

## **The experience of lung cancer in Aboriginal and Torres Strait Islander peoples and what it means for policy, service planning and delivery**

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# The experience of lung cancer in Aboriginal and Torres Strait Islander peoples and what it means for policy, service planning and delivery

## Abstract

**Background:** Aboriginal and Torres Strait Islander peoples experience inferior outcomes following diagnosis of lung cancer.

**Aim:** To examine the experience of lung cancer in this population and identify reasons for poorer outcomes and lower levels of treatment compared to non-Aboriginal and Torres Strait Islander peoples, and opportunities for early intervention.

**Method:** Literature was sought via electronic database searches and journal hand searching for the period from January 1995 to July 2010. Databases used included Indigenous Health *InfoNet*, SCOPUS, PsycInfo, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Health *Insite* and Google Scholar.

**Findings:** Exposure to risk factors, cultural and spiritual values, remoteness and geographic characteristics, entrenched socioeconomic inequalities and racism contribute to reduced service access and poor outcomes. The review highlighted a complex interplay of individual, social, health system and environmental factors that impact on optimal lung cancer care and lung cancer outcomes. Considering the burden of lung cancer with broader social determinants of health is necessary for policy, service planning and delivery.

**Conclusions:** It is imperative that the disproportionate burden of lung cancer in Aboriginal and Torres Strait Islander peoples is immediately addressed. Whilst strategic interventions in lung cancer prevention and care are needed, service providers and policy makers must acknowledge the entrenched inequality that exists and consider the broad range of factors at the patient, provider and system level. Primary care strategies and health promotion activities to reduce risk factors, such as smoking, must also be implemented, with Aboriginal and Torres Strait Islander peoples' engagement and control at the core of any strategy. This review has indicated that multifaceted interventions, supported by enabling policies and that target individuals, communities and health professionals, are necessary to improve lung cancer outcomes and disparities.

**Key words:** Aboriginal and Torres Strait Islander peoples, Indigenous, Lung cancer, health services, health policy

## **Background:**

Aboriginal and Torres Strait Islander (hereafter, Aboriginal) peoples are over-represented in cancer deaths<sup>1</sup> and are 2.5 times more likely to die within five years of cancer diagnosis than non-Aboriginal Australians.<sup>2</sup> From 1992-1996 four groups of conditions accounted for almost 70% of the total excess deaths in the Aboriginal population of Western Australia and the Northern Territory.<sup>3</sup> These conditions included; circulatory conditions including ischaemic heart disease, cerebrovascular disease and hypertension (26%); injury and poisoning including homicide, assaults, suicide and transport injuries (15%); respiratory conditions (16%); and endocrine conditions including diabetes(10%).<sup>3</sup> As a result, chronic conditions including heart disease, stroke and diabetes have been the focus of health care, policies, and interventions for Aboriginal Australians. Whilst addressing these chronic conditions remains central in improving the health of Aboriginal Australians, cancer, particularly lung cancer, is also an important health problem in this context.

Smoking rates in Aboriginal Australians contribute significantly to morbidity and mortality.<sup>1</sup> Lung cancer is the most common cancer amongst Aboriginal Australians and accounts for the most cancer mortalities (nearly 5% of all deaths of Aboriginal people).<sup>4</sup> In 2005-2006, lung cancer was the most common reason for hospitalisation amongst Aboriginal males of all malignant cancers (a total of 140 hospitalisations). During the same period, of all malignant cancers lung cancer was the second most common reason for hospitalisation amongst Aboriginal women accounting for 112 hospitalisations, second only to breast cancer (140 hospitalisations).<sup>1</sup> This suggests there is a need for a greater focus on the prevention and early diagnosis of lung cancer in Aboriginal Australians. To date, there are minimal data available reporting lung cancer survival rates for Aboriginal Australians.<sup>5</sup> While the high mortality rate can be linked to high incidence, there are other explanations which are discussed throughout the paper.

**Aim:**

To examine the experience of lung cancer amongst Aboriginal Australians and identify reasons for poorer outcomes and lower levels of treatment compared to non-Aboriginal Australians, and opportunities for early intervention.

**Method:**

An integrative review was undertaken, including both experimental and non-experimental studies, to obtain information regarding Aboriginal Australians and lung cancer. Literature was sought via electronic database searches and journal hand searching for the period from January 1995 to July 2010 using the search terms 'lung cancer', 'Indigen\*', 'Aborig\*' and 'Australia'. Databases used included Indigenous HealthInfoNet, SCOPUS, PsycInfo, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, HealthInsite and Google Scholar. Reference lists from articles retrieved were also searched for additional articles or information. Articles were included if they addressed lung cancer care in Australian Aboriginal and Torres Strait Islander people. Information was extracted using a standardised data extraction tool based upon the Critical Appraisal Skills Programme (CASP) tools.<sup>6</sup> Thematic analysis was then undertaken to identify key themes emerging from the literature.<sup>7</sup>

**Findings:**

The key word search retrieved 37 articles that met the aims of this study. Aboriginal Australians have poorer rates of survival than non-Aboriginal Australians, often experience late diagnoses, and receive less aggressive treatment than non-Aboriginal Australians. Aboriginal Australians with lung cancer are younger, more likely to live in rural or remote areas, and to have a greater economic disadvantage than their non-Aboriginal counterparts.<sup>8</sup> Most cancers overrepresented in Aboriginal Australians are largely

preventable, with lung cancer providing a good example where rates in non-Aboriginal men have been declining.<sup>2, 9-14</sup>

Poor quality data is a consistent barrier in identifying and analysing cancer incidence and outcomes within the Aboriginal Australian population.<sup>5, 10, 12, 14-18</sup> The problems of identifying and classifying Aboriginal status have been well described and there are many gaps in the data on Aboriginal deaths and mortality. Cancer registries obtain data on Aboriginal status from hospital admission and death records.<sup>19</sup> The quality of this data is generally poor and needs to be addressed.<sup>19</sup> In addition, there is a lack of national cohesion as there is no national data on cancer incidence due to the questionable quality of data within some jurisdictions.<sup>12, 13</sup> Furthermore, Passey and colleagues noted a shortage of literature regarding the treatment and care of Aboriginal people with cancer.<sup>20</sup>

The review revealed potential barriers to optimal lung cancer care and management for Aboriginal Australians. These include; exposure to risk factors, cultural and spiritual values, remoteness and geographic characteristics, and socioeconomic status. Themes generated from the review include; individual beliefs and behaviours, healthcare systems issues and environmental issues.

#### The impact of individual beliefs and behaviours

Health risk factors impact on the diagnosis, prognosis, and management of many conditions, including lung cancer. Risk factors, for cancer and other conditions, need to be understood within a broader environmental and structural context including factors such as education, socio-economic status, culture, communication and discrimination.<sup>12</sup> Aboriginal Australians are particularly vulnerable as a result of the increased prevalence of risk factors for lung cancer in their communities.<sup>10</sup> In order for lung cancer incidence and mortality to be reduced, risk factors and other determinants of health beyond personal risk behaviours, such as tobacco smoking, must be examined and addressed.<sup>5</sup>

## *Smoking*

Aboriginal Australians have high levels of tobacco use.<sup>5, 10, 11</sup> Within the Aboriginal population, smoking constitutes a major risk factor for lung cancer and many other diseases and chronic conditions. *The National Aboriginal and Torres Strait Islander Health Survey, 2004-05* identified that Aboriginal Australians are 2.2 times more likely to smoke than non-Aboriginal Australians.<sup>21</sup> The results also indicated that half of the respondents smoked and that there has been little change in smoking behaviour since 1995. Within the Northern Territory Aboriginal population, there are indications that the incidence of smoking-related cancers is increasing<sup>5</sup>, indicating that the measures being taken and/or implemented to reduce and eliminate tobacco consumption are not working. Addressing fundamental social inequalities and recognising that smoking can be perceived by Aboriginal people as an acceptable coping mechanism is a crucial step in formulating effective interventions.<sup>20</sup>

The data from the review indicate a pressing need to address tobacco smoking through a range of strategies sustained over a long period of time. Lessons from mainstream approaches to tobacco control will be useful but are obviously insufficient as they may represent a top-down approach further reinforcing the legacy of colonisation and paternalism. Prevention of smoking uptake is as important as efforts to increase smoking cessation.<sup>5, 9, 10, 12</sup> Strategies have been reviewed comprehensively elsewhere<sup>22-25</sup> and the Australian Government has recently committed significant funding to enhance efforts to address tobacco control within the Aboriginal Australian population. These measures are particularly important since the evidence suggests that smoking-related cancers have a greater impact on younger compared to older Aboriginal people relative to other Australians.<sup>5, 12</sup> Compared with non-Aboriginal Australians, the relative risk of cancer death was much higher for traditional language speakers.<sup>26, 27</sup> Therefore, smoking cessation programs need to be designed within the context of

Aboriginal health and address the social, economic, historical and cultural reasons why Aboriginal Australian people smoke.

### *Lung Cancer Knowledge and Health Literacy*

Research in Western Australia has found a number of misconceptions about cancer, the study included both individuals who had direct or indirect experience of cancer.<sup>28</sup> Similar findings were reported among those who participated in the documentation of an end-of-life care model.<sup>29</sup> These misconceptions included cancer as a form of punishment, the role of sorcery and cancer being contagious.<sup>28, 29</sup> This belief that cancer is contagious can result in cancer patients being ostracised from their communities or unwilling to tell others about their cancer.<sup>30</sup>

Health literacy describes how individuals and communities obtain, understand, process and communicate health information and then making decisions based on this understanding.<sup>31, 32</sup> Poor health literacy is a result of inadequate education, low socioeconomic background and a range of delivery system issues are discussed below. Educational materials must therefore take into consideration not only literacy levels but socio-cultural factors.<sup>33</sup>

### *Spiritual and Cultural Beliefs*

Traditional spiritual and cultural beliefs may influence perceptions of why a person may have cancer. For example, in some Aboriginal Australian cultures, there is no word for cancer and as a result, the Western scientific term is not always understood.<sup>29</sup> Some believe that their cancer is resultant of having offended a relative whom that part of the body represents, and they are thus receiving justified 'payback',<sup>27, 29, 34</sup> and hence refuse treatment. This also has implications for risk factors, such as tobacco as less emphasis is placed on its role in causing cancer.<sup>35</sup>



For many Aboriginal Australian people, cancer is seen as a death sentence. Research on an end-of-life model documented a participant stating; 'frightened, frightened. Cancer bad, make people die quickly.'<sup>29</sup> p. 244 This perception and fatalistic view is strongly related to poorer survival.<sup>2, 12</sup> In a Western Australian study, this belief was considered a major factor explaining why people ignore early symptoms and do not access treatment even after medical diagnosis.<sup>28</sup> In addition, many Aboriginal Australians are not familiar with being in a hospital environment and may feel very uncomfortable in that setting.<sup>27</sup>

However these data may not be generalisable to all Aboriginal Australian communities as there are currently gaps in knowledge around whether or not differences in cancer beliefs exist between urban, rural and remote populations.<sup>36</sup>

#### Healthcare systems issues

The issues discussed below are linked to structural, organisational and interpersonal issues that are underpinned by a legacy of discrimination and alienation. Although not emerging from the data retrieved on lung cancer it is important to consider the diverse and complex issues that result from the interface of mainstream and community controlled organisations and the importance of community based organisations and community health care workers in improving access to care.<sup>37</sup>

#### *Late diagnosis*

Many Aboriginal Australians experience a late diagnosis of lung cancer<sup>2, 5, 12, 13, 38, 39</sup> possibly as a result of the higher prevalence of co-morbidities.<sup>40</sup> Both chronic bronchitis and emphysema, and diabetes are almost twice as common among Aboriginal Australians and at markedly higher levels in younger ages.<sup>1</sup> In addition, the generally poor health status of many Aboriginal communities in Australia, can deter seeking diagnosis if feeling unwell is commonplace.<sup>41</sup> It is also unclear how these factors impact on the decision to undergo chemotherapy or radiotherapy.<sup>42</sup>

A study conducted in the Northern Territory (NT), Australia, by Condon and colleagues revealed that Aboriginal people with lung and other cancers were less likely to be diagnosed with advanced disease than non-Aboriginal people,<sup>2</sup> a finding counter to that for the other cancers examined (colon and rectum, breast, cervix and non-Hodgkins lymphoma). The authors noted possible explanations to include high prevalence of other chronic respiratory diseases including tuberculosis in Aboriginal people in the Northern Territory, which may have necessitated frequent chest x-rays and other screening procedures as part of their clinical management and follow up. Alternatively, the authors noted that the proportion of Aboriginal people with regional disease at diagnosis may have been underestimated if Aboriginal patients with lung cancer were less likely to have intensive investigations, such as mediastinoscopy, thoracoscopy, and exploratory thoracotomy.<sup>2</sup> Stage of diagnosis information is often not available where there is reasonable Aboriginal identification, but Condon et al.'s findings differ from those of Coory et al.<sup>8</sup> who reported that a larger proportion of Aboriginal patients had no information about cancer staging in the chart examined (23% v 13%), and where a smaller percentage of those staged had localised disease (22% v 30%). This highlights that findings may differ with health service programs and variations in care delivery in jurisdictions across Australia.

#### *Access to services*

There are limited specialist cancer services in regional Australia,<sup>27</sup> access to lung cancer treatment usually involves travel to a large regional or major city hospital.<sup>12</sup> This often places pressure on financial resources and family responsibilities. Amongst Aboriginal people, those that lived in remote areas were associated with higher risk of cancer death for all cancers.<sup>26</sup> Compounding the problem of distance and transport are difficulties that relate to geography and weather.<sup>8, 43</sup> Family responsibilities, community obligations and support networks also affect treatment decisions.<sup>12</sup> Often patients and their

families have to organise and pay for their own transportation, thus placing additional financial burden and stress on them.

Aboriginal Australians receive proportionately less active treatment, including chemotherapy, radiotherapy and surgery, than non-Aboriginal Australians.<sup>8</sup> The potential reasons for this are complex and involve patient, provider and system factors. They are also more likely to experience delays, suboptimal or incomplete treatment.<sup>5, 13, 38</sup> Low hospital admission rates also reflect the less active treatment experienced by Aboriginal Australians.<sup>10</sup> Results of three studies demonstrated this less active and suboptimal treatment. A study conducted in the Northern Territory revealed Aboriginal patients were less likely to use private medical services, less likely to be recommended for curative treatment and when curative treatment was recommended less likely to choose and complete treatment, and less likely to travel interstate when referred.<sup>26</sup> A Western Australia study found Aboriginal patients were less likely than non-Aboriginal patients to receive surgery.<sup>38</sup> An analysis of Queensland data found only 46 percent of Aboriginal patients received active treatment with chemotherapy, radiotherapy or surgery compared with 72 percent of non-Aboriginal patients.<sup>8</sup>

Lower rates of lung cancer survival have been acknowledged in South Australia, Queensland and the Northern Territory.<sup>12</sup> Coory et al. considered the differences in survival between Aboriginal and non-Aboriginal Australians to result from discrepancies in treatment.<sup>8</sup> However, even after adjustment for stage at diagnosis, cancer treatment, and greater co-morbidity, Aboriginal Australians have poorer cancer outcomes than non-Aboriginal Australians suggesting a need for better understanding of structural barriers and cultural differences in attitudes to cancer and its treatment.<sup>41</sup>

These differences, and poor utilisation rates, could be explained by systemic and provider characteristics contributing to late diagnosis, inoperable cancers, or other co-morbidities complicating

surgical prospects. In addition, there are few, if any, Aboriginal Australian cancer specialists.<sup>38</sup>

Aboriginal Australians may refuse treatment due to beliefs about and previous experiences of health care.<sup>44</sup> Whereas advanced technology, characteristic of modern cancer treatments, is located in major urban centres, Aboriginal Australians may experience social and cultural dislocation if they are required relocate from remote communities for treatment. These factors make it difficult for Aboriginal people to obtain culturally competent and sensitive specialist care for lung cancer treatment. This raises difficult questions for Aboriginal people with lung cancer and of where their priorities lie in relation to being with their community or relocation to receive more appropriate treatment. Accessing treatment may involve alienation in a new and often hostile environment and a fear of not returning back to their country.<sup>45</sup> Addressing the fundamental social and health inequalities that perpetuate these adverse outcomes appears to be the way forward.

Cancer treatment can be a financial burden, not only for the individual but for their family as well.

Many Aboriginal Australians do not have private health insurance or any income protection,<sup>27</sup> Coory et al.<sup>8</sup> showed that 21.2% of non-Aboriginal patients with lung cancer were treated in a private hospital only whereas only 4.4% of Aboriginal patients were treated exclusively in a private hospital. In addition, Aboriginal people often have responsibilities to care for children and family that may make them reluctant to leave their home and community. Therefore considering the financial and caregiving responsibilities of the individual is important for facilitating access to treatment.

### *Communication and Cultural Competency*

Communication is a major hindrance to timely diagnosis and effective treatment.<sup>46,47</sup> A lack of culturally sensitive public health campaigns, limited cancer specific information and ineffective preventive strategies by the health community produce and sustain barriers to effective patient provider communication. Providers bear the primary responsibility for ensuring that patients have an adequate

understanding of all aspects of the cancer journey.<sup>46</sup> Communication between provider and patient may be hindered by the lack of cultural competency of the health professional. Cultural competence refers to the ability to appreciate and understand the social and cultural influences on a patients' health beliefs and behaviours and taking steps to incorporate these understandings into interactions, interventions and services.<sup>48</sup> Cultural competence cannot be developed overnight nor will it be automatically developed after a workshop, in the context of Aboriginal people's health in Australia, it is an ongoing process that recognises and challenges the social, economic and geographical realms which impact on appropriate and accessible care for Aboriginal Australians.<sup>49</sup>

Where the clinician and patient are from different cultural backgrounds, there is greater likelihood of misdiagnosis and non-cooperation with treatment and disease management.<sup>50</sup> According to the Australian Institute of Health and Welfare, 11% of Aboriginal Australians reported that they had difficulty understanding and/or being understood by service providers. Aboriginal Australians living in remote areas were more likely than those in non-remote areas to report experiencing difficulty with communication.<sup>1</sup>

Shahid et al.<sup>47</sup> described a range of factors relating to communication that impact on cancer services. These factors include; failure to provide adequate information, explanations and check-ups, failure to establish an ongoing personal relationship, differences in communication styles, differences in non-verbal cues and body language and a lack of respect for privacy as contributing to mistrust and communication failures around Aboriginal people and cancer care.<sup>47</sup> Contextual factors such as the history of colonisation and the subsequent impact on inequity and the hospital environment being alienating, can also impede effective service delivery to Aboriginal Australians with lung cancer.<sup>28</sup>

### Environmental factors

Unfortunately most environmental factors can be attributed to poor socioeconomic status including low income, low level of education, high rates of unemployment, greater risk of being involved with the legal system and poor or substandard housing including overcrowding and inadequate facilities and structures.<sup>51</sup> Environmental and occupational factors, such as exposure to asbestos and other risk factors further place Aboriginal Australians at a greater risk of lung cancer. Due to remoteness, many mines in Australia were staffed with an Aboriginal workforce, such as the Baryulgil Asbestos Mine in northern New South Wales.<sup>52</sup> Occupational risk is not the only threat. Evidence of environmental pollution has been seen in the Pilbara region in Western Australia where, due to the mining at Wittenoom, the incidence of mesothelioma within the region is one of the highest population-based rates recorded.<sup>53</sup> Lung cancer risk is increased with exposure to both asbestos and cigarette smoke.<sup>54, 55</sup>

Many Aboriginal Australians are exposed to environmental tobacco smoke, a factor that places them at additional risk.<sup>35</sup> A Western Australian study of Aboriginal women found that among the non-smokers, 35% were exposed to environmental tobacco smoke inside their homes.<sup>56</sup> Another study conducted in remote Northern Territory Aboriginal communities indicated that of the 220 children interviewed, 98% lived in a house with at least one smoker, whilst 43% lived with five or more smokers. Exposure to environmental tobacco smoke not only can cause lung cancer but has immediate and long term adverse effects on the cardiovascular and respiratory system.<sup>57</sup>

Indirect risk factors also exist that may complicate the treatment and management of lung cancer. For example, poor environmental conditions and unsafe housing, which increase the risk of infectious diseases, may also increase the risks associated with cancer treatment including chemotherapy and radiotherapy.<sup>5</sup> The issues for individuals living in rural, remote and urban areas are likely to be different but equally as challenging.

A matched cohort study of Aboriginal and non-Aboriginal patients diagnosed with lung cancer between 1996 and 2002 and treated in Queensland public hospitals found that Aboriginal patients were more likely to live in rural or remote areas.<sup>8</sup> Whilst this finding may not be able to be generalised to all states this has many implications for the delivery of services and health care. Being remote from community support is an important factor in promoting adherence to treatments.<sup>47</sup>

### **Implications for policy, service planning and delivery**

This review identifies a complex interplay of individual, social and health system factors impacting on lung cancer care and lung cancer outcomes. However, many of the articles reviewed focused on the behaviours and views of Aboriginal Australians,<sup>5, 8, 16, 30</sup> rather than critically questioning systemic issues and relationships between patient and health care providers. A recent review by Thompson et al.<sup>58</sup> has shown that there is slow and consistent progress being made in increasing access and acceptability of services for Aboriginal Australians.

#### *Service planning and delivery*

As lung cancer is largely preventable, prevention within Aboriginal Australian communities must be a focus of healthcare delivery. One component of this must include education on risk factors and symptom recognition, in both health professionals and consumers. In particular, appropriate targeted education for Aboriginal health professionals about the prevention, risks, symptoms, management and palliation of lung cancer must be implemented. Early diagnosis can be facilitated by improving access to and knowledge of primary health care. Ensuring that primary care facilities are both affordable and culturally competent are important considerations.

Systems-related issues, particularly the capacity to access culturally appropriate care, are likely limitations that can be addressed through appropriate training and quality improvement initiatives.<sup>44, 59</sup>

Racism and discrimination continue to permeate the Australian healthcare system and may be directly or indirectly targeted at Aboriginal Australians, with potentially disastrous implications for their health and wellbeing.<sup>44, 60</sup> Discrimination can occur at multiple points of the health care system including access to services, disease management and outcomes.<sup>12</sup> Whilst many health professionals believe that racism is no longer an issue, Johnstone and Kanitsaki<sup>61</sup> and Durey et al.<sup>62</sup> have identified that discrimination, racism and cultural misunderstandings continue to plague the Australian health care system undermining the quality of care to Aboriginal patients. Durey et al. advocate for environments that are more welcoming for Aboriginal people. Such environments can be established through a collaborative model of care which incorporates building capacity in Aboriginal and non-Aboriginal personnel, recruiting more Aboriginal health professionals, increasing knowledge and skills to develop trusting relationships between mainstream providers and Aboriginal patients, and delivering care that is respectful and culturally competent.<sup>63</sup>

For effective and sustainable solutions to be achieved, the need for effective engagement in building relationships with Aboriginal communities must be the centre of any strategy. In other areas of Aboriginal health, such as cardiac rehabilitation<sup>64</sup> and mental health,<sup>65</sup> the involvement of Aboriginal Health Workers (AHWs) has proven to have a beneficial effect on outcomes and should be considered as an integral element of care. Multidisciplinary cancer care teams also need to include and engage AHW's.<sup>66</sup> Demand for places in a Western Australian Cancer Education Course suggests that AHWs are interested in developing the knowledge and skills that are needed in cancer control and care,<sup>67</sup> however such efforts must be ongoing rather than one off programs. Initiatives to train Aboriginal lung cancer specialists should also be investigated.<sup>38</sup> It is hoped that by implementing such education and training strategies improvements will be seen in Aboriginal cancer support services, specifically in lung cancer.



The impact of risk factors, particularly smoking must also be reduced in addition to strategies to prevent late diagnosis. With no measurable improvements seen in smoking patterns, it seems that tobacco control programmes have thus far been ineffective.<sup>26</sup> Culturally appropriate smoking cessation programs should be implemented in all settings. Strategies to improve health literacy via the dissemination of culturally appropriate educational resources must also be explored.

Spiritual beliefs and traditional approaches to health play an important role in the cancer treatment choices for some Aboriginal Australian patients<sup>68</sup> therefore such practices need to be incorporated into mainstream medical care. For this to occur, mainstream health practitioners need to understand and acknowledge spiritual beliefs, traditional healing and treatment approaches surrounding cancer in order to work and communicate effectively with Aboriginal patients.<sup>27, 28</sup> Further research needs to be conducted as to what inhibits and facilitates this understanding so it is represented in policies and translates into practice.

### *Policy*

Policy should focus on a national approach to address issues in cancer control for Aboriginal Australians.<sup>31, 38</sup> Within this process, policy makers need to enable Aboriginal peoples' ownership, participation, partnership and control with Aboriginal people represented at all levels of decision making.<sup>28</sup> Furthermore, policy must be evidence based, therefore research to explain and analyse reasons for delayed diagnosis and treatment choice must be analysed to ensure that barriers to early diagnosis and treatment are minimised. Such research must be conducted in sincere collaboration with Aboriginal people.<sup>38</sup>

Attempts should also be made to reduce inefficiencies and limit the effect community politics has on community controlled health organisations. Currently funding is complex and fragmented, and is often

only for short term goals or projects.<sup>69</sup> Associated with this is low salary levels, difficulties in recruiting for temporary positions, and a heavy burden of administration and reporting.<sup>69</sup> A more streamline approach to funding must occur with funding be made available for sustainable and long term programs.

Improvement of the identification of Aboriginal populations within datasets also needs to occur. This means that policies need to be implemented to improve data collection. For this to occur, data needs to be regularly collected on a systematic basis and must incorporate nationally agreed upon definitions.<sup>13</sup> Any policy must acknowledge past treatment and the impact of colonisation, the cultural diversity of Aboriginal people, recognise the impact of the structural causes of inequality and include support for community-based and community-driven interventions.<sup>27, 28</sup>

Attention should be paid to the specific needs of different communities,<sup>66</sup> policy makers must realise that the Australian Aboriginal population is not homogeneous, for example the needs of urban communities may be very different to those living in rural or remote areas. People from rural and/or remote areas are more likely to experience worse outcomes in lung cancer and lack adequate cancer facilities,<sup>34, 70</sup> under servicing and lack of access in such areas disproportionately affects Aboriginal Australians because they are more likely than other Australians to live in these areas.<sup>12</sup>

A limitation of this study is that many of the studies reviewed were smaller studies confined to geographical areas or particularly communities. Given the diversity within the Aboriginal Australian population, particularly between rural, remote and urban areas this may make the findings difficult to generalise to all communities. Whilst the issues discussed may not necessarily apply to each Aboriginal Australian community this review has shown that there is a clear need for further attention to address the lung cancer disparities experienced by Aboriginal Australians. It is also acknowledged that this

review focussed on only published studies, it is important to consider this approach in an evidence-based approach to policy and practice. The potential for publication bias was also considered, yet emergent issues were also manifest in government reports and other documents. In spite of these limitations these data provide a useful summary to inform future policy, practice and research.

### **Conclusions:**

The disproportionate burden of lung cancer in Aboriginal Australians warrants urgent attention. A multifaceted approach is required to address access issues, reduce health disparities and recognise the complex interplay of social determinants in moderating health outcomes. This requires acknowledging entrenched inequality and addressing factors at the patient, provider and system level. As smoking is the largest risk factor for lung cancer, smoking cessation programs are critical and initiatives at the Federal government level are encouraging. Although the importance of prevention is underscored, particularly through smoking cessation, in the short term the burden of lung cancer in Aboriginal Australians is likely to persist. There is a dire need to ensure Aboriginal Australians have access to culturally appropriate cancer services, in both urban and rural areas and strategies for early diagnosis promoted.

Mainstream health care needs to reflect upon the impact of colonisation on Aboriginal people and consider alternative beliefs and healing methods when determining treatment options. Tailored and targeted lung cancer prevention and care strategies need to be developed, in addition, health disparities must be address through coordinated policy initiatives across health and social policy. Effective engagement and partnership with Aboriginal communities must be at the centre of any intervention or policy.

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## References

1. Australian Bureau of Statistics, Australian Institute of Health and Welfare. The Health and Welfare of Australia's Aboriginal and Torres Strait Islander peoples. Canberra: ABS, AIHW2008 Contract No.: ABS Cat. No. 4704.0. AIHW Cat. No. IHW 21.
2. Condon JR, Barnes T, Armstrong BK, Selva-Nayagam S, Elwood JM. Stage at diagnosis and cancer survival for Indigenous Australians in the Northern Territory. *Medical Journal of Australia*. 2005;182(6):277-80.
3. Ring I, Firman D. Reducing indigenous mortality in Australia: lessons from other countries. *Medical Journal of Australia*. 1998;169(10):528-33.
4. Australian Bureau of Statistics. Causes of Death. Australia. 2008. Canberra: ABS; 2010 [3303.0]; Available from: <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3303.02008?OpenDocument>.
5. Condon JR, Armstrong BK, Barnes T, Zhao Y. Cancer incidence and survival for indigenous Australians in the Northern Territory. *Aust N Z J Public Health*. 2005 Apr;29(2):123-8.
6. Crombie IK. The pocket guide to critical appraisal: A handbook for health care professionals. London: BMJ Publishing Group; 1997.
7. Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research and Policy*. 2005;10(1):45.
8. Coory MD, Green AC, Stirling J, Valery PC. Survival of Indigenous and non-Indigenous Queenslanders after a diagnosis of lung cancer: a matched cohort study. *Medical Journal of Australia*. 2008 May 19;188(10):562-6.
9. Coory M, Thompson A, Ganguly I. Cancer among people living in rural and remote Indigenous communities in Queensland. *Medical Journal of Australia*. 2000 Sep 18;173(6):301-4.
10. Condon JR, Armstrong BK, Barnes A, Cunningham J. Cancer in Indigenous Australians: a review. *Cancer Causes Control*. 2003 Mar;14(2):109-21.
11. Condon JR, Barnes T, Cunningham J, Armstrong BK. Long-term trends in cancer mortality for Indigenous Australians in the Northern Territory. *Medical Journal of Australia*. 2004 May 17;180(10):504-7.
12. Cunningham J, Rumbold AR, Zhang X, Condon JR. Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia. *The Lancet Oncology*. 2008;9(6):585-95.
13. Stumpers S, Thomson N. Review of cancer among Indigenous people. 2009 [cited 2010 June 20]; Available from: <http://www.healthinfonet.ecu.edu.au/chronic-conditions/cancer/reviews/our-review>.
14. Cottrell J, Street J, Chong A, Roder D. Comparing cancer profiles and survival of aboriginal and non-aboriginal patients in South Australia: where are the opportunities for improving Aboriginal health? *Asian Pacific Journal of Cancer Prevention*. 2007 Oct-Dec;8(4):495-501.
15. Boffa JD. Cancer care for Indigenous Australians. *Medical Journal of Australia*. 2008;188(10):560.
16. Supramaniam R, Grindley H, Pulver LJ. Cancer mortality in Aboriginal people in New South Wales, Australia, 1994-2002. *Australian and New Zealand Journal of Public Health*. 2006 10;30(5):453-6.
17. Roder D. Epidemiology of cancer in Indigenous Australians: Implications for service delivery. *Cancer Forum*. 2007;31(2):85-90.
18. Chong A, Roder D. Exploring Differences in Survival from Cancer among Indigenous and non-Indigenous Australians: Implications for Health Service Delivery and Research. *Asian Pacific Journal of Cancer Prevention*. 2010;11(4):953-61.

19. Cancer Australia. A National Cancer Data Strategy for Australia. Canberra: Cancer Australia 2008.
20. Passey M, Gale J, Holt B, Leatherday C, Roberts C, Kay D, et al. Stop smoking in its tracks: understanding smoking by rural Aboriginal women. 10th National Rural Health Conference; 17-20 May; Cairns, QLD 2009.
21. Australian Bureau of Statistics. National Aboriginal and Torres Strait Islander health survey, 2004-05. Canberra: ABS; 2006 [cited 2010 25 February]; Available from: <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/C36E019CD56EDE1FCA256C76007A9D36>
22. Ivers RG. A review of tobacco interventions for Indigenous Australians. Australian and New Zealand Journal of Public Health. 2007;27(3):294-9.
23. Harvey D, Tsey K, Cadet-James Y, Minniecon D, Ivers R, McCalman J, et al. An evaluation of tobacco brief intervention training in three Indigenous health care settings in north Queensland. Australian and New Zealand Journal of Public Health. 2002 Oct 2002;26(5):426 -31.
24. Briggs VL, Lindorff KJ, Ivers RG. Aboriginal and Torres Strait Islander Australians and Tobacco. Tobacco Control. 2003;12(suppl 2).
25. Thomas DP, Briggs V, Anderson I, Cunningham J. The social determinants of being an Indigenous non-smoker. Australian and New Zealand Journal of Public Health. 2008 Apr 2008;32(2):110 -6.
26. Condon JR, Cunningham J, Barnes T, Armstrong BK, Selva-Nayagam S. Cancer diagnosis and treatment in the Northern Territory: assessing health service performance for Indigenous Australians. Intern Med J. 2006 Aug;36(8):498-505.
27. Lowenthal RM, Grogan PB, Kerrins ET. Reducing the impact of cancer in indigenous communities: Ways forward. Medical Journal of Australia. 2005;182(3):105-6.
28. Shahid S, Finn L, Bessarab D, Thompson S. Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. BMC Health Services Research. 2009;9(1):132.
29. McGrath P, Holewa H, Ogilvie K, Rayner R, Patton MA. Insights on Aboriginal peoples views of cancer in Australia. Contemporary Nurse. 2006;22(2):240-54.
30. Prior D. Don't mention the 'C' word: Aboriginal women's view of cancer. Aboriginal and Islander Health Worker Journal 2005 29 (6):7-10
31. Keleher H, Hagger V. Health literacy in primary health care. Australian Journal of Primary Health. 2007;13(2):24.
32. Devitt J, Cass A, Cunningham J, Preece C, Anderson K, Snelling P. Study Protocol – Improving Access to Kidney Transplants (IMPAKT): A detailed account of a qualitative study investigating barriers to transplant for Australian Indigenous people with end-stage kidney disease. BMC Health Services Research. 2008;8(1):31.
33. Gill J. The lung story. Aboriginal and Islander Health Worker Journal 1999 23 (1 ):7-8.
34. Hall SE, Holman CDJ, Threlfall T, Sheiner H, Phillips M, Katriss P, et al. Lung cancer: An exploration of patient and general practitioner perspectives on the realities of care in rural Western Australia. Australian Journal of Rural Health. 2008;16(6):355-62.
35. Ivers R. Indigenous Australians and tobacco: a literature review. Darwin: Menzies School of Health Research and Cooperative Research Centre for Aboriginal and Tropical Health 2001.
36. Shahid S, Thompson SC. An overview of cancer and beliefs about the disease in Indigenous people of Australia, Canada, New Zealand and the US. Australian and New Zealand Journal of Public Health. 2009;33(2):109-18.
37. Abbott P, Gordon E, Davison J. Expanding roles of Aboriginal health workers in the primary care setting: Seeking recognition. Contemporary Nurse. 2008;27(2):157-64.

38. Hall SE, Bulsara CE, Bulsara MK, Leahy TG, Culbong MR, Hendrie D, et al. Treatment patterns for cancer in Western Australia: Does being indigenous make a difference? *Medical Journal of Australia*. 2004;181(4):191-4.
39. Shahid S, Beckmann KR, Thompson SC. Supporting cancer control for Indigenous Australians: initiatives and challenges for cancer councils. *Aust Health Rev*. 2008;32(1):56-65.
40. Roder D. Comparative cancer incidence, mortality and survival in Indigenous and non-Indigenous residents of South Australia and the Northern Territory. *Cancer Forum*. 2005;29(1):7-9.
41. Valery PC, Coory M, Stirling J, Green AC. Cancer diagnosis, treatment, and survival in Indigenous and non-Indigenous Australians: a matched cohort study. *The Lancet*. 2006;367(9525):1842-8.
42. Davidson PM, Jiwa M, Goldsmith AJ, McGrath SJ, DiGiacomo M, Phillips JL, et al. Decisions for lung cancer chemotherapy: the influence of physician and patient factors. *Supportive Care in Cancer* [serial on the Internet]. 2011.
43. McGrath P, Holewa H, McGrath Z. Practical problems for aboriginal palliative care service provision in rural and remote areas: Equipment, power and travel issues. *Collegian: Journal of the Royal College of Nursing Australia*. 2007;14(3):21-6.
44. Durey A. Reducing racism in Aboriginal health care in Australia: where does cultural education fit? *Australian and New Zealand Journal of Public Health*. 2010;34(s1):S87-S92.
45. McGrath P. 'I don't want to be in that big city; this is my country here': Research findings on Aboriginal peoples' preference to die at home. *Australian Journal of Rural Health*. 2007;15(4):264-8.
46. Davis TC, Williams MV, Marin E, Parker RM, Glass J. Health literacy and cancer communication. *CA: A cancer journal for clinicians*. 2002;52(3):134.
47. Shahid S, Finn LD, Thompson SC. Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting. *Medical Journal of Australia* 2009 190 (10 ):574-9
48. Betancourt JR, Green AR, Carrillo JE, Ananeh-Firempong O. Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*. 2003;118(4):293.
49. Fredericks BL, Thompson M. Collaborative voices: Ongoing reflections on cultural competency and the health care of Australian Indigenous people. *Journal of Australian Indigenous Issues*. 2010;13(3):10-20.
50. Durie M. An indigenous model of health promotion. *Health Promotion Journal of Australia*. 2004;15(3):36-50.
51. Lindorff K. Tobacco Time for Action: National Aboriginal and Torres Strait Islander Tobacco Control Project. Canberra: NACCHO2002.
52. McCulloch J. The Mine at Baryulgil: Work, Knowledge, and Asbestos Disease. *Labour History*. 2007;113-28.
53. Musk AW, Nicholas HK, Jan LE, Janice H, Keith BS. Malignant mesothelioma in Pilbara Aborigines. *Australian Journal of Public Health*. 1995;19(5):520-2.
54. Erren TC, Jacobsen M, Piekarski C. Synergy between Asbestos and Smoking on Lung Cancer Risks. *Epidemiology*. 1999;10(4):405-11.
55. United States Surgeon General. The health consequences of smoking - Cancer and chronic lung disease in the workplace. Rockville, MD: US Department of Health and Human Services1985.
56. Gilchrist D. Smoking prevalence among Aboriginal women. *Aboriginal and Islander Health Worker Journal*. 1998;22(4):4.
57. U.S. Department of Health and Human Services. The Health Consequences of Involuntary Exposure to Tobacco Smoke: A Report of the Surgeon General-Executive Summary. Washington, D.C.: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Coordinating Center for Health Promotion, National Center for Chronic Disease Prevention and Health Promotion and the Office on Smoking and Health2006.

58. Thompson SC, Davidson PM, DiGiacomo M, Pilkington L, Shahid S. 2010 Cancer Council environmental scan on Aboriginal and Torres Strait Islander health initiatives: documenting progress in Aboriginal and Torres Strait Islander cancer control. Perth: Cancer Council WA2011.
59. DiGiacomo M, Davidson PM, Taylor KP, Smith JS, Dimer L, Ali M, et al. Health information system linkage and coordination are critical for increasing access to secondary prevention in Aboriginal health: a qualitative study. *Quality in Primary Care*. 2010;18(1):17-26.
60. Paradies Y, Harris R, Anderson I. The impact of racism on Indigenous health in Australia and Aotearoa: towards a research agenda. Darwin: Cooperative Research Centre for Aboriginal Health2008 Contract No.: Discussion paper No 4.
61. Johnstone MJ, Kanitsaki O. The spectrum of 'new racism'and discrimination in hospital contexts: A reappraisal. *Collegian: Journal of the Royal College of Nursing Australia*. 2009;16(2):63-9.
62. Durey A, Thompson SC, Wood M. Time to bring down the twin towers in poor Aboriginal hospital care: addressing institutional racism and misunderstandings in communication. *Internal Medicine Journal*. 2012;42(1):17-22.
63. Durey A, Wynaden D, Thompson SC, Davidson PM, Bessarab D, Katzenellenbogen JM. Owing solutions: a collaborative model to improve quality in hospital care for Aboriginal Australians. *Nursing Inquiry*. 2011.
64. Taylor K, Smith J, Dimer L, Ali M, Wilson N, Thomas T, et al. "You're always hearing about the stats ... death happens so often": new perspectives on barriers to Aboriginal participation in cardiac rehabilitation. *Medical Journal of Australia*. 2010;192(10):602-.
65. Nagel T, Thompson C. Aboriginal mental health workers and the improving Indigenous mental health service delivery model in the "Top End". *Australasian Psychiatry*. 2006;14(3):291-4.
66. Newman C, Butow P, Knight R, McMillan K, Treloar DC, Kippax S, et al. Cancer and Aboriginal people in Australia: A review of the literature. *Critical Public Health*. 2008;18(1):65-75.
67. Croager EJ, Eades T, Pratt IS, Slevin T. Impact of a short, culturally relevant training course on cancer knowledge and confidence in Western Australia's Aboriginal Health Professionals. *Australian and New Zealand Journal of Public Health*. 2010;34(s1):S76-S9.
68. Shahid S, Bleam R, Bessarab D, Thompson SC. Research" If you don't believe it, it won't help you": use of bush medicine in treating cancer among Aboriginal people in Western Australia. *Journal of Ethnobiology and Ethnomedicine*. 2010;6(18).
69. Dwyer JM, Lavoie J, O'Donnell K, Marlina U, Sullivan P. Contracting for Indigenous Health Care: Towards Mutual Accountability. *Australian Journal of Public Administration*. 2011;70(1):34-46.
70. Underhill C, Bartel R, Goldstein D, Snodgrass H, Begbie S, Yates P, et al. Mapping oncology services in regional and rural Australia. *Australian Journal of Rural Health*. 2009;17(6):321-9.