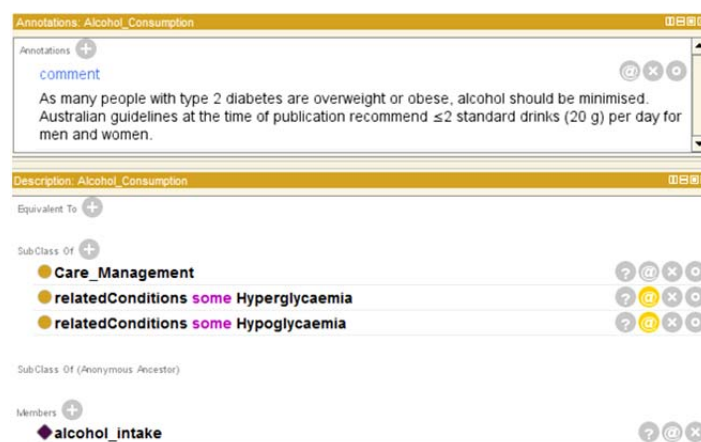


Figure 88: Property assertions ‘blurred vision’ and T2D concept alcohol_intake

Alcohol consumption is annotated as in figure 89, combined with description subclasses in figure 90.



Figures 89 and 90: Annotation and alcohol consumption subclasses with semantically related member alcohol_intake

Some technical words and acronyms overheard by the Aboriginal patient during a PPIE require future acculturation and translation work to fit with AE pragmatics for independent use by patients. This example refers to a commonly cited test.

Aboriginal patient Question 3 is “What is the HgbA1c test?”

The SPARQL query is shown at Figure 91, with the annotation in Figure 92.

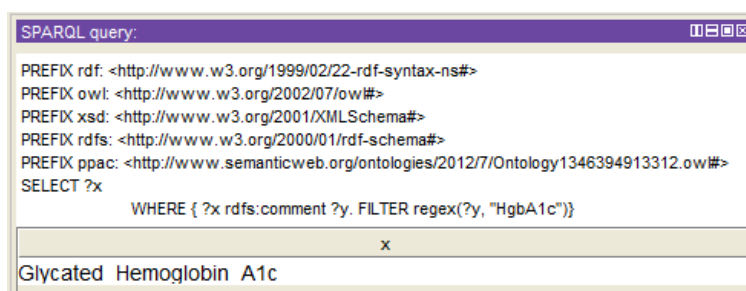


Figure 91: SPARQL query HgbA1c test

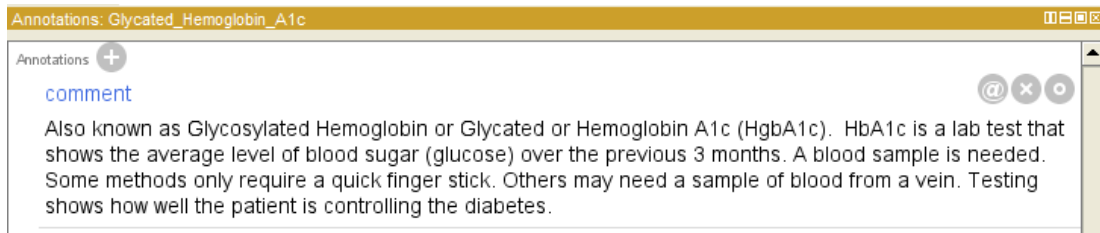


Figure 92: Annotation for Glycated Hemoglobin A1c (aka HgbA1c)

A further ([Aboriginal Question 4](#)) is: “What kind of testing may have to be done?”

Figure 93 displays the query and results

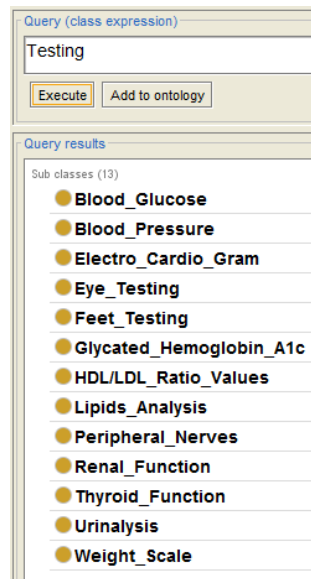


Figure 93: ‘Testing’ query and results

8.5 Constraints affecting AE health talk pragmatic expression queries

The foregoing Aboriginal patient query examples are intended to prove the concept, not the end product, as this part of the system is not yet Aboriginal-user friendly for reasons stated in Chapter 3. This requires investment in future work as proposed in Chapter 9 in order to secure the intended level of AE health talk competence and to be able to get the query right; and equally produce the right results. A research based store of possible and probable Aboriginal user queries and SAE answers for T2DM care exists, with the example:

“Doctor talks about diabetic ‘risk’, what does he mean?”

One point of reference is HDL/LDL ratio values.

In Standard Australian English the explanation is that High-density lipoprotein, or HDL, is the ‘good’ cholesterol which carries cholesterol back to the liver and in so doing helps cleanse the bloodstream of cholesterol; whereas Low-density lipoprotein, or LDL cholesterol, is the ‘bad’ cholesterol. Overly high levels of LDL increase the risk of a heart attack. Accordingly a higher HDL/LDL ratio indicates a higher risk of heart disease; a lower ratio indicates a lower risk. Future work to satisfy this query will engage a variety of AE expressions which simplify concepts such as ‘lipoproteins’, ‘cholesterol’ and ‘ratio’ as well as ‘risk’ in context.

8.6 Chapter summary

I have conducted and illustrated the query input and resultant output. Queries were first demonstrated and validated as an explanation-supporting component of the Chapter 7 elucidation of the framework ontology development. For ease of back-reference these are located as follows:

- 7.6.1 Figures 43 and 44, 46 and 47;
- 7.6.2 Figures 49 and 50
- 7.6.6 Figures 57, 58, 59, 60, 61, 62, 65 and 66

Chapter 8 has extended these six Chapter 7 query process validations with a further nine queries results and detail based on system competency questions.

8.6.1 Concluding remarks for this validation chapter

The PPAC ontology does not contain any contradictory facts in which logical consistency of the ontology is checked through Pellet and Racerpro. The PPAC ontology has also concept satisfiability i.e. a class in PPAC ontology can have instances. If a class is unsatisfiable, then defining an instance of that class will cause the whole ontology to be inconsistent. The PPAC ontology has a complete class hierarchy (classification service). The class hierarchy can be used to answer queries. The PPAC ontology (realization service) is able to find the most specific class to which an instance belongs. From the experiment the PPAC ontology is consistent. As a framework it is ready for adoption in the preparatory process of application software development, as now proposed in the final chapter of this thesis.

References

- [1] V. Venkatesh, S. A. Brown, and H. Bala, "Bridging the Qualitative–Quantitative Divide: Guidelines for Conducting Mixed Methods Research in Information Systems," *MIS Quarterly* 2013
- [2] W. Shadish, T. Cook, and D. Campbell, "Statistical Conclusion Validity and Internal Validity," in *Experimental and Quasi Experimental Designs for Generalized Causal Inference*, W. Shadish, T. Cook, and D. Campbell, Eds. Boston: Houghton Mifflin, 2002, pp. 33-63.
- [3] C. Teddlie and A. Tashakkori, "Major Issues and Controversies in the Use of Mixed Methods in the Social and Behavioral Sciences," in *Handbook of Mixed Methods in Social and Behavioral Research*, A. Tashakkori and C. Teddlie, Eds. Thousand Oaks, CA: Sage Publications, 2003, pp. 3-50.
- [4] E. Sirin, B. Parsia, B. C. Grau, A. Kalyanpur, and Y. Katz, "Pellet: A practical OWL-DL reasoner," *Web Semantics: Science, Services and Agents on the World Wide Web* vol. 5, pp. 51-53, 2007.

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Chapter 9: Recapitulation and Future Directions

9.1 Introduction: Summary outline of this research

Summarizing the background and progress of this work I am able to review the drivers for the original undertaking and for pursuing ultimate goal outcomes.

Distance, terrain, climate and inadequate medical resources seriously constrain health care service accessibility for rural and remote Indigenous communities of Western Australia (WA).

Management of the chronic condition Type 2 Diabetes Mellitus (T2DM) requires a complex assortment of time-sensitive measures and continuous knowledge exchange to avert serious complications. Timely interventions for T2DM patients are often critical. One example of a potential solution to overcome the mentioned constraints, is the feasibility for patients and health practitioners to rely upon ICT systems that avail communities of remote management healthcare support. Voice and text communication must however emulate face to face encounters. These however are too frequently unsatisfactory in the context of shared cognition.

Communications barriers arising from pervasive cultural misunderstanding in primary care transcend language differences. Practitioners and patients presently lack the capability to facilitate dialogue for shared meaning in the examination and testing discourse.

Indigenous patients are especially disadvantaged through low levels of ICT engagement; but receptivity to technology by adolescent members of Aboriginal communities offers particular promise. *A culturally sensitive purpose-driven informatics approach is required.*

The work described in this thesis is intended to counter the adverse wellbeing conditions affecting Australia's Aboriginal communities by significantly improving and establishing equitable primary care consultations capabilities, specifically

targeting type 2 diabetes. Among many serious health care concerns my research findings show that failures in communication contribute to these outcomes. The proposition is that the increasing popularity of computer technology applications used on mobile devices represents an opportunity to overcome communications barriers and misunderstandings between health providers and Aboriginal patients.

A model framework is presented that provides the foundation to capture Aboriginal rural and remote ways of communication; and to intelligently connect different forms of expression that will enable patients and practitioners to share a health care ‘lingua franca’. This simply means a common way of communicating between two different cultures. As an education tool, the eventual Patient Practitioner Assistive Communication (PPAC) system will help patients and their GPs in particular make sense of different ways of describing, for example, signs and symptoms; and the treatment and care advice.

9.1.1 Future development and design influence

A software engineering preparatory projection is dealt with in this chapter, looking beyond the conceptual framework to contemporary market development of user applications. Throughout the course of this research however it has been necessary to anticipate and plan for more than a single application or outcome. It has been sensible to ensure that the data and target user domain sources are continuously reviewed; with the prospect that multiple applications will evolve through exponential ACT development and market demand. In Chapter 2, Omachonu and Einspruch are cited for their perception of ‘new organizational practices’ facing health care practitioners and the ‘*multiple empirical disciplines*’ of cognitive science in play across the healthcare service domain[1].

Describing a web access repository named BioPortal, Noy et.al write of an integrated functionality scenario in which biomedical ontologies ‘provide domain knowledge to drive data integration, information retrieval, data annotation, natural-language processing and decision support’ [2]. Community-based participation in the evaluation and evolution of ontology content will be enabled through design features to allow addition of notes to ontology terms, mappings between terms and usability reviews. Noy et.al further state: ‘BioPortal not only provides investigators, clinicians,

and developers ‘one-stop shopping’ to programmatically access biomedical ontologies, but also provides support to integrate data from a variety of biomedical resources. This form of ontology access and usage development offers the promise to extend the worth of new ontology-based applications, functionality and refinement through an integrated network of clinical and non-clinical health and healthcare knowledge and service driven repositories. The literature effectively confirms that integration capabilities can and will take the most basic of domain ontologies into a new world of relationships representing multi and inter-domain applications that in the past may have been too complex to contemplate.

The total design maxim introduced by Pugh and widely acknowledged as a major contributor to advances in design methodology, brought a systematic ‘start to finish’ process formula to product engineering[3]. Prior to the publication of Pugh’s book, production design and engineering activities had mostly been conducted in ad-hoc isolation from other parts of the invention to end-user cycle. These failures to follow an orderly collaborative process; to organize integrate and synchronize all of the objectives, processes and goals of production; too often resulted in commercial failures. The learning experience was successfully countered later by adoption of the Pugh Total Design philosophy. Total Design is structured to allow integration of technological and non-technological portions of the production process. In Pugh’s words:

“Total design may be construed as having a central core of activities, all of which are imperative for any design, irrespective of domain. Briefly, this core, the design core, consists of market (user need), product design specification, conceptual design, detail design, manufacture and sales. All design starts, or should start, with a need that, when satisfied, will fit into an existing market or create a market of its own.”
[3]

9.2 Cognition and Communication Lessons for future work

The achievement of understanding, combined with justifiable mutually shared confidence in the intended semantics of a conversation between two people, is an

elusive outcome when cultural distance barriers are involved. Hence a multilayered dialectical bank serving as an assistive agent and aide to two-way Aboriginal English health care pragmatics is needed.

Fortunately the foundation work on Aboriginal English and the ontology based conceptual framework provide research investigators with good guidance on the prerequisites and best methods in community engagement for the purpose of identifying, collecting and using Aboriginal English home talk schema data within the intended PPAC system model. Moreover, detecting the absence of significant prior provider interest in Aboriginal English 'health talk' this author believes that the potential scope and value of the concept are not visible to the majority of observers. The research findings offer confidence that Aboriginal English is a frequent and prolific facet of daily social intercourse in the homes of Australia's rural and remote Aboriginal people. It is abundantly clear that discussion involving health and health care matters is conducted in the AE dialect; and equally that uniquely AE words, phrases and expressions are not documented in written form, and are therefore in the majority of cases unknown to health care practitioners. Envisaging the search, collection and ontological integration processes it is necessary to formulate a set of objectives which will take optimal advantage of the research findings. This applies most especially with regard to the cross-cultural engagement barriers that have been identified and qualified for ongoing design goal purposes.

9.3 Longer term need for research and development of PPAC

More work is necessary to strengthen the data quality and content of the PPAC, to refine work already completed for primary care consultation processes, and to develop techniques leading to a commercial production outcome. The next stage would be a combined early proof-of-principle and pre-seed stage; with a prototype applications model anticipated thereafter. One of the most significant and essential shifts in the research work profile will be the engagement with representative communities capable of helping to design, evaluate and refine the eventual assistive communications product.

Having completed the development of the conceptual framework and backbone implementation the next stage toward introduction and productive use of the PPAC system within Aboriginal patient country communities and their health care service provider communities is three-fold:

- Pragmatic content enrichment and scope expansion phase
- Development of a commercial grade software application based on the completed conceptual framework
- Field trials of the PPAC system model using contemporary user-friendly devices

9.3.1 Pragmatic content enrichment and scope expansion

An updated review of the relevant literature at the close of this research cycle confirms that little attention by the health care service culture is given over to the specific role of Aboriginal English dialectal preferences found in the homes of Australia's Aboriginal people. By contrast this has been heavily researched and published in the primary and secondary education sector; which is a leading grammatical, linguistic and paralinguistic source illustrating the characteristics of Australia's acculturative inadequacies. The plan to remedy this pragmatic deficit and to thereby enrich and expand the scope of the ontology in support of the eventual application is discussed later in this chapter.

9.4 Cross-cultural healthcare communications development imperatives

At the latest practical stage in the chronology this work, and for the purpose of setting sights on justifiable pursuit of eventual production of a PPAC system prototype the health care discussion and statistical source concerning the health status of the Aboriginal community has been revisited. Prior to and during the years of this research the Australian federal and state effort to address the extraordinary impact of T2DM and other chronic diseases has been a continuous investment. It is a reasonable thought that sufficient if not significant regression of the incidence of chronic disease and comorbidities would suggest that methods for preventive disease and care management applied are working; perhaps to the extent that two-way communication in PPIEs has improved and even that the ontology-supported PPAC

system concept is less relevant compared with late 2009 when this work commenced. This is not the case.

The seriously adverse conditions noted at the outset of this research have not significantly abated despite the considerable investment of time, money and effort by government. The Aboriginal and Torres Strait Islander Health Performance Framework 2012 reports that chronic disease contributes to two-thirds of the health gap between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians [4]. It should be noted that while the majority of information comes from a broad demographic, not all state-based data sets within the report represent the whole of Australia, with small variations arising through incomplete data from one (variable) state in some sets.

The serious diabetes and diabetic comorbidity factors appear to be persisting in spite of many years of the COAG 'Close the Gap' health care agreed interventions mentioned in Chapter 1. Although the AHMAC Framework 2012 data show that there has been a significant decline in Indigenous mortality rates, the report states that the current rate is twice the non-Indigenous rate and that the pace of improvement must accelerate if it is to meet the planned goal at target date. As advised in Chapter 1, a major goal is to halve the life expectancy gap by 2031. While acknowledging this marginal improvement in the overall mortality rate the AHMAC Framework 2012 also reports the following data that illustrates the continuing burden of chronic disease affecting Aboriginals:

- Sixty-eight percent of deaths in 2006-2010 were due to chronic diseases.
- During the same period for NSW, QLD, WA, SA and the NT combined around eight percent of Aboriginal deaths were due to diabetes; representing seven times the death rate of non-Indigenous people.
- Aboriginal death rates from kidney disease (commonly associated as a diabetes comorbidity) increased by eighty-nine percent between 2001 and 2010; a much faster rate than that for non-Indigenous patients. This gap factor has widened.

- Since 1991 the numbers of Aboriginals with end-stage renal disease who commenced renal replacement therapy has also increased; by a worrying 96 percent, at a rate seven times greater than non-Indigenous patients.
- While often but not exclusively related to diabetes, eye health data from 2008 shows that approximately nine percent of adult Aboriginals had low vision capability and two percent were blind. Of those with vision impairment twelve percent were attributed to diabetic retinopathy.

9.5 Research barriers

The barriers encountered in the research subject of this thesis, as discussed in the ‘problem’ Chapter 3, are compounded when contemplating future work extending the scope of the ontologies and the design of a viable PPAC system model. Chief among these are the rural and remote Aboriginal community researcher engagement factor; and the funding needs of the project. Obstacles can be negotiated and circumnavigated and are not always absolute barriers; but the excessive consumption of time due to extended and protracted negotiations, together with unforeseen and unavoidable conflicts such as Aboriginal intra-community and inter-community rivalries, is a risk. This may translate to financial cost impacts and efficiency loss through breaks in research team staffing and continuity. Research funding is a highly competitive theatre; without adequate funding inclusive of a contingency budget, the prospect of successful engagement in the Aboriginal communities is fragile. As has been mentioned in the literature cited in Chapter 3, examination of the history Aboriginal research reveals many obstacles [5-8]. Building trusted relationships are essential but commonly take more time than labour intensive projects can accommodate. It is no coincidence that the majority of research papers concerning direct community engagement in Aboriginal health and healthcare reflect activity of relatively short duration and limited outcome data. One other observation of the exacerbated research barrier to be anticipated in the extended work is the logistics dimension. Physically negotiating with communities; field work travel and associated environmental demands on researchers and their work will tend to increase the risk of exceeding timeline and budget projections.

9.6 Aboriginal English healthcare communications fieldwork

A proposed research plan is described as three phases of activity. The descriptive text that follows is intended to lay down engagement fundamentals that are designed to record research-based advice and provide guidance for best future research and development outcomes.

9.6.1 First Phase Aboriginal Community Field Research

As the desirable outcome of this work is unlikely to be achieved unless the reported barriers to research are successfully mitigated; and recognising the uniqueness of the inter-related many-faceted research findings, included here is a descriptive advice for a culturally competent process of data collection. The precept is that before researchers are in a position to substantially enrich and populate the ontology support for the PPAC system, we must first calculate and invest in a process methodology that at the human interaction level will maximize the return on investment in field work. This is not only intended as a data enrichment project, but as a simultaneous education exercise for the stakeholders, not least of the reasons being that ownership and efficacy of personalized healthcare information system applications presents the opportunity for all users to self-populate ontological elements supporting the PPAC system. This observes and actively promotes the essence of the World Wide Web Consortium (W3C) philosophy encouraging shared and expandable universal access to ontologies.

The planned process to achieve the healthcare lingua franca content enrichment and scope expansion objective is to assemble an investigations team capable of expanding the AE ontology data population based on Aboriginal real-world health and health care concepts.

For the first phase this will require a team selection process in which project-proficient Aboriginal researchers will undertake a lead role in field work engagement with remote Aboriginal communities within or bordering the Australian bush

Initial project preparation necessitates orientation and tutoring based upon the conceptual framework. The objectives are (a) to establish a confident shared understanding of the principles embedded in the combined Aboriginal English and

Type 2 Diabetes concept ontologies; (b) to provide team guidance on the conduct and objectives of focus groups and interviews within Aboriginal communities; and (c) to agree a set of disciplined protocols. These protocols will accord with NHMRC standards of scientific research rigour; with ethics in the conduct of the research project; and with professional accountability. This preparatory time will allow sufficient opportunity to facilitate synergic team building and to test-run research data collection equipment including audio-visual media recording devices.

The final portion of the foregoing preparation will be the composition and trial modelling of focus group planning and implementation; and a contributory team design of interview questionnaires and techniques. Considerable and extremely demanding intellectually intensive work is required in the preparation of focus group and interview guide materials as a priority will focus on de-construction and reconstruction of T2DM care guideline clinical terminology per ontology concept and per ontology relationship so that the resultant new Aboriginal English home talk and health talk schema collection and collation can be efficiently structured to enable machine readability and user interface efficiencies.

Strong emphasis will be placed upon Aboriginal team member and related cultural research advice for the benefit of consistency in the establishment and maintenance of a relationship of trust between research team members and cooperating communities and individuals. The priority of respectful engagement with community Elders will be a dedicated activity in this process.

After the preparatory stage field investigators will spend time within the selected voluntary collaborative Australian Aboriginal communities. Within an agreed, appropriate and negotiated time schedule one male and one female Aboriginal investigator will visit and stay with or nearby the same community; and the third investigator will provide support for recording and security of collected data. During 'fieldwork-break' periods, home based workshops will be required; to include participation by other project stakeholders such as Aboriginal mentors, academic source expert advisers and healthcare professionals. The objectives of these workshops is to continuously share the formalised findings, refine field work

methodologies and document those less anticipated incidental research findings that have value to the efficacy of the PPAC system.

Field work community time is most likely to consist of ‘yarning’ with focus groups as approved by community Elders. Focus groups consisting of eight or less community member volunteers will also be augmented with two separate focus groups convened for culturally and gender sensitive health care discussion, regarded by Aboriginals as ‘men’s business’ or ‘women’s business’. If acceptable to the community, and within appropriate protocols, a combined gender focus group can be conducted. In the case of separate gender groups, privacy will be carefully observed and only the researcher of the same sex will be present, acting as the moderator.

Field work community time will also involve face to face interviews of volunteer members of the community, observing the same privacy protocols as above. In all cases, participants will be de-identified. The subject matter and purpose for all forms of data collection will concentrate on learning Aboriginal English PPIE pragmatics and will avoid any direct or indirect reference to the personal health status of any individual.

The purpose of repeat visits and breaks is to reduce data overload and the risk of researcher isolation and burn-out. A further benefit is that community member volunteers may change. This may adversely influence continuity but may also offer fresh insights and new data. It is anticipated that care with communication of the eventual outcome will help to encourage community interest and readiness for the ultimate productive engagement. A significant by-product effect drawing from the T2DM Diabetes Australia/RACGP Care Guidelines is education and greater knowledge of self management priorities.

9.7 Furthering the development of ACT using the Lingua Franca concept

The intention is to use the work reported here as a design base to offer a computerised communications application that can be employed via convenient and ubiquitous devices to assist patient and practitioner interview encounters that are otherwise disadvantaged by cultural differences and consequential communications

and cognition barriers. Accordingly, as a researchers and designer this author will have to prepare with mental orientation for instructing software engineers on the design features of the PPAC system. This section discusses the approach to the technical end-product pathway.

The basic task-generating schema for constructing the focus group and interview style and content is the Type 2 Diabetes ontology annotation described in Chapters 5 and 6.

From the ontology annotations work preparation is required for a dialogue that simplifies clinical terminology. By de-constructing descriptive data and with the help of Aboriginal advisers, it will be possible to re-construct a set of words and phrases, with various options that when used in focus group yarning or personal interviews, will invite and prompt Aboriginal English home talk equivalents which will subject to validation populate the ontology.

First as an example the concept '*Condition_Description*' which is annotated as 'Written text or spoken words using recognized clinical terms that describe a health-condition'; has thirty six subordinate concepts or individual instances.

One clinical '*Condition_Description*' instance is named **Eruptive xanthomatosis**. This implicitly creates a communications barrier for people unfamiliar with professional healthcare language and semantics. The ontology annotation is recorded as follows:

Eruptive xanthomatosis: This condition may occur when triglycerides rise to extremely high levels. Severe resistance to insulin is associated with difficulty for the body to clear the fat from the blood. With extreme elevations in these blood fats, people are at risk for pancreatitis, an inflammation of the pancreas. Eruptive xanthomas appear as firm, yellow, waxy plaques (pea-like bumps) on the skin. The bumps – which are surrounded by red halos and are itchy – usually are found on the face and buttocks. They also can be seen on the back side of the arms and legs as well as in the creases of the extremities

The team work necessary to simplify this description would work on the assumption that a patient may need to know and understand the meaning of a particular term or explanation. The effort to achieve a higher degree of cognition in the T2DM context represents an assistive communications feature of particular benefit to the Aboriginal patient.

When considering the PPAC system contribution to the work of the health care practitioner, the 17 (seventeen) instances of the *Signs_and_Symptoms* concept provide a good example of engagement capabilities **Signs & Symptoms** are annotated as: Any indication of disease perceived or outwardly visible or internally experienced and reported by the patient; such indications of greatest significance to the health care provider that may help establish the identity of an illness.

One instance of *Signs_and_Symptoms* is as follows:

Fungal A yeast-like fungus called “Candida albicans” is responsible for many of the fungal infections affecting people with diabetes. Women in particular are prone to infection with this fungus in the vagina. Other commonly seen areas of infection include the corners of the mouth with what is known as “angular cheilitis,” which feels like small cuts on the corners of the mouth. Fungus also can occur in between the toes and fingers and in the nails (onychomycosis). This fungus creates itchy, bright red rashes, often surrounded by tiny blisters and scales. These infections most often occur in warm, moist folds of the skin. Three common fungal infections are: jock itch (red, itchy area on the genitals and the inside of the thighs), athlete’s foot (affects the skin between the toes), and ringworm (ring-shaped, scaly patches that can itch or blister and appear on the feet, groin, chest and abdomen, scalp, or nails).

Generally the clinical classification terminology denotes some form of PPIE contribution emanating from a practitioner. This may appear in a written document as well as in (for example) a side conversation between practitioners within the hearing of the patient. Signs and symptoms however are mostly initiated by the

patient contribution, and then acquire a clinical term such as ‘fungal;’ in the diagnosis process. To prepare a comprehensive set of concepts and relationships for growing the ontology, the above ‘fungal’ annotation must also be de-constructed so that it can be re-constructed in the form of a listing of simple English descriptions before being worked into the focus groups and interviews to generate Aboriginal English data concept equivalents and options.

9.8 The semantic web and social media influence on PPAC

Contemplating the contemporary status of health literacy and its role in communications efficacy, future work must examine societal trends in seeking and attempting to understand health and healthcare information. Research by Kamel Boulos discloses that in 2011, over 30% of the world’s population had access to the Internet and that health information online searches are becoming increasingly common[9]. But the author also points out that large proportions of adults in developed countries have poor health literacy skills. In Chapter 2 the literature review gave a 2006 Australian survey perspective of unsatisfactory health literacy skill levels. The AHMAC ‘Framework 2012’ report under Literacy and Numeracy made it plain that education is a key factor for health and wellbeing improvement among Aboriginals. Effectively this research work supports health literacy elements of the ‘Close the Gap’ campaign and specifically I and others are moving the educational challenges and solutions into the relatively new era of interactive web based knowledge transfer. Unfortunately this source tends to generalise and provide a fairly timid, data deficient accounting of contemporary health literacy performance capabilities within the Aboriginal communities. Specifically referencing rural and remote communities, it is conjectured that grounded health literacy data collection and analysis has been elusive and perhaps ‘too hard to do’; and this is to be factored into future work planning and orientation. There is however reason for optimism that the PPAC concept can be refined and successfully introduced through careful design considerations that skilfully confront the data collection, analysis and acculturative communications difficulties that have not been previously overcome.

In a July 2013 article in the Medical Journal of Australia, Melissa Sweet described in outline the successes resulting from innovative use of social media. Sweet references the early adoption of social media by The National Aboriginal Community Controlled Health Organisation (NACCHO) which now uses social media to distribute daily Aboriginal health news alerts. Downloads of NACCHO's policy submissions have reportedly increased after being introduced and promoted via Twitter and other social media channels.

Notwithstanding the 'digital divide' as touched upon in Chapters 1 and 3, social media is gaining traction within Aboriginal communities. As advised by Sweet in her article a notable example of success 'is the Kasa Por Yarn ("just for a chat") campaign, funded by Queensland Health'[10]. Facebook, YouTube and text messaging are apparently proving effective in reaching the target audience of 15 to 24-year-old Torres Strait Islanders. It will be a necessary process element of the future work plan to seek out and both qualitatively and quantitatively identify examples of such successes, with the objective of adopting proven best social media and web channel practices that justifiably contribute to PPAC design goals and ultimate improvement in patient wellbeing outcomes.

Audio recording and to a lesser extent, video or still photo recording will serve a separate purpose from the focus groups and interviews. It is acknowledged here that Aboriginal spiritual beliefs place constraints on the use of visual images which identify individuals, especially those who have died since pictures were recorded. The PPAC system is designed to support Aboriginal ways of communication, and in rural and remote areas of Australia this is by oral and physical forms of body language and gesture, not by the written word. It is the intention to reproduce what is expected to be a 'community friendly' feature of computer based media by tagging web links in the annotations, of recorded Aboriginal voices and pictorial matter showing physical gestures that can be retrieved as familiar sounds and images for the patient, while mapping with Standard Australian English and T2DM terms. Once found either within the application database or recovered from the worldwide web, sounds and images can be saved/embedded by the user.

9.9 Software Engineering Approach

Drawing upon the foregoing postulations and forecasting of future use of assistive communications technology, it becomes prudent to set out parameters for instructing software engineers for the PPAC application design process.

9.9.1 PPAC Knowledge base

There are two main phases/stages of the proposed system namely Knowledge Assimilation and Knowledge Dissemination as shown in Figure 94. The Knowledge Assimilation phase is responsible for capturing and representing the domain specific terminological knowledge in a formal conceptual model that is linked with similar terms present in other controlled vocabularies. The Knowledge Dissemination phase exposes the captured knowledge base to the different type of users and applications. Both phases are discussed in detail in the following subsections.

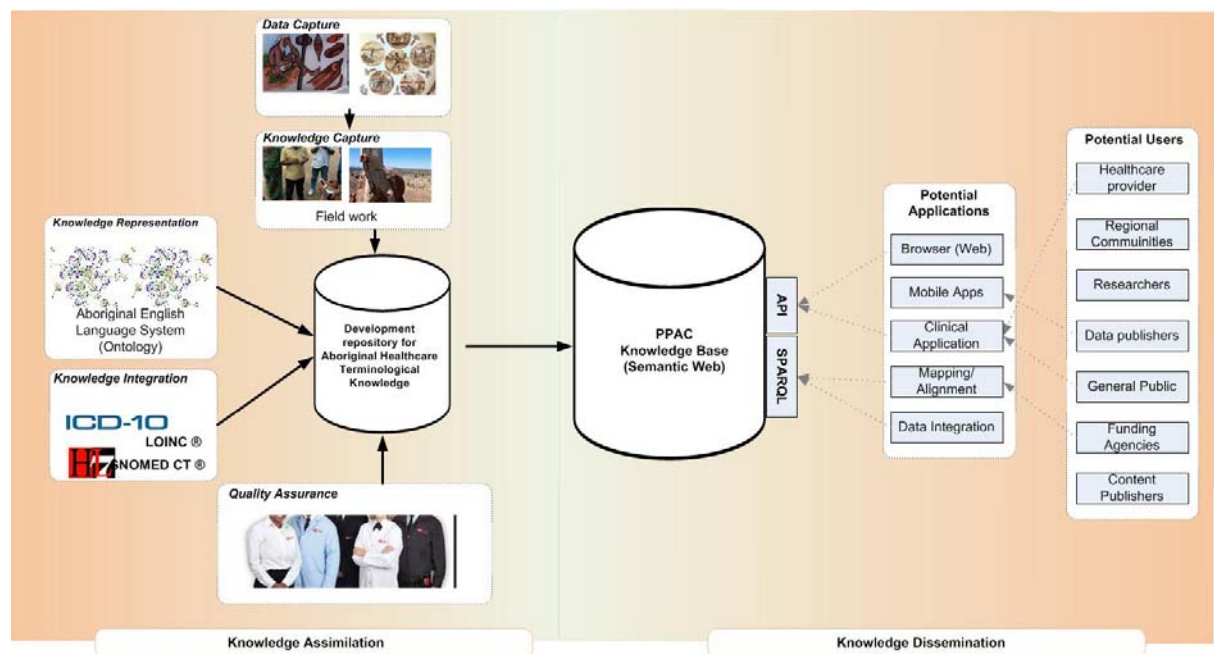


Figure 94: High level architecture diagram of the PPAC Knowledge base

9.9.2 Knowledge Assimilation

The aim of Knowledge Assimilation is to represent the healthcare knowledge in a computational model that is accessible to different type of applications. The captured knowledge specific to type 2 diabetes care is conceptually represented using the ontological model which is presented in Chapters 5 and 6 of this thesis. This

ontological model will be used to capture the actual local human language being used to denote/represent the terms defined in the ontology. It is necessary for the vocabulary defined in the ontology to be aligned with other similar ontologies for increased information interoperability. For this alignment, ontology mapping techniques are used to create meaningful and context aware relationships between different terms referring to the similar concepts. Before enabling client facing application or services to make use of the knowledge represented in the knowledgebase, the data captured and stored should be evaluated and verified by the domain subject experts. This means that the captured knowledge and its mapping with different vocabularies must negotiate a quality assurance process to ensure the production of quality information. This quality assurance process will help in generating the production grade knowledge base that is exposed to the different type of users and applications.

9.9.3 Knowledge Dissemination

The aim of Knowledge Dissemination is to impart the healthcare knowledge to different type of applications and users. To cater to the diverse type of consuming applications and user needs, the knowledge base must be represented and structured in such a way that it is capable of providing granular access to the information. Since there could be numerous applicable circumstances that will benefit from the PPAC knowledgebase, for proposed future work I plan to develop an information publishing/dissemination platform to offer the required scalability and interoperability.

In the following section, each of these phases is discussed in greater detail.

9.9.4 Knowledge Assimilation

As mentioned earlier the aim of knowledge assimilation is to represent, capture, integrate, and refine Type 2 Diabetes specific terminological knowledge for healthcare related services. The terminological knowledge which is formalized using the ontological model represents the key concepts, terms, and relationships between different terms to semantically describe the domain specific knowledge. As the objective of the PPAC knowledge base is use by healthcare practitioners and health carers it is therefore of paramount importance that the process of capturing and

refining knowledge should be developed using a formal methodological approach. The proposed methodological framework is comprised of five stages namely Knowledge Representation, Data Capture, Knowledge Capture, Knowledge Integration, and Knowledge Refinement. Each stage will be developed based on the most suitable set of technologies, tools, methods and techniques. In the following subsection, I present the blueprint conceived for the stages of the solution process.

9.9.5 Knowledge Representation

The Knowledge Representation stage formalizes the conceptual model to semantically describe the domain of Type 2 Diabetes which is mainly based on the T2DM Diabetes Australia/RACGP Care Guidelines. In Chapters 5, 6 and 7 this thesis described the methodology, semantic concept discrimination and content validation being used to develop the construction phases of the ontology.

For the implementation of the PPAC knowledge base, the same knowledge representation framework will be used to capture, integrate, and refine the knowledge base. The knowledge representation framework is the ontological model comprising of the concept, relationships, attributes and axioms to formalize the shared commonly agreed domain knowledge. Concepts help to represent the entities (real word or conceptual) which depict the domain; and entities are related to each other based on their relationship with other entities. The entities' state is represented through the attributes generally known as data properties. The tacit knowledge that is essential in order to represent the domain knowledge (also known as heuristics or rule of thumb) will be described using axioms in the ontology as this will help in incorporating tacit knowledge of the domain.

9.9.6 Data Capture

I continue to pursue the main objective of the PPAC system to assist the Aboriginal communities and healthcare professionals in understanding each other in such a way that both can share expressions and cognition in a more effective and efficient manner. In particular for Aboriginal communities experiencing language barriers, communicating full details about self-observed sign and symptoms of their medical conditions is often challenging. Likewise, on the other side of the spectrum

healthcare professionals including paramedical staff experience barriers due to unfamiliarity with regional languages, culture and norms such as yarns [11] and may not understand the important and possibly urgent parts of the conversation. As this communication gap hampers the delivery of best health care services to remote communities it is very important for PPAC to capture the raw data that comprehensively represents the domain knowledge that is being used in their day-to-day discourse and social interactions. The provision to capture and store the raw data that is contextualized by supportive evidences such as pictures, yarning (stories) and drawings, is a key component of the proposed PPAC system.

Because the purpose of data capturing is to store all the possible raw information, it is designed to function at human interaction level and in the contemporary consumer setting requires a mobile solution that is not only capable of recording different type of information but also easy to use and secure. The data capturing processes involve the development of a mobile application for a hand-held device to enable users to record the information anytime anywhere; and of the field work to train and supervise the data capturing process. The proposed data capturing process may include the following stages:

- The development of mobile application for hand-held device
- Training remote communities on the use of applications and devices
- Visit and interaction with the communities during the data collection period to supervise the activities and learn from the real-world experience
- Importing of data from devices to the development (interim) repository of Aboriginal Healthcare Terminological Knowledge
- Review of captured data and enrichment by attaching more context specific information

The above mentioned set of activities is not sequential but iterative in nature. The steps which involve training and supervision will be performed iteratively to have frequent interaction with the remote communities and observe the data capturing experience. Field trips will be made to remote communities to supervise the data capturing event and provide necessary training to ensure that high quality data is being captured and all possible supporting evidences with annotations are being

accurately attached to the captured data. For example, a patient who is using the mobile device may record through audio voice commentary all the symptoms he is experiencing or observing related directly or perhaps indirectly to skin sores on his leg. It can also be possible to capture the condition pictorially with sufficient digital imaging detail to enhance the signs and symptoms history taking for the healthcare professional; thereby facilitating better treatment and care advice over physical distance. Options of store and forward or real-time capture will be supported by the PPAC system in its role as a two-way communications tool.

The data captured from the Data Capture phase is subsequently used by the Knowledge Capture phase to represent the information in a more formal structure, making it understandable and processable by different type of users including human and machines. The depiction of Data Capture device capable of recording audio, video and pictorial details about patient's health condition is shown in Figure 95.

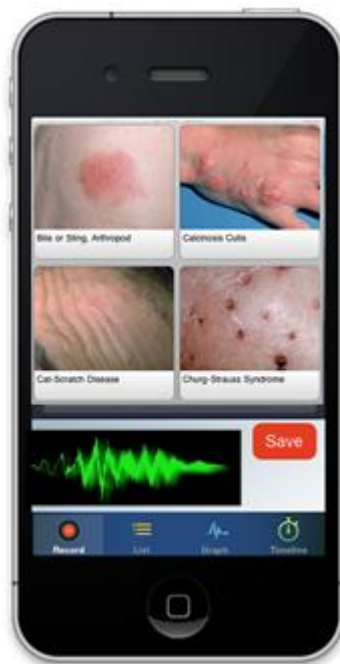


Figure 95: Data Capture hand-held device

9.9.7 Knowledge Capture

The purpose of the Knowledge Capture stage is to gather the commonly used vocabulary by Indigenous people to describe their health related discourse. This includes written as well tacit knowledge. In order to collect and synthesize the spoken language, a fieldwork-friendly methodology is needed to capture the explicit,

implicit and tacit knowledge through the discourse, and interactions with territorial and indigenous communities.

In other to facilitate and support knowledge capturing process, various options exist and their selection will be based on a combination of research management practicalities and cultural receptivity factors within the communities. One option is for a mobile application to be developed that will equip healthcare field practitioners and other fieldworkers to capture the local knowledge when and where it is available. The proposed mobile solution will be capable of working offline and online considering the lack of internet connections and limited communication infrastructure in remote locations. In the following sub section I briefly describe Mobile Knowledge Capturing Application (MokCa) .

Mobile Knowledge Capturing Application (MokCa)

MokCa is a mobile application which runs on tablet device capable of recording audio and video. The main objective of the application is to facilitate the fieldworker or healthcare professional by providing them with an easy-to-use application to capture the knowledge anytime anywhere when it is available. MokCa will enable users to not only record the local knowledge about the different healthcare related vocabularies being used within regional communities but possibly link it with similar terminologies being used in other controlled vocabularies.

Figure 96 provides the potential proposed interface layout of the application. The interface of the application is envisaged as keeping in view the interaction mechanism available on the modern tablets available in the market such as the iOS based tablets or Android based devices. This allows the interface to support the multi-touch interaction experience and exploit the built-in multimedia features to contextualize the information by augmenting it with available supporting data such as audio, video, and still pictures.

The application will be rely upon four main components in order to implement the knowledge capturing methodology. The first component displays the main categories of the conceptual knowledge model. In this research and design case, those are the main concept (super concept) of the ontology describing the Type 2 Diabetes domain

knowledge. The second component, allows users to retrieve the specific concepts that describe the entities and domain knowledge more precisely.

The textual description (human readable information) will be displayed to provide the additional information regarding the concepts and entities represented by the concept. There are different world knowledge sources which will be considered for providing the supporting information such as Auer [12] Belleau [13], and Momtchev [14]. These sources maintain a rich set of Semantic Web data that not only describes use of healthcare terminologies but also interlined with other semantic repositories.

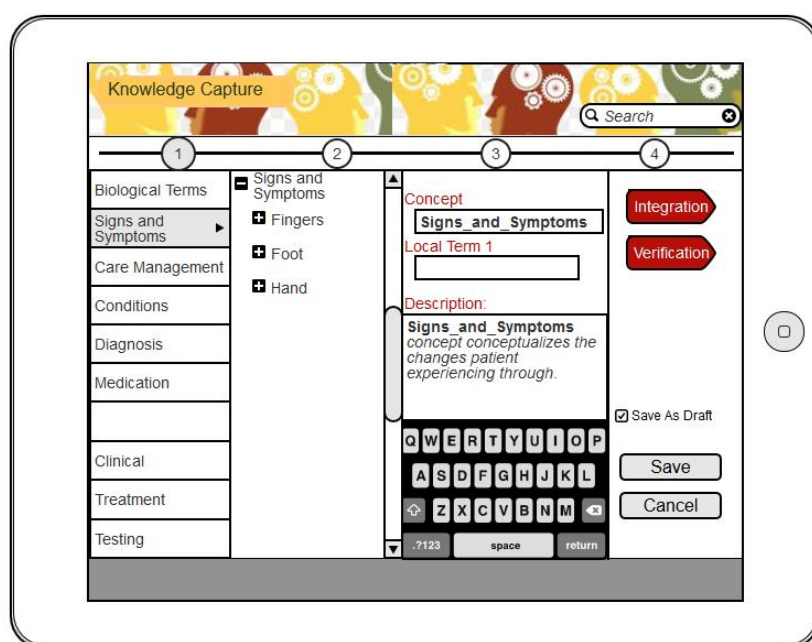


Figure 96: Mobile Knowledge Capturing Application interface (proposed)

MokCa will allow users to enter the local terms referring to the formal term being used in the healthcare profession lexicon using the soft keyboard as well as recording audio or video to representations that help contextualize the captured information. The proposed layout also enables the provision of integration with other standard controlled vocabularies to align local knowledge with standard terminologies. The integration mechanism is discussed in the next section.

9.9.8 Knowledge Integration

The objective of Knowledge Integration is to align the AE Ontology with other ontologies and controlled vocabularies to achieve information interoperability. As discussed by Noy (2009) [2], ontology alignment (also referred as ontology matching in the literature) is the name given to the process of determining correspondences between concepts, the outcome of which is an alignment. Generally speaking, ontology alignment tools and techniques are used to find classes of data that are semantically equivalent or similar (see Figure 95 alignment diagram from Abolhassani [15]). For example in the British version of Standard English the word "Truck" is similar to the word "Lorry" in terms of describing the real world entity. These are sometimes regarded as synonyms but also may be referred to as examples of near-synonymy, depending on surrounding context. In alignment, concepts are not necessarily logically identical however there are three possible dimensions of similarities according to Euzenat [16]. These three dimensions are syntactic, external, and semantic. There are number of tools and frameworks that have been developed for aligning ontologies. These can be either used or extended for the specific alignment requirements. In the case of my proposed application, I intend to use the Silk framework which is a tool for discovering relationships between data items within different ontologies and Linked Data sources[17]. The advantage of using Silk is that its server-side service provides a REST interface that handles an incoming data stream of newly discovered entities, while keeping track of known entities which then enables us to perform alignment with multiple knowledge bases or repositories.

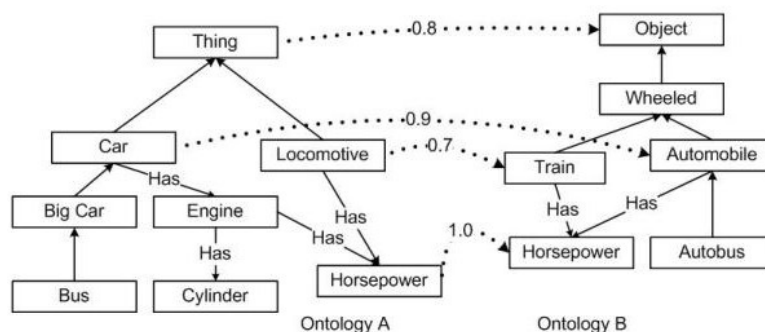


Figure 97: Ontology Alignment example (Abolhassani) [15]

9.9.9 Potential Ontologies and Controlled vocabularies for integration

The largest repository of Biomedical related ontologies is the Open Biological and Biomedical Ontologies also known as OBO Foundry [18]. While this repository provides numerous ontologies describing the healthcare and biomedical domain, however it lacks coverage of most of the healthcare services-related ontologies. Therefore, for the ontology, I have selected a few of the ontologies which will be considered for the longer term alignment in the implementation of PPAC Knowledge base and MokCa. These ontologies and vocabularies are namely ICD-10[19] and SNOMED-CT[20]. They are sophisticated systems based on medical knowledge designed to serve the professional health care domain and will only be introduced over an extended period with due account and allowance being made for the intercultural communications barrier mitigation objectives of this work. I will also consider BioPortal (NCBO's ontology repository) [2], Ontology Lookup Service (OLS) [21] and OBO Foundry [18] term lookup services to find more relevant terms for alignment. It is worth mentioning that all the sophisticated computational operations such as ontology mapping and information integrations will be done in an automatic fashion to avoid the demands of unnecessary complexity for the user. This means that the algorithms required for these sophisticated tasks will be automatically executed as an implicit backend operation without user notice to offer easy-to-use and user-friendly experience to the users.

9.9.10 Knowledge Refinement

The ultimate objective of the PPAC Knowledge base is to provide high quality data to different types of application and users relative to the terminologies being used by the Indigenous people pertaining to healthcare discourse. This requires a robust verification, and therefore a verification mechanism in place to ensure the availability of that high quality of data and information. It is very important that the data and knowledge stored in the knowledge base is maintained at a high quality standard and integrity for it to remain useful. To ensure the high quality of the data, I plan to implement a hybrid mechanism to verify and validate the captured data before committing it to the knowledge base. The proposed methodological approach is based on two workspaces; one for development and the second for production. All the queries will be answered from the production system. Ongoing knowledge

capturing and verification transactions however will be managed through the development knowledge base as depicted in Figure 92.

The earlier statement is reemphasized; that the purpose of knowledge dissemination is to enable different types of user and applications to access the knowledge base to retrieve the healthcare related information. The information is semantically described using AE ontology and annotated with the equivalent or near-synonymy terminologies being used within the Indigenous communities. In the following section, I briefly describe how the information will be exposed when accessed by different type of users and users and applications.

9.9.11 Application Programming Interface (API)

The knowledge base is essentially a semantic repository based on a graph model. It stores the information in the form of RDF statements which are essentially tuples comprising of subject, predicate and object known as resources. In the Semantic Web resources are defined using Universal Resource Identifiers (URIs) which are then used to describe the resources and interlink with other resources. In order to expose the knowledge base to the outside world, I plan to use the SPARQL end point as this enables any consuming application to pose queries to the semantic repository (RDF triple store). In certain cases, where the consuming application is not SPARQL aware, I propose implementing Web API as a Representational state transfer (REST) based service[22].

9.9.12 Expansion: Type of User

As the extended term objective of the PPAC Knowledge base is to provide an authentic source of healthcare related information annotated with different regional languages (and dialects) therefore, it will serve a wider, diverse range of audience. Here follows a brief mention a few of the potential users who could access the system.

Healthcare providers: The healthcare providers (professional practitioners and service delivery support staff) can benefit from this system as it will enable them to access the terminological knowledge being using in a particular Indigenous

community. The different healthcare service engagement entities can thereby anticipate plan and prepare for a more optimum, culturally equitable and competent PPIE interaction. For example outpatient and hospitalization services can use the PPAC as a readiness tool to overcome inefficiencies arising from inflexible poorly equipped reception and care procedures. They can either look up the alternate terms, phrases being used to represent a concept in English or find synonyms to expand the search query.

Content Publisher: In order to publish the healthcare related material either through print or electronic media, publishers can access the specific terms being used or adopted by different remote communities.

9.9.13 Consumer Applications

The potential exists for a different type of application which can access the information represented in the PPAC. Examples of such applications include:

Mobile Application: In order to provide assistive technological support, the mobile application can access the knowledge base to retrieve the healthcare related information anytime anywhere. Such an application can work offline and online depending on the availability of the communication infrastructure in a particular region.

Clinical Application: Clinical applications can make use of this knowledge base to access the relevant regional vocabularies to assist the general practitioners (GPs) and medical/surgical specialists and nurses while interacting with the patient experiencing a communications difficulty.

This thesis previously touched upon inclusion of interpreters and patient carers in the PPAC access and user groups. A number of PPAC protocols will be required to accommodate privacy and other sensitivities when these third parties are considered as participants in live PPIE applications. Moreover there is the prospect for consideration, of designing specific separate forms of compatible application modules to suit interpreters and carers and offer helpful functionality without intruding into personal and professional relationship which exists or is sought between the patient and the practitioner.

9.9.14 Application Wizard

This section demonstrates how the PPAC knowledge base will be used to provide a solution to a practical use case scenario. As a reminder, the Knowledge Assimilation stage is responsible for building the knowledge base based on the captured data, information, and knowledge that is further interlinked with standard controlled vocabularies. The Knowledge Dissemination facility is responsible for providing granular access to the knowledge base through the support of different mechanism such as Web API, REST-full API, and SPARQL endpoint. Using the knowledge base representing the healthcare domain knowledge annotated with Aboriginal English; and ultimately with other ethnic/regional languages and dialects; and the APIs providing programmable access to the knowledge base, the client facing application will be developed to facilitate better healthcare experience beginning with remote and Indigenous communities. With the help of a use case scenario, the working of an application that is based on PPAC is discussed below.

9.9.15 Use Case scenario guide for engineering

A patient in the remote community is suffering Type 2 Diabetes and plans to see a doctor in a week's time. He would like to use the digital device to record and capture all the signs and symptoms that are causing concerns. The patient uses the application that is developed based on the PPAC knowledge base to record all the events when and where they happen. All the complexity such as the recognition of local terminology, the categorization of information, and tagging of artifacts such as images, audio files, videos with relevant medical terminologies will be hidden from the user as those are being encapsulated by the PPAC knowledge base and through the use of Semantic Web technologies and ontologies. Similarly, when the patient encounters the doctor or paramedical staff, all the information that is recorded on the device is securely transferred to the clinical system for doctor to access relevant information pertaining to the symptoms that are causing concerns to the patient.

These two separate but related applications will be developed using a semantically rich knowledge base and their development approach is described as follows.

9.9.16 Patient Assistive Application

Patient Assistive App is a mobile (hand-held device) application which enables patients to record the signs and symptoms they are or have been recently. The system encourages contemporaneous notations and thoroughness in this patient descriptions data entry/selection process. An ontology and knowledge base resource drop down menu for commonly recognized ‘typical’ T2DM and general Signs and Symptoms reflecting well-being perceptions will ease the stress of this exercise. Other options can be offered. For example when the user wants to record the signs and symptoms then the interface will be displaying the textual, or presenting audio details in the local languages to enable the patient to select the appropriate option. From the user experience perspective, the application will be designed to keep in view the target audience expertise level and to avoid unnecessary complexity. However, the application will be able to perform the complex operations that interlink, map and translate the different terminologies to the user language setting and will be hidden from the user.

Revisiting to expand this explanation, the words (starting with signs and symptoms as a category) are likely to be recognized from a voice recording but will be found through the choice of a pictorial icon and a text reference. As an example, the text key words might be ‘Fingers’, ‘Foot’ or ‘Hand’. All are instances of the class concept Signs_and_Symptoms. This may also correlate with another instance: Feeling. The patient as a diagnosed type 2 diabetic wants to confirm and record the fact that physical sensations he/she is experiencing are in need of attention and may have implications for diabetes complications. Suffering occasional tingling feelings in his/her extremities, the patient goes to (for example a drop-down) selection that includes the Aboriginal English words in textual and audio form, “Buzzing” and/or “Flashies”. These terms are mapped with the Type_2_Diabetes_Concepts clinical terminology concept class Condition_Description instance: Neuropathy*. Eventually the annotations for this concept will offer Aboriginal English voice and text explanations to help the patient understand the context and possible implications of the signs and symptoms known as “Buzzing” and “Flashies”. Ultimately mappings

will provide the option to find self-management advice under the concept class Care_Management.

The foregoing discussion provides a walkthrough of some of the conceivable features possible through PPAC. The ability of knowledge integration and mapping among Aboriginal English, local dialects and standard healthcare terminologies opens up a dynamic new level of healthcare services for better and healthy life in remote areas.

9.9.17 General Practitioner (GP) Assistive Application

The GP Assistive App is an application that integrates the information from different sources to provide comprehensive and contextualized information to the healthcare professional. The availability of integrated information helps doctors and paramedical staff in better decision making by bridging the language gap through the use of services provided by the PPAC knowledge base. In the case of the above mentioned use case scenario, when the patient visits the doctor along with the device (which has recorded all the symptoms that are causing concerns), the doctor can import (and synchronize) the information with his own clinical system. Since both systems are using the same knowledge base the information will appear in the doctor's application, annotated using the standard clinical terminologies. The patient can also play all the audio or video files to explain the present and prior-visit situation causing concern.

The ability of the PPAC system to semantically annotate and describe the user intended and requested information in a machine processable format helps in addressing several problems faced by a health professional working in or using telehealth systems to connect with patients in remote areas. This includes but is not limited to:

- Based on the user's recorded information, annotation using different labels according to the intended individual user's natural language and expertise level
- Contextualization of the information by linking it with relevant information
- Tagging the information for searching and clustering
- Relating the current medical situation to the existing electronic health record

- Integrating the medical record with hospital and clinical management systems
- Assisting and educating healthcare workers working in remote location about the regional languages, culture and norms. This would be a perennial process aimed at building high levels of cultural competence.

The above mentioned GP Assistive App will be developed using the APIs exposed by the PPAC to retrieve the healthcare related terminological knowledge from the knowledge base.

9.10 Concluding commentary

The model domain combined ontology is a conceptualization that will provide a unifying framework for functional understanding and task facilitation between the community, of health care providers, the patient and in time, an integrated cluster of electronic monitoring devices. The ontology approach is being used for several reasons. Primarily these include

- Standardization, for the extended role of the perceived future prototype as a learning environment tool;
- Systematization of semantic layers such as disease, symptoms, remedial actions and options. This serves the Indigenous human-device interaction and confronts in a structured form the ‘digital divide’ communications barrier to Indigenous engagement with ICT, linking the ontology with the user-friendly interface.

As explored by Tomiyama et.al in their Design Theory and Methodology (DTM) paper [23], *combination-based design* advice together with *modification-based design* principles have been utilized. Combination-based design assumes that the building blocks of existing digital communications devices, their operating protocols, and also the communications transport platforms, already exist and can be reconfigured to arrive at a new integrated design solution. That integrated design is centred on the goal of pragmatic two-way intercultural shared cognition communications. Modification-based design principles have applied parametric conditions to accommodate eventual application system hardware and software additions, exchanges, mergers and removals. Ontologies rely upon constraints for

reliability; and on shared access for continual improvement. The interactive domains are structured to support a dedicated T2DM healthcare ecosystem. Generic and specific taxonomic hierarchical ontologies, in part relating to existing pertinent and clinically acceptable diagnosis and treatment ontologies have been utilized. These have now been augmented with a new agent of knowledge exchange represented by the Aboriginal English dialect.

This thesis has fulfilled the primary objective stated at 1.9.1 *to introduce a shared knowledge representation model and data transformation process as a framework foundation for intercultural communication technology development.*

The three sub-objectives at 1.9.2 (*structuring T2DM GLs for mapping with AE*); 1.9.3 (*structuring AE dialectal data as a base for ICT supported communications*); and 1.9.4 (*to conduct bi-directional communications problem and solution analysis*) have been met and tested to satisfaction as to reliability for building the PPAC.

In consideration of the possible cause of Aboriginal healthcare disparities, as stated in the introduction chapter; and recognizing similar implications affecting other ethnic minority groups; the Australian western medicine approach to healthcare service delivery has been closely scrutinized. This scrutiny has been mostly from the combined Aboriginal community and healthcare literature review perspective, while respecting the high value of clinical practice guidelines and their contribution to the framework model.

Viewing the suspected shortcomings of the absence of equitable and shared cross-cultural cognition in primary care PPIEs, the framework has pursued improved efficaciousness in knowledge exchange; aiming to overcome previously and still current unrecognized and/or unresolved communications barriers. The use of computer ontology and mapping methods offers the potential assistive communications technology support through a sense-making intervention concept that provides a 'lingua franca' model for mutually beneficial engagement.

Accordingly the discussion on future direction and specifically on software engineering advice as in 9.9 has been included in this chapter as a demonstration of confidence in the framework as the intended foundation for ICT/ACT development. The shared knowledge representation model is dedicated to the ultimate goal of equitable communications engagement.

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Appendix A

Focus Group preparation

- Participant information sheet (One page)
 - Advice Script (Three pages)

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Participant Information Sheet

My name is David E. Forbes. I am currently completing a piece of research for my Doctorate (PhD) degree at Curtin University of Technology.

Purpose of Research

I am investigating how to help rural and remote Aboriginal diabetes patients communicate with health care doctors and nurses in local clinics in Western Australia.

Your Role

I am interested in finding the best choice of words in Aboriginal English and culture for health care conversations.

I would like to find out how we can use technology, such as a computer or mobile phone, to help with Aboriginal patient communication.

I will ask you to participate in one or more groups of six (6) to eight (8) people of similar age or occupation to answer questions on usage of Aboriginal English and technology for communicating with health care doctors or nurses.

This focus group session will take about 60 minutes.

Consent to Participate

Your involvement in the research is entirely voluntary. You have the right to withdraw at any stage without it affecting your rights or my responsibilities. When you have signed the consent form I will assume that you have agreed to participate and allow me to use your data in this research.

Confidentiality

The information you provide will be kept separate from your personal details, and I will only have access to this. The interview transcript will not have your name or any other identifying information on it and in adherence to university policy, the interview tapes and transcribed information will be kept in a locked cabinet for five years, before it is destroyed.

Further Information

This research has been reviewed and given approval by Curtin University of Technology Human Research Ethics Committee (Approval number HR72/2010). If you would like further information about the study, please feel free to contact me on 0404 625072 or by email: david.e.forbes@postgrad.curtin.edu.au Alternatively, you can contact my co-supervisor, Dr. Jaipal Singh on (08) 9266 9281 email j.singh@cbs.curtin.edu.au

Thank you very much for your involvement in this research, your participation is greatly appreciated

Script - Marr Mooditj Focus Group

Audio visual recording equipment, large sheets of paper (minimum A3) erasable marker pens, white board, DVD (laptop) capability and screen. Refreshments, gift vouchers (\$20 petrol, \$30 groceries) – later determined by participant numbers but can be exceeded and held over for further FGs.

Welcome and Introductions –

- Moderator Melanie Robinson
- David Forbes, Curtin University PhD Research Student
- Dr. Jaipal Singh, Research Fellow, Curtin University

The plan for today's focus group session –

This is not a test – there are no right or wrong ideas, answers or suggestions - You are in charge

- Yarning, scribble notes and drawings
- Tea break
- Yarning and suggestions, recommendations from the group members
- Lunch and chat

Advice:

- This is for Aboriginal type 2 diabetes patients but will help Aboriginal patients with all health conditions in the future. Although this is focused on Aboriginal patients, with your permission we will speak about 'us' and 'our patients' because we sharing our hopes for the future.

- We must try to remember what it is like for our rural and remote Aboriginal community patients both in their own country and when visiting a clinic or hospital in Perth
- Today is all about better communication to improve health in the Aboriginal community
- This work recognizes that Aboriginal patients deserve more respect for the way that they communicate in the family home. Nurses already know, and doctors are beginning to learn, that the dialect that some of us know as ‘Aboriginal English Home Talk’ has a proper and very valuable place in clinic or hospital interviews. It is not good enough to force patients to try and understand so called ‘proper English’ but your advice is needed to help us change the way that health practitioners think and behave.

Some Background

- We use the word ‘practitioner’ as it is a single word that covers many different healthcare occupations. So we don’t have to keep saying nurse or doctor or health worker or podiatrist etc.
- With your help we are designing a conversation system that we call the P-PIE or Patient-Practitioner Interview Encounter^{©™}
- The words and expressions that you recommend will eventually find their way onto such things as touch screen computers in the clinics, or mobile phones
- The healthcare conversations of the future will be very different because Aboriginal patients will be able to use Home Talk to take a more confident lead in describing how they are feeling, their symptoms and their worries

Why? Why are we doing this, and what is the importance of that question – Why?

- Too often, the Aboriginal patient is not offered an easy to understand explanation of his or her condition, the reasons for tests and treatment, and the possible results of recommended care or the lack of care. Failing to explain and failure to understand make health care treatment and recovery more difficult; and increase the risk of dangerous complications
- There are many other barriers to successful diabetes healthcare for Aboriginal patients. But always present are the barriers of Fear, Shame and Death. If this work can reduce these barriers, we will make good progress with the health and life expectancy of our diabetes patients

Some more barriers –

- Cultural differences, lack of knowledge of Indigenous communications
- Power distance between healthcare practitioners and patients
- Big and technical words used by practitioners
- Talking about or at the patient - without talking with or to the patient
- Poor practitioner listening skills
- Inappropriate interview location
- Practitioners and patients in a hurry – lots of reasons

The barrier we hope to avoid in this focus group –

- Sometimes Aboriginal people feel that they must behave and speak in a way that is approved by non-Indigenous people, especially people in authority such as teachers, doctors and managers in positions of power. That will not help us all here today because it is not natural to patients in a family home yarning situation, which is where we will find a more open honest conversation
- Please feel free to behave and speak in a manner that is natural to you when you are among family and friends

Teaching us the value of Yarning – this is for our education

- As you begin to talk about the way patients and practitioners discuss type 2 diabetes please try to imagine what this experience is like for both you as a nurse, and your patient
- We know that direct questions and check lists such as multiple choice questions can often seem too aggressive for the patient, and can cause confusion leading to mistakes that the practitioners do not always recognize. As nurses you need answers to important questions concerning diabetic conditions – information from the patient about recent health history. How do we obtain those answers? Is there a better way?
- We will provide some sample questions in printed text and invite you to think about these and others that you may be able to change so that they are more suited to the trust and confidence in the patient- practitioner relationship

- Whatever way you choose to show how to improve communication is welcome- for example if drawings or expressive sounds replace written or spoken English, these also have a proper place and value for progress

Questions that are important - but should they be changed?

- Special note: If the patient is encouraged to say what is causing worries and to ask questions, (including Why?), then we can break down even more barriers. At the moment it seems as if most of the questions are asked by the practitioners and these invite statements or answers (not questions) from patients. Here we have a very small sample of possible questions and statements from both

Practitioner questions (Standard Australian English):

- What do you mean by ‘feelin crook’?
- When did you last see a doctor? (Or nurse?)
- Are you peeing much at night? (Then – ‘How often?’)
- When did the rash first appear?
- Can you tell me about your eating habits?
- What about drinking? Do you drink alcohol? How much, how often?
- Have you been feeling faint? (and – If so, in what circumstances?)
- You have some sores on your feet. How long have they been there?
- Why did you leave the hospital before your treatment was finished?

More questions – these are printed in a Standard Australian English form and we invite you to comment/change these to the way in which the patient might express them

Patient questions or statements

- I don’t feel well, what’s wrong with me?
- I am always feeling tired and thirsty and I pee a lot more than I did last year
- I there something wrong with my heart?
- Can you give me some medicine?
- Why don’t these sores and this rash go away?
- There is blood in my pee
- My eyesight is getting blurred, I can’t see things as clearly as I could before
- I am afraid to go to hospital. I might die there
- I left the hospital because I felt better

Appendix B

Transcript

Aboriginal English Type 2 Diabetes Care Focus Group

Held at Marr Mooditj Training on Thursday 14th April 2011

Focus group members: (De-identified) Members of Aboriginal communities.

7 (Seven) female trainee nurses

3 (Three) male trainee nurses

Two female Aboriginal staff acted as advisers/moderators.

In attendance as observers:

Dr. Jaipal Singh (PhD), Research Fellow PhD Curtin University

David E. Forbes, Postgraduate PhD Research Student, Curtin University

Start 00:00:17

So when you say body language, you're talking about you know, the way people sit, the way they look at you

The way they're talking...

The way they...communicate

Yea

So it's that, the non-verbal

Yea it is, 'cause you know we have all known when we go outside, maybe to a shopping centre and how people withwe got a bit of money on us and we wanna go buy something, and next thing ya know we've got someone strutting around eyeing you...

Yes, Yes

Facial expressions would go on that one too, ay

Yea

Makes us all a bit uncomfortable ya know

Yea, Yea

What I don't like is that the body language where, they're saying one thing but they're showing another thing

Yes

And what I say to a lot of people in Cultural Awareness is, when you're dealing with aboriginal people, they can read your body

Yep

And your words not mapping up to your body and they're going ayy, I'm onto you, so

laughs

Some of us, especially with our meeting down in Fremantle, the way we, it's like a big uh executive health building

Got all the aboriginals, all the staff from like diabetes van, um, directions, got a directions....van that's got paintings on it...tell me no it's all ours....we have to build up all this trust with them, trust with another one and then now 'cause he must of said something to another government worker, now he's gone

Oh

That's that um confidentiality....

Yea, well I know, that's how it happens, yea they asked him to resign and now we gotta find work with another person and they gotta go build up and now that's a female

You have to start again

Yea

You build that trusting relationship again

So you build that relationship trust and then they move on and you gotta start again and I think that leads to burn out as a worker, doesn't it ya know like, 'cause you spend all that time teaching them, showing them and then they go somewhere else and you start over again

What maybe upset most of the people there is um...that he never said goodbye to us

unclear talking

He's just packing stuff up over there and here we are, we worked with him and we talked to him and we even said personal stuff to him.....and this stuff is yea...and he's just got up and moved on

The new person might have a different way of doing things

And the new person's gotta um, start all over, different day, different angles

Like before he was talking to an Italian couple and now he's got this Irish lady and yea
Most of the um committee, they're all trying to find it hard to get back out and explain everything
'cause they thinking they gotta do it all over again, yea
Gotta get their trust back again
When we got all these things in place
We got these ALO's in hospital
We got um, another clinic down in Mandurah and we're trying to get one for South Metro here, as well
But you need that consistent person, don't you, 'cause how you going to set up services, if, 'cause different people come in with different ideas as well
Yea if you have something training under them...that's the best
Yep
What you need is you fellas to be in charge, don't ya?
Well that's what the health system...
only works sometimes
Why? Why doesn't that work?
A lot of them from where I'm from, you have to be a certain family member...
Oh ok, So like family connections
So like first day
unclear talking
Yea that's true... That's not only there cousin, that's everywhere
That is everywhere
It's pretty hard to get into that workforce when it's like that because I know only certain family members...
And they won't accept you
So has that an issue, like getting jobs?
Yes
It is
It's a lot that way up there, up north
Yea. And same for... Can I just bring this up as well, like going into aboriginal medical services, do you see a lot of that, I know 'cause when I'm in derby, ya know certain people won't go to that service because of who works there; Have you seen a lot of that?
'cause there's no confidence
That's like Fremantle hospital, we used to say to the mob down there, they'd be just going into surgery and some of them are in body bags....
Some of them don't even get medication...and they sit in this hospital for a while, ya know
So...And now we like try, the community members to give
unclear talking
And they just got all this paperwork
From like what's going on and how to help people from the country
You don't even know the person, you just wanna get someone in the office so they can interpret
Someone to do, um.. Just helping them
Someone to translate

unclear talking

And then at the end of the day, no one's seen them so they just walked out and like had a heart attack or....gone and got drunk again or got back on the drugs and abused themselves
They need even more... Work experience or traineeships
We're trying hard to do that, yea we're trying....A lot of aboriginal people into it, So we all feel comfortable talking to each other ya know, being in this kind of environment... with these service providers around, at least um we didn't acknowledge the nungas as well....the service providers...we workin together with them as well.
You shoulda see some of the meetings we had, the nunga mob arguing with the (?)...and the whites ya know, just arguing with them about this and about that but at the end of the day, ever since they got put down together as one, we all worked it out together so now we um...we working with the doctors
unclear talking..... we got Mar mooditj....*unclear talking*
So it's almost like that putting partnerships together isn't it ya know, trying to get agreement on what the community wants and trying to get them to change as well, so changing the culture in the hospitals so ya know people wanna go to hospital and wanna get the care and stuff and they feel safe to do that,

so remember we were talking about cultural safety the other week and how important that is, that if people don't feel safe, they're not gonna ask the questions, they're not gonna look after themselves, they're not gonna go.....

But also that link with hospitals that um ya know family members have gone there and died when they been there, how that creates that fear as well

In Anglo and English too

And that's a huge issue um for the staff to realise, is that a lot of people are scared of going into hospital 'cause of what might happen

Yep

Right good, that's good

I got one

Yes,...*unclear talking*

Interpretation sort of thing, Like we got a lot of like what do you call it, Ethnic doctors from different countries, they come through Derbarl and I always have clients walking up saying "I don't understand a word he just said"

I reckon that's a big deal for the employees...'cause we got a couple of ALO's up there as well, so if a couple walk in, they can interpret that

So I've had to go up and down and explain a lot of things the doctor's said

And does that create,'cause I've heard stories from regional areas where doctors have gone in and ya know um actually divided communities just by making a comment....Like there was one lady that had 'opal' on for, ya know, cultural business and the doctor told her that and he was African ya know, "you mob are so dirty, not like the people in Africa" but he didn't realise, and that upset her and she obviously told all her family and it created this huge issue in the community because he had actually offended her 'cause he didn't take the time to work out...ya know....

unclear talking

Yea and it wasn't his fault, he didn't realise what he was doing, but one simple thing like that, like a judgement...

Yea

Some are quite judgemental

mmmm....

....It's understandable but

So a lot of your job Jeffrey and you guys that are working in healthcare is about tryin to you know, trying to stop that from happening, trying to pull them doctors and say ya know...you shouldn't have said that, or you need to apologise

You just gotta understand the cultural differences *unclear talking*....the judgement and stuff like that, it's all cultural...so understand the cultures

And really, like for all cultures we're not all the same so don't treat us all the same and that's the big issue isn't it

Yea

We're all individual, we're all different....we're just people at the end of the day

And when they teach about...when I learnt about relating to clients and stuff, I had this beautiful yarn to them and find out their story, don't assume 'cause this person is that colour or this culture that they're like....you need to find out from them, let them tell their story, so...yah that's a really good point

00:11:20

So ya know you got this list of um different terms and things, like medical terms and stuff, I guess what we can do is start talking about you know some of the phrases, some of the words, how can we help and get the information from our clients, how do we get that story, ya know how we been talking about about doing soapy and get that story

I'll just spell it out I reckon...

When they crook they say....

Blue eye or....

For all you know when they say....giddy...they mean insulin or...

And some refer to....they say I need my sugar chopped

Ohhh...I haven't heard that one, that's good aye

Um for diabetes, you hear sugar sickness a lot....up north

Or funny, they say funny sugar, like funny sugar

Yea well that's a term....like giddy

What language we use and how we ask it

What about if we're talking about lifestyle and stuff, how do we talk about that stuff, because ya know yourself, ya know we don't like being told what to do aye, is that true to say? Like we don't like people telling us, which is common for anybody...how do you get people yarning about their lifestyle, ya know about what they eat?

Well you can yarn like do they still eat like hangry or bunga or ya know something like that or ya still out fishing...them simple little things

They say like nah not for a while or haven't tasted that for a long time or something

unclear talking

Yep, yea

And this is a big thing, the diet thing in hospitals....like they don't realise if you're not eating

Yea they won't eat the hospital food....'cause the mob fellas they got the????, they got the pa,...they got all these menus there, they like their... meat,

....like lots of gravy is good aye,

unclear talking

Nevermind your diabetes, look what they got here, Muffins

They got up & said something, with all the help *unclear talking*

laughing

unclear talking

Salad

Sorry what you say

Kangaroo meat

unclear talking

Hospital bed

What is something you found...kangaroo meet

Going through all these changes and they just wanting bush tucker

When it comes down to it, it'll probably be healthier for them anyway

Thing is they just wanna go home....

Yea they wanna get out

unclear talking

Soon as they get a taste of the food....

So I think that's probably something really important you say, that is if you know you wanna go home, you wanna get better, then this is what we gotta do to get you, but ya know, get them to focus on where they wanna end up, 'cause that's really important, they'll do whatever they need to do to get that

I think that the diet thing is a huge thing ya know, if you don't have the food you're used to eating

Then it comes to finances, 'cause if you haven't got the finances, you're just gonna go out and buy sweets, ya know drink coffee and cake and buy your children lollies instead of giving them healthy...

Soon as the trolley comes around....

Mr whippy

unclear talking

Ya know the sweets

So how can we, and when I say we, like we all health workers now, like how can we help people to understand that you don't need a lot of money to cook, and ya know they did a lot of programs where they had taught people how to cook stews and stuff, ya know there's that um 'deadly tucker cook book' and stuff like that, and I think that's a really good way to show people about nutrition, rather than standing up and showing them what you shouldn't eat, what you should eat all that, but actually showing them how to cook, how to shop, that you can buy stuff for little money and make a lot of food and I think that's more realistic than ya know....

Well we see, like the older fellas, they get like the black and white stuff, ya know 'black and gold', all the savings, the cheap stuff

Unfortunately yea

They gotta stick to their own finance, their own little budget, so...

Well that's the only thing they do know, ya know, they see that label there, they buy all the time, they shop like that so they buy that stuff all the time, and that's like where being able to read and write properly and what they see and if they see that all the time, that's what they buy

Wondering if the other thing...this is a big thing up north

Ya know when you buy a big load of food

Ya know when family come to stay, they eat all your food

That happens a lot

They don't wanna spend a lot of money on food

They know you got a lot of food in their fridge
 Having stuff people won't eat
 Like stuff you have to make
 That's a big issue up north, like family, when they know you got money...
 Yea...
 And there's all that, stealing their pensions
 Since they bought in cards up there...that's been a big problem, people
 Used to be safer with the bank book 'cause they'd hide it
 Grannies sneaking in and taking the card, no ones checking ID 'cause they got the PIN number
 Yea
 Well that's right
 That's probably what happened with that guy, ya know in the goldfields there, he was takin all the
 money willy nilly
 That's just no respect
 No, exactly
 So when we talk about drinking alcohol, how, what are some ways we can talk about alcohol stuff, ya
 know without making people feel embarrassed and that
 'cause ya know what, when your doctor asks you how much you drink, you don't really tell them the
 truth do ya
 Yea, that's true
 For whatever reason...I never do when they ask me
 It's like when big family comes down and everybody drinks
 And If you're not drinking, they put pressure on you
 Yea, oh yea
 Especially the old fellas like say, Say oh here you want a drink, you feel really...like you don't wanna
 say no
 Say what you bein funny for?
 Well that's right, if you talk about alcohol, if you show a picture, would that make it easier for
 They got rid of the flaggins....up there , they got rid of cask wine and now they drinkin bottles of
 wine
 When you sharing a bottle, how do you know how much you drinking if you're not putting it in the
 cup, how do you know from a bottle
 Ya know a lot of that culture is about passin them around
 Like in the morning til lunchtime, or lunchtime til sun goes down
 'cause if it's all day, you know it's from morning to night
 'cause that's all, on a different day, it's from morning to night
 Or the next day...you go to sleep
 Then did you have something to eat before you drink
 You can always eat as you drinking
 I know a lot of oldies...they also
 She drank everyday...she always ate, like salads and all that ya know
 Some of them don't eat and that's what makes them really
 Water too....Plenty of water to drink....dilutes some of it
 Breaking the alcohol down
 What did u say before corin?
 Did you say the eating...must have been that
 Also with alcohol, would it be good to ask how you feel when you drink 'cause you know, you can
 sorta tell when people getting drunk....what you do
 Start Falling down when you been drinking
 That's right and start talking about what you going through when drinking, are you....Like do you feel
 sad,
 How do you become when you've had a few drinks?
 Identify how much someone is drinking by how they behave
 What do you do when they drink
 Like some people like when you drink with them, like if you drink with them all the time, You know
 how they do
 You know im going to start, you know I'm off
 And then if you're drinking with other people, like if they're on medication...you don't wanna mix all
 that together
 Mix all the drinks too like beer, spirits, mixing different alcohols

Does um, opening up the question, does it bring about shame?
 About drinking?
 When you talk to the patient
 The patient doesn't volunteer straight away that they drink too much, none of us do that do we
 But If you raise the subject with your patient, are they gonna talk openly about it?
 Some, some may say mind your own business
 nah
 Some do
 It's not your life....
 Depends on how much of their trust you got, if you been seeing them for a well
 Yea charging last night, yea party animal
 Charging?
 Yea, like drinking
 That's the phrase?
 These are the golden words
 coughing
 Getting blue, yes
 Good stuff
 Plumber
 Livenar
 Yea, I'll just have a livener
 Having a livenar
 How the hell do you spell that?
 A livenar?
 Live - nar
 I've heard chargin before, I haven't heard livenar
 A livenar is a morning drink, to fix you up,
 Ohhhh
 Like 'oh I need a livenar, I got the shakes'
 Yes, they think a livenar will spruce them up
 So people would say hair of the dog would be a livenar?
 Yea, exactly
 Yep and then the people that know that, they can tell you been drinking and that, then people know if
 they talking about then they having bacon and eggs, you having bacon and eggs as well
 Ohhh
 It's flowing now
 Look at ya, you mob are full of this stuff, ay
 If you had a drink, they'll know that you're a drinker, if you had a livenar...they'll have Bacon and
 eggs
 Ohhh, wow
 They'll have their breakfast
 And then they'll be right for the day then
 Yea, a livenar in the fridge, if they get up or...ya know
 Yea, they'll do that sign, yea, need my drink
 Like the hand signal
 Yea
 Be like where you going?
 I'm going to charge
 unclear talking
 Is it a fist or is it...?
 It's like a bottle, a drink bottle
 A gesture?
 The hand signal
 unclear talking
 Where you mob going to?
 Going to down to...
 unclear talking
 Laughing
 I need money
 That's a really good one, ay

I hope you don't see it in the waiting room

Laughing

Oh well you might do

Or they use their lips going...

Oh yes

Laughing

Do we wanna say anything about skin stuff, you know how we learnt about skin sores and scabies and that sorta stuff...

Do we wanna go into any of that, ya know, what....How can we talk about skin?

Can I make a point maybe...

Yes

Most of us walk into our doctors fully clothed and so ya know it's up to us to talk about things that aren't readily visible, even if we're embarrassed

Mmm

So with the diabetes conditions, there's so many skin possibilities that will give signs, um the question really is, How best for both nurse or patient to bring out the subject of skin to try and make sure everything is openly discussed? So that we don't have someone going away for example with an ulcer on their foot because they haven't taken their shoes off and nobody asked them, ok, so how do we talk about it or how might the patient talk about it?

Hmmm

Oh now we stuck here, like

Let them talk first, see why they're here, put up their story

Make up a story, so they feel comfortable bringing something up

They might feel uncomfortable everywhere else

Ask them if they got any rash or skin sores or something like that

unclear talking

Give them that silence, to give them a chance to bring it up themselves...so you don't sit there yarning nonstop...you give them a chance to talk

Give them some knowledge of what happened to someone else 'cause of a skin infection, so they can um relate to it more...so you can say, um someone...*unclear talking* Oh it must be 'cause they out on the farm or something working in the sticks or out on the Rubbish tip or something and a fly come along...maybe they got some bites from there or maybe sitting around at home...

Or if they, ya know like if they walk in and they got no shoes on, and say oh it's hot outside now brother, how come you got no shoes on, or sister, ya know

Yea, yep

And then they might say, oh they might come out and be open with ya, they like, oh no I got a sore underneath my foot, ya know

Ohhh

And then you can go from there then

It's really hot up there, up north

Yep

But ya know...similar things like that

So almost in a way, it's finding a way to get there without asking the direct question, it's a roundabout way

Yes

Yes, it's a roundabout way, that's right

Which you can't...I dunno how to explain to people how to do that, 'cause that's really hard to...

It's a real skill

Yea, it's that roundabout and it's about taking that time to let them to go that roundabout, to come back here

It'll amaze ya, like someone...they'll have clothes on...like all a sudden shirt or something rips open or shirt comes off & then they might see it on their body & identify from something like that

Yea, mmm

Like before the bandaging...in hospital, some will sit there and keep maybe picking at it...

A lot of it as well, that's a really good point victor, but also a lot of it is just watching people

Yea

How many times have you been yarning to someone and they start and you'll be like, you alright there?

Yes

So it's like, it's almost like that stuff where they don't, they're not saying it but you're seeing them, like the way they're holding their arm when they walk in the clinic or the way they're walking, that sorta stuff, so a lot of it we do, we see, before they say

It's just like um, like a family member when I went to a funeral and ain't seen a family member for a while, and I went up to greet him, like a normal hug

Yea

I went to hug him and yea, he goes 'ooh hang on brother' ya know and I'm all 'what's wrong?' and he goes 'Oh well I just got stabbed'

Ohhh

Yea so, so, I...didn't recognise, that yea, that he got stabbed in the back, yea

It sounds like brother and sister, in the way that you say it, like you were saying just now, make a good connection for the conversation, is that right?

Yea, yep, my uncles and aunties

Yea, old boys, uncles and aunties, ya know? It's just that respect thing, ya know?

So, a lady who comes in to see you doesn't have to be your auntie to be called auntie

Yea

Ok, thank you

And then when you going through and looking at like your skin problems maybe some women don't like to be seen by men and some men don't like to be seen by women, ya know, it's just....

Yea

We got some of that coming up

It's a shame thing; ya know that they don't want another one looking....they more comfortable with the same...ya know

Another way too, like if you can't bring up their...somebody's name you can't remember, so you go around and say brother or sister

mmm

So that would seem strange coming from a non-indigenous person though, wouldn't it?

Yea...you couldn't...if you weren't aboriginal you couldn't....

laughing

So I'm not allowed to call you brother? Ok

Laughing

Yea, you'll get smashed for that

laughing

Yea

unclear talking

That's alright; we just don't want our Nigerian doctors copying the computer

No

laughing

We've got um like um, we've got a couple...ya know, we respect them 'cause they been around the family a lot, ya know...yea some of them...

That's different

Yea that's different

And that's at your choosing hasn't it?

Yea, we give them the respect 'cause they're with the elders, been around the family for like years and years and so we give them the respect for that

Ok, thank you

Even the high school kids now, it's how to catch what they nungas are doing

Yea

Yea, they love our culture and they try to talk like us and be like us, ya know doing their little signs and everything ya know and it's just like...I get a bunch of them come up to my partner and call him 'dad' and I said how can you be like...ya know? Like I was shocked first until I knew, it's how they respect him in the prison system, but yea so, 'cause he's got that, he's like counsel to everyone in the prison system...

Yea...right....

Same as, like um, the primary school down in Willagee there, I've got these two little um nieces that I met their mum...through years back when they separated male and female down there but now they go to the same school as um my kids

Oh ok

And when they go there, my kids come home and go 'they called you uncle!'

Yea

Laughing

And they're going 'what?' and yea their my nieces...but then the other guys are around thinking, or their cousins are going....'what the hell's he... *unclear talking*

Laughing

This is like from their point of view

Yea

And then they turn around and say to their family, no, that's my uncle, that's my mum's friend... 'cause they have, they treat us with the same respect...

Just as an aside, in the post war years that I was brought up in, we had Aunties and Uncles,uh that were not related to us, very common to us

Yes that's right, that's just respect, like all.....who you grew up with, like the adults, like around ya family, like that's your uncle, your auntie

That's good

We got a big family

laughing

It's the same thing...makes us feel comfortable that these guys, they know us, they know the respect of us, so we can talk what we can talk about

Yea

Their kids grew up with your kids; you treat them the same way ya know

Yea

That's a good.....now they want me to go down and teach on Fridays

Oh really?

And for a joke, I said we should put a pigeon box in the foyer.....then I'll come every day

laughing

That's really good you guys

Getting the story

Can I just make a point, um, in the studies that we're talking about in regard to grammar ok, the way in which somebody says something, we're very much aware that words like 'there' and 'that' become 'dare' and 'dat' and that kind of thing....Now what happens is, that we all speak in a flow, and sometimes the way it all joins up, a clinician might not understand it ok....so if there's anything that comes to mind about how somebody describes themselves or explains themselves, which tends to cause other people to step back and say what did he say, what did he mean? If there's anything like that you can think of, that would be uh really worth us looking at. We know how to try and put the grammar together right in the aboriginal English way, but it's when you're starting to talk about the specifics that you're going through, you know, the condition of the body...

Hmm ok

I think it's maybe....like the definition of the word

Him and her, like, him there, her there ya....or like him, that fella there, ya know

They don't understand the books, what's written in the books, but if you show them the pictures and this is a pet's name, they know what that pet is

Hmm

So like you know, there's a um...like up in Moora they got this um pig, and they say in like Speech therapy that um ...*unclear talking*... 'what's this?'

They knew what it was but didn't actually recognize what the word was

As soon as you say, 'oh that's Johnny'...they go 'oh pig'

laughing

Yea, you know what I mean...

See what I mean?

I'll give you an example of one from the book ok, from our researcher's

"The student said, "Mmm, instead of weak we say winyarn too"" so what does that mean?

Winyarn is like...how would you say it, like winyarn mean like um like marning

It can mean lots of things ay, like no good

No good, that's a good way of...

But then again I'm just guessing spelling

00:40:25

So when we talk about um things like the nervous system, so things like feeling in your arm ya know, have you got tingling, funny sensation, that sorta stuff...how do people talk about that, how do they talk about ya know when they get numbness and buzzing, yea?

It's called Flashies

unclear talking

Can I ask a question about the elders in particular, would consider the spirit effect on what's happening in their bodies, and they've expressed themselves in the past as it being something of a spirit nature ok, is that very often used at all today?

Yea

Yea, my father's always like that like I...

Ok

So anything goes wrong and he...

Like traditionally, now they rubbing me ya know, he talks like that ya know....or something like that 'cause if I'm *unclear talking*...it's just little things like that, they still got that...

Is that like being sung?

Yea like being sung and all that, ya know

And that plays a lot on your mind too

I just wondered if... could we easily fail to understand what they're saying when they talk in that way or would they...?

Oooh yea, you could

Yea, you might, yea

Like if your dad went to the doctor and he said that...that would be missed

But he still believes in that, because he's got his medicine, he's got his own medicine with him see

And ya were bringing up Bush.....

Yea, Bush medicine

Ah

Yea

Which is again, something that's not talked about

Yes exactly

Yes you don't....

That's cultural's business, you don't share that

That's why I wasn't going to say anything....

That's only for...

Sacred

Yea exactly

Certain people they'll talk to

Unless you have that trust and then you bring it up, they're not gonna share that with you, if you ask them are you taking any other...nah

One of the things um uh I'd like mention is that, we know that sometimes the patient wants to go and talk with family about a matter that's come up in the middle of the consultation, the interview, ok...um and obviously there are reasons behind that but most doctors, from overseas certainly, wouldn't understand what was going on...um just a thought that um, sometimes there are breaks in the conversation, how might that be explained? I don't suppose it is really, it just happens, yea?

I'll give you an example, a patient um was diagnosed with a cancer and he needed to speak with family before he could give an answer to the doctor about certain things and about the decisions, and he went away and came back and asked the doctor to then accompany him, which he did, and he sat down with about twenty members of the family ok,

Yep

...and the family were anxious that he should take the doctor's advice and go to hospital,... the story doesn't really lead anywhere so much as trying to illustrate how the conversation was influenced by other members other than the patient, which is part of the importance of understanding this...

Like you get some, like you've got that doctor and patient ya know confidentiality, and like you get some old fellas they don't like to say they're sick, unless you're like closer to them, but things like that really deep like that they ya know, like they won't say much, like they'll say oh I've gotta go for a check-up down here but they won't say what they're going for ya know

Oh ok

But then again, they might not really understand too but all they know is the Big C, ya know like cancer or whatever...and that's when they start getting no good...

Yea

I think it's also really important to acknowledge how a lot of people wanna take someone with them

Hmm Yes

Ya know that person, and they might speak for you 'cause they know your business ya know what I mean? And that's not allowed in the medical system is it? You've got to tell your story not somebody else

Yes

Even though that person might know better than you, even though they're not you, do you know what I mean?

Yes

That's a big deal

Yea, well I mean we know that um thirty percent (%) of aboriginal people are hearing impaired, so there's a problem right away that ya know if you have a hearing problem and you're trying to get medical advice, you do need help, I mean the way that we see this is, again we don't have to stick to westernised rules, we're all about successful communication, so.....

I guess it's more just um like you've got someone there with you going to see someone else, like a doctor about this thing that's really nagging you ya know....within your life, but you need that comfort there and I mean...you never see us by ourselves, we're always together ya know?

Yea, yea

We've always been together like family or two of us ya know? And that's them things there like you'd wanna feel more comfortable so you can be there and you might have been by yourself when you were growing up but when you got things like that, you want someone close to you who knows your business and knows what you've been through, and yea

Yea

And if that happens, um does the patient kind of openly give permission for the family member to speak on their behalf, is that what happens?

Yea

Yep

And the doctor or nurse knows that?

Not always, not always

Might need to ask that? Yea, ok

Yea

Alright thank you

But they're not gonna have like the biggest mob of them, it's always gonna be that certain one or couple people ya know that you're really close to, it might be your mum or dad but it might be your cousin ya know?

Only time you'd have a big mob is if it's bad news

Yea

Then you'd have it, wouldn't ya?

Yea, that's true

And that mob would gather without you doing anything

Yep

unclear talking

laughing

Yea, that's true

That's good

Now this other thing I'm gonna bring up, is um, ya know and I've seen it a lot where um doctors are talking to a client and they listening....and they don't say anything

Hmm

And sometimes they see that as non-compliance and that, but it's not, it's 'cause they're thinking about what they're saying and this leads into that pause in the conversation

Hmm

So I think it's important to put in there David, that um ya know as a health person, to be aware that there's not always talking and you know if you're rushed and you've got ten minutes with someone, you want it to be over quick, but sometimes it's gonna take longer than you think, 'cause there's not always that talking...I mean how many people do you see they're taking it in and they're thinking about it and they're not ready to speak back to you or answer your question

So they could be asked a question and they have that long pause ya know

Yes, I know

And that's ok, like ya know and I think sometimes for me when I'm code switching, I wanna rush them up and go, but ya know they need that time to think about what you've said, it doesn't mean they don't understand what you're saying, it just means I need time for that to sink in

Hmm

It's a jumble...jumble when you're thinking or something.... you're trying to think of something, but you're trying to think down like the proper wording....

Yea

...to come out with it...

Yea
 Well again, you're possibly influenced by trying to please the doctor
 Yea, yea
 There's a phrase called gratuitous concurrence, it's a bit of a long thing, but it means, I'm gonna say what this person I think wants to hear, in part 'cause I wanna get out of here, alright ok?
 Yea
 And um, uh it comes up quite a lot
 And it's strange that, because when you go see the doctor, like you were saying Melanie...
 Yea
 ...How they sit down and ya know take it all in and as soon as they walk out of that room, they just let them out
 Yea
 ...They just let it all out
 Yea
 That's why I was saying, like they need that ya know...if they feel really uncomfortable you can ask them, ya know, you want, ya know, any family members there with you or anything like that, ya know, you can bring in or anybody else there?
 Hmm
 Yea, you know that...
 Yea
 That gives me a...
 That's some...some, not everyone
 Yea, not the same for everyone
 That's interesting, after the event it comes out, yea
 Yea...I mean...yea, I've experienced that with some I went with and then it just came all out but I...you'll be sitting there and then when the doctor left and it just came all out...
 They say it out loud not softly
 Really?
 Laughing
 Yea, they do, yea
 Hmm
 And I think in some ways that's why it's really good having an aboriginal health worker with you...
 Yes
 ...because once that doctors gone, you can have a yarn after and gather some...and I've seen that in hospitals like when doctors go in with a patient, I wanna be there 'cause I wanna know what they've said, because then it might be two hours later and I'm doing something and then they start telling me stuff, ya know and then I can go well the doctor did talk about this so you're reinforcing that message, I think it's...having a support person is a really important thing isn't it, whether that's a family member or an aboriginal health worker or aboriginal liaison, whatever that looks like or you might want nobody...but it's rare for people not to want nobody
 Yes
 So next we're looking at um feet, so things like pain in your legs, swelling, um ya know, redness, rashes, all that sort of business
 So I think when you talk about feet you talk about like um, ya know no good walking or...how's your walking...how do you say that? I'm trying to think now
 If they're walking in funny, what happened to your gina, ya know? What happened there?
 unclear talking
 Boogadie
 That's uh...
 Gina...
 Gina...gina...gina boogas.....that's it...um
 ...gina boogadies...
 unclear talking
 Ohhh
 Down southwest...down at south metro, we uh put um booras
 Shoes, that mean shoes yea
 That does mean shoes...
 How do you spell that?
 How do you spell gina?
 G.i.n.a

And what's the booga thing...
 Shoes!
 That's the shoes
 I'm learning new words here
 I know gina but I don't know about...
 Alright.....Ok, I think...has anyone else got anything about feet?
 Eyesight now
 So that's...that'll be um gooras
 Can you spell it?
 Alright I'll do it
 So that's your eyes, aye?
 g.o.o.r.a
 Had a dictionary
 There was um...an old fella from Derby, Mick I think, Fuller aye, old boy
 Yea yea
 Gave the kids a dictionary...and it had all the languages and the meanings for it boy
 Where did he get that from?
 I think he was an ex pilot, aye, old boy
 Yea he was
 That man had a lot up here
 Yea
 Hmmm, yea
 Oh...that was years ago...I think...it just...
 I used to have a tape, a language tape and we can find it now, we were all freakin out 'cause you can't
 get that stuff anymore, like where my mob come from, the language that they speak was on the tape
 and I don't know where it went
 What do you say for glasses down here? Like glasses?
 We say goora bludgers
 Hmmm
 I dunno, what do you say?
 Glasses....
 The old people say where your goora bludgers?
 Coke bottle, coke bottle lens
 "Second eyes"
 Yea say that, second eyes
 Ahhh second eyes....
 Ahh second eyes, that's interesting
 Otherwise, they just give that sign...wear these things, ya know
 *unclear talking**laughing*
 If we talk about sexual stuff, that's men & women's stuff aye?
 Yea
 Cooyee eyes.....
 So what's that, is that sore or?
 Cooyee eyes is when you start to see all the conjunctivitis,
 Oh ok....
they say you got cooyee eyes mate
 The American's call it pink eye I think....
 Or "bung eye"
 Yea...bung eye
 Bung eye? Ok
 That's a good one
 So I've just said for sexual stuff that there's men and women's business, and that's really important to
 have ya know the right worker for that, isn't it, ya know? You often don't wanna talk about stuff your
 own people stuff with someone that's not...
 If we were to use um a poster with the anatomy in it of a man or a woman um, but according to men's
 business and women's business, would that be a useful way of getting a patient to talk more openly
 about it, to point to things...Is that an easier, more comfortable way, do you think?
 Hmm...Not really
 Nah...not really
 I think it all depends on how you present it to them

Yea, depends...yea
.....there's a wrong way of saying, wrong words for certain parts of the body
Just depends on how...like before, how long you've known that person or if they've been in your life for years or...
Yea
unclear talking
'Cause it's the same as like on television, you can't say 'shit' ya know...but....well...if it doesn't sound uncomfortable or if they say it like our way of saying it like bungait doesn't seem so offensive all a sudden, or like yasi
unclear talking
Yea...
It's a way that can be said properly to make that person comfortable...
Yea...
I think they'd be more comfortable bringing things like that up there...with somebody that they've known...like they've been in contact with that doctor or health worker, ya know
And I suppose when you think about it like, ya know sometimes it's really hard to talk about that stuff like isn't it?
Yea
One *unclear talking* like uh...he had uh Gastro...you say well you've got like....*unclear talking* bum
Yea
Last time, came up with something like...there's a lot of water coming out...and be like what...where's the water from?...That's...made him feel more comfortable that I realised what he had, like gastro
Yea
I found out when the womans came in, half of them didn't like to talk about stuff but they'll go....oh what's bought you in today...they'll go oh womans business
Yea
So I'll type in like client here to discuss womans business...could be a pap smear could be anything
Yea
The blokes will be like, I have come to discuss 'ma old fella'...
...Yea.so that's pretty simple
Yep
Just to make a point about the type 2 diabetes guidelines, ya know when we try to follow the clinicians guidelines, it.....the sexual matter comes up because of the way the condition can influence the capability of the man ok and the readiness of the woman if you like, though I'm trying to put it as neatly as I can ok. So what happens is that there are failings in the sexual relationship in the family that lead to conflict and problems, more stress, etc., etc.
Um...where as we're concerned about type 2 diabetes and it's a...one of the symptoms that can occur, um, obviously learning how to manage that conversation is very important because of the...the side effects, if you like, of diabetes if lead to more complications such as violence in the home and that kind of thing
Well, there's a big one for the sex but I don't know if um anyone feel comfortable with me saying it....'cause we're.....all around table...some other*unclear talking* sister says it
Girls will talk to girls and boys will talk to boys, ya know....we can talk...
Yea
Is there any sign that generationally, we all know that our kids are different from us as time moves on....
Yes...
....is this opening up a little bit, at all?
It's just that....my grandfather used to say.....these fellas were.....they wouldn't say they was out having sex...they'd say....*unclear talking*
laughing
Yea
We can say to each other...but we wouldn't say...
Otherwise...they'd probably give the sign...
Yea
laughing
unclear talking

So would you recommend then from what you're saying.....that as move on with our research, when we get into interviews, that we organise a womens only session and a mens only session?

Yea...

Certain names forjust to make them feel comfortable...when they say, if you say sex it's going to make them feel....

Yea

unclear talking

Ok, good

'Cause even within a family there's something you don't talk about, and that's one of those things...even with your partner aye?

Yea

01:01:29

Alright, poor healing, the minor infections, injury or after surgery, so that's probably like not getting better

Yea....

Ya know?

What else have you heard, like when people aren't getting out of hospital quick enough?

Still crook...

Under the weather

Under the weather.....yea

Alright

Weightloss or weight gain? Hmmm

Winyarn again, they tell you winyarn...*unclear talking*

Yea...weight gain would probably be.....sometimes they say oh "dunee number"...yea weight gain

For that weight gain "Oh you're putting a bit of beef on"

And again, with weight gain and loss, it's not really a conversation that ya...

Hmm

...do you know what I mean? I mean...I know like...you've gotta be careful, about what you say

There's like certain people...your closest friends that you'll talk to about that

Yea...

Um....we did drowsiness didn't we? Or were we talking about....

No we didn't

...You guys did...

And maybe that comes in a bit too...ya know like malaise, when you feel weak

Giddy and that

Yea...

"You been falling over and all that?"

Yea

And so malaise and fatigue are similar you know you feel tired, you feel weak

I've only ever heard people say 'I feel weak'

Alright...and now we gotta do looking at like drinking, so ya know drinking water and stuff, so how much you're putting in and how much is coming out, so you know when we talk about with diabetes being really thirsty, going to the toilet a lot, getting dehydrated, ya know not replacing enough fluid

We're getting tired now...lunch time

unclear talking

laughing

....doing the hand signals as well....

unclear talking

Yes

For water...the hand signal, not the drinking one but the glass

The glass....

Yea, like the glass....Yea like a normal one, yea....not that kinda drinking

If it's with your head back it means you're charging but if you just want a drink....

Yea...that's true

Hmmm

There's that difference isn't it? No head

Imagine how could much we put into signals, aye

laughing

There's a whole language there isn't there?

Yea

Like the hand signals...

Yea

Alright...there's bedwetting for kids on here

Just make a point on that...

Yes....

Something I learned after we prepared this and that is that a lot of kids are sleeping in the same bed, and so um... the discussion about bedwetting because we're worried about kids getting diabetes now...ya know it used to be called the 'adult onset' disease, it's not anymore,...um but the difficulty...part apparently is when you've got a lot of children who share a bed, um where's the bedwetting come from? And of course the kids naturally try and cover it up anyway, so it's very difficult to actually tie this down....so I imagine, I'm just suggesting that maybe it's a difficult area to discuss anyway....

Just makes it uncomfortable when there's only one child and the other child made a huge....*unclear talking*...I think it's how you make them feel comfortable and explaining what they've done

Well that's the point isn't it, that one of things again we've learned that if you associate it with having done something wrong...and if you kind of blame the patient for the disease, then everything breaks down, nothing works, ya know

I think that comes like um, I think that comes like uh, mentoring these kids, they might have seen someone get injured or some of them have been shouting, shouting at them, making them feel *unclear talking*...or they might have been scared by...um a movie, something like a scary movie

Alright, yea

Nightmares and things like that?

Yea, nightmares and emotional things...

Hmmm

Might just don't wanna move from the bed....yea

Yea, dreams of going to the toilet, ya know

You're trying to stop...

Some of those that are young are too frightened to get up to go ya know...'cause they need the light on, they might be too frightened...I know I was frightened...ya know, that one light gotta be on ya know?

Yea, yea

unclear talking ...seen one of the old fellas hitting the bottle or... *unclear talking*

Or they're not even allowed to leave the room when people are drinking, ya know if there's a house all full of people drinking, mate you gotta stay in that room, that's where you're staying

Kids with kids....

Yea...

I think the bedwetting is not discussed in isolation, what happens is that if a child is presented with a number of symptoms and the bedwetting is one of them, that might take the doctor or nurse toward the diabetes diagnosis...um and the problem we've got is that, because it's unusual but it's growing in number...um it doesn't get looked at as a possibility so soon, ya know

But then when they do...they stop

Oh yea...oh yea, yea

They stop 'cause....don't know if they've got themselves struggles...or actually got rid of what their thought was...whatever brought them down or that person who was around them...ya know

Hmm....

Yea

I guess it's always to provide their children, see if they've been ya know, did they go toilet, ya know "you been toilet before you went to sleep" ya know, things like that...

unclear talking

Drink a lot of fluids, drink a lot of coke...and...yea

And that cold weather too

The time they want to stay in bed like during the night if it's cold...

Yes...yes

If they're warm they're not gonna move from that bed, warm bed

Hmmm

Ok, aches and pains, muscle aches, muscle cramps

Maybe we just pause for a moment and add this, what we do know about type 2 diabetes is that sometimes there are no symptoms, so when we go through a list like this...we know that the symptoms could be something else entirely, 'cause I ache quite a bit...

Hmm...

but...so it's always.....we're always talking in the sense of what part it might play in, in the diabetes, not for a diagnosis so much as knowing somebodies already got diabetes and some of these symptoms lead us towards complications like heart disease, um eye problems, blindness and failure of the kidneys and so on...

So things like when you have aches and pains and headaches and stuff, again it's just a sore head, sore leg or...what do people say?

'Crook'

Crook?

'Crook leg'

'Me Back's crook'

Crooks anything....

laughing

'Crook in the head'

Alright, um....ooh, emotional and mental well-being, so under that there's irritability

'No good'

Hmm...gettin tired now

Alright and then we've got um, looking at the mouth and that, so feeling sick, nausea, vomiting

Ya know we talked about the other day that, um that, sweet smell on your breath, ya know how you can get that mixed up with the alcohol smell and problems breathing as well

So again I mean, feeling sick, like nausea and that is just feeling crook, feeling sick

Yea

Coonyee...

Yea...

...coonyee

And that's like feeling sick, isn't it?

Yes

Saying like winyarn too, oh I feel winyarn

Yea...again

Um...poor heart and circulation, so looking at, ya know having a rapid pule or a fast pulse, feeling dizzy again due to low blood pressure...so looking at ya know how your hearts feeling

'My ticker don't feel good'

Yea

Hmm

Or it's.... 'your tickers playing up'

Yea...my tickers playing up or something wrong with my ticker

My goodadul's no good

Sorry, what was that?

It means heart, yea

Nah, I'm just thinking about how he said it

Um stomach...so stomach pains, again.....

Winyarn...

Crook...

Crook in the stomach

Pointing and that

Oh pointing yep

Or they rubbing....

Rubbing, yep rubbing

Tummy, belly, gut ache

Yea...tummy, belly...

...gut ache....

I put here, guts aching, gut ache,...guts ache

Sore, sore

01:15:15

Alright, any other signs and symptoms

Right...so...signs that the family members notice, things that happen in the mind or the body which doctors and nurses don't seem to ask about very often and you know any other expressions about like how your feeling...which I think you've said all them, aye....

Sounds like it...

Yea

Hmm

Ya notice when people...like when they're health they sit straight up, when they're crook, they sit like this, ya know...they've got that worried look on their face, ya know
And like in some ways, in healthcare you can sense that, can't ya, when people are feeling different and that's something you can't...
Sometimes the...
Yea...
Don't wanna break down and go...ask...*unclear talking*
Only got family, like you might have the mother saying to the son, oh you've been kardie the last couple days...
laughing
Kardie...*unclear talking*
Or kartwarra...
My pens run out
And what's this...the direct costing thing?
Yea, um, this is actually designed for the interviews that we'll be eventually doing, but um...I'll just run through it, just for any comment, what's the recommended way, home talk words, for the nurse or patient, to find out how long in time the patient has, for example, suffered from a rash, vomiting, blurred vision, doesn't matter what it is, but it's describing how long, because what we know is that, where as a westerner would say well two weeks, two days, that does not always work for the aboriginal perspective of the world and for example, it might be when auntie was here or near Christmas, this kind of thing...so I'm just wondering when you talk to people about when something happened, what's the, the most favoured way that they tend to use by telling you the timing of something?
There for a long time...
Ok...
...don't know how long it is basically, but there for a long time...yea
And what we have learned then is that long might be loong time...yep?
...loong...yea
And that's a legitimate way of really saying it is a long time, like biiiig, right ok, that's right is it, that that's the way?
Or you can put it like, if any special occasion coming up, like Christmas time or Easter or...
Birthday...
Yea, birthday, things like that, ya know
They're kind of markers then...
Yea...and you say oh that long ago? Oh ok
But not so much months or dates or...
Yea...
How many moons?
Yea, moons is a good one
'Cause what you can see then is that the Clinician is going to move through, well how long is long?
And this kind of stuff and somehow we're trying to help the process of narrowing it down as much as we can
How many sleeps...
How many sleeps, that's a good once actually, yea
It might be a long time but they might have had it since they were a teenager ya know, they might be thinking that way, like long long time or whatever
Um...
...so yea...
Is there any example that you can think of, and it doesn't matter if you can't, where something a nurse or doctor has said has really confused you or a patient that you know about?
...just the high words, the long words...
Hmmm
...that's really, they're saying oh you got this and this and that...and you're saying...hmmm...yea ok...if they explained it more like properly, like they could put it down into, ya know like demonstrate it ya know, like whatever like for your kidney or your kidney...that's...diabetic ya know, no medicine getting into your kidney making it no good ya know or...picture little things like that
Yea
Diagrams...
And a big one is medicines...
Yea...yes

...how often to take medicines, three times a day...well what's three times a day?

That's breakfast, lunch and dinner

That's right...so really those pictures of ya know where the sun is or ya know meal times are good aren't they, you know when you have your feed, you need to have your medicine

Yea

It is annoying isn't it; when you get your prescriptions you can hardly read it, I mean my eye sight is not as good as it used to be and they...most of the labels are black on white so you can read....

I think the doset boxes...haven't they?

Yea

Well, I think we have covered some good ground, thank you ever so much...

Let me just tell you a very brief story that's come out of some of the work as well. A little boy in a school, uh a little aboriginal boy was helping a young non-indigenous child who was struggling with her computing and he was good, so uh...sorry he was struggling with his computing, she was good. And she was a very uh open child, who would help anybody, and she stayed with him, worked through this computing and he really got a grip of it. So he turned to her and he said you an orss; now apparently um the child was in tears being called a horse, as she saw it ok. Um now, it was explained subsequently how it was a compliment, that she had done him a great favour and that he respected her for it. Now, unfortunately the literature doesn't explain the whole story as to, what was he saying? I mean it's easy to think well 'you're awesome'...but what was he actually expressing, what was he actually saying?

You're a boss

Yea

You helped me along the way

Thanks for helping me with the work on the computer...just thanks

Just a good little example...

He was feeling low...and now she taught him how to use it and now he feels

Spruce right up

Great...Excellent

Well, um, I thank you all very very much, it's been lovely going through this with you, long way to go as you know, I hope that we get to talk to you again and let you know how we're getting on and hear how you are getting on as well...we're going to have some tucker

laughing

What I've been told, the strongest piece of advice we ever get is if you're trying to talk to aboriginal people, don't forget tucker...I don't know why they say that because I'm quite fond of it myself, ya know

unclear talking

Anybody on any last minute questions for us at all?

Have a yarn now

Right yea, well that's something we're learning as well, ya know really storytelling and yarning is a very natural human trait, it's been drummed out of a lot of us, 'cause we've been told there's no time and it's costing a lot of us

Just a last point, when all of this comes together, what we're talking about, is trying to prevent people from really suffering the complications and dying at a young age, um because it's, it's really bad and we um have to try and be optimistic and spread hope out there. So, what we're seeing at this moment still, is that the aboriginal patient gets into complications and serious co-morbidities as they call it, before coming for help and what we're trying in this process is to say 'how can we communicate better so that help is looked for earlier and so we don't have to send people to hospitals and dialysis units, um so soon?' And if we can get this into the younger generations as they grow up then we'll see some success I'm sure

What about the legal guides? Do they, how do they come into play?

Well of course, yes they do, I mean um because um generally speaking the confidentiality between clinician and patient should be secure, but this a barrier, this is another barrier

That's right

Because I mean the drug world, let's not beat about the bush, is penetrating all of our young generations, ya know

That's exactly right yes

I heard yesterday on the radio, that there is a new drug that apparently it's five times stronger than cannabis but it's not detectable, and apparently they're pumping it out like crazy in Busselton

Yea

And uh ya know the problem is, that ya know the young women who actually phoned in to talk about it anonymously said, I wouldn't want to be driving a car or running a machine, because they were talking about the mining resources companies that apparently during their breaks, I don't mean their lunch breaks, I'm talking about when they come away on fly in fly out, they're binging on these drugs.

Yea

Um, so we've got lots and lots of social problems...

That's right yea

And if you look at your history, which I'm sure you know as well as I do but better, the value system of the aboriginal communities that originally were in this country for forty thousand years was much stronger than anything we see today, and if we can in some way, I'm not being ya know trying to go overboard but, if we can bring back that value system, then it'll contribute greatly to the whole social scene but it's a long long way to go, I shan't see it in my day I guess but...

Hmmm

There's this thing now we've tried *unclear talking* has got into the community now

Yes

How do you try to stop someone from using intravenous?

You know, all of these things can only be done in small steps, baby steps and uh there comes a time when you know that you're not winning and you have to move on but what we always look for are champions ok and the champions are sometimes the kids growing up. It's easy to look at football and say well look we've got some great aboriginal players, but that's not the complete story is it because what it does is say, well if you're not good at football what are you good at, ya know that's not the right way to be looking at things

As you're saying yea, we do have champions and then as soon as they get to that teenage age, you suffer as well

That's a minefield age for us all ya know

Yea

That's the thing we all worry about kids and grandkids coming through that

How do you find that one individual and other individuals with his group?

I think that the essential word is try...the more of us who are trying the more good things will happen

That's just like, how you supposed to tell, like a lot of people from the country area are coming down here because the bottle shops are open early down here, up in the country area they open about ten o'clock or eleven o'clock

Ten thirty

And now they come down here, and I said why are you coming, why did you leave your town to come down here for? And they go oh because the bottle shops open early and the drink is cheaper

And I said yea but do you know what it's doing to your insulin? A lot of our people just don't understand so...I blame a lot of alcohol, *unclear talking* really need to take in the communities yea...but ya know you can't tell everyone

Yep, that's right, unfortunately we can all come across as lecturing and that turns people off anyway

Our intent is good

Exactly

But ya know...the point is we cannot stop trying ya know, uh because I think that if I look back on my childhood, there are lessons that I learned much later, that I was told way back and didn't learn right, I made some of my own mistakes but other people made mistakes that I've learned from as well and it's funny how late in life you kinda look back and think ooh what a good escape that was, I didn't...I could have gone that way or that way ya know

So I mean the message mainly is um to keep talking with the kids, um without having to lecture, it's unavoidable, but to keep talking to them, optimistically, about um...having values, and it's tough, especially when you start reading the figures on sexually transmitted diseases, out in the remote areas, it's eighty percent

That's what I mean yea

You know and you can get depressed about that, the reality is depressing isn't it, but when you get good groups coming together like we are ya know, that brings us hope

Thanks again, really appreciate it

Thank you

End 01:29:07

Appendix C

Literature source list for Qualitative Gap Analysis (QGA) of PPIE communication barrier characteristics

Appendix C Qualitative Gap Analysis Source Reference

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Appendix D

David E. Forbes Attendance Certificates

Diabetes Education Program Marr Mooditj Training
June 2010

ABC of Two-Way Literacy and Learning
October 2010

11th National Rural Health Conference
March 2011

MARR MOODITJ



DIABETES EDUCATION PROGRAM FOR DIPLOMA OF ENROLLED NURSING

Presented by Credentialed Diabetes Educators Western Australia

Certificate of Attendance

David Forbes (Observer)

(28 hrs) 08/06/10-11/06/10

Content included:

Diabetes Self Management Model
Risk Factors, Prevalence and Prevention
Aetiology and Pathophysiology
Blood Glucose Monitoring
Interpreting BGLs
Lifestyle Simulation Program
Medications and Insulin Therapy
Insulin Pen Injector/Syringe Workshop
Acute and Chronic Complications

Footcare and Workshop
Groups with Special Needs
- Children and Adolescents Diabetes
- Type 2 Diabetes in Children
Healthy Eating
Diabetes Supplies/NDSS/Websites
Pregnancy and Diabetes
Role Plays/Case Studies/Daily Tests

Diabetes Showcase by Students facilitated by David with thanks.

Gloria M Daniels

Gloria M Daniels

CNC Diabetes CDE

Sir Charles Gairdner Hospital



"Putting Aboriginal Health in Aboriginal Hands"



Department of Education

ABC of TWO - WAY LITERACY AND LEARNING

CERTIFICATE OF PARTICIPATION


This is to certify that

David Forbes

participated in a two-day
awareness raising workshop
on Aboriginal English and
Two-Way Bidialectal Education held at
Mantra on Hay, Perth
on
6th & 7th October 2010


Patricia Konigsberg

Manager
ABC of Two-Way
Literacy and learning


Glenys Collard

Senior Consultant
Aboriginal English

**RURAL AND
REMOTE AUSTRALIA**
THE HEART OF A
HEALTHY NATION

11th National Rural Health Conference
Perth 13–16 March 2011



Certificate of Attendance

This is to certify that

David Forbes

attended the

11th National Rural Health Conference

13–16 March 2011

Perth Convention and Exhibition Centre
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David E. Forbes

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