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Lung cancer in rural and remote Aboriginal and Torres Strait Islander
communities in Queensland:

Awareness and identifying health needs in a cultural context

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Abstract

Background

Aboriginal and Torres Strait Islander peoples are nearly twice as likely to receive a diagnosis of lung cancer and twice as likely to die from their lung cancer as non-Indigenous Australians. Studies have shown Aboriginal and Torres Strait Islander peoples with lung cancer are less likely to receive the full range of cancer treatments and this can potentially contribute to poorer lung cancer outcomes. Remoteness of residence, culture, health literacy and difficulty accessing appropriate lung cancer diagnostic treatment and support services are thought to be factors which influence people's decisions to seek cancer care, and commence or complete treatments.

Aims

The aim of this research study is to

- survey the level of lung cancer awareness in Aboriginal and Torres Strait Islander communities.
- identify cultural influences on health beliefs, health service utilisation and resources that contribute to barriers for the early diagnosis and treatment of lung cancer.
- identify where knowledge gaps for health professionals exist in the current pathway for suspicious lung cancer which potentially impact on access to health services.

Method

Using a mixed method research design, interviews were conducted in three Aboriginal communities involving three target population groups (1) patients referred for medical treatment with symptoms suspicious of lung cancer or confirmed lung cancer, (2) Indigenous health workers, and (3) Indigenous community members aged 18 years and over. Demographics, current health status, access to and utilisation of health services were analysed by frequency distributions and cross tabulated with age, education attainment, socio-economic characteristics, cultural influences, lung cancer awareness and knowledge. Themes which arose from the narrative responses were analysed and merged with the quantitative data to further validate and assess relationships.

Results

Fifty-one community members aged 18 years and older, 14 Indigenous health workers and two patients were recruited. One patient was from an outer regional community (referred to as non-urban) and one patient was recruited from a major city (referred to as urban).

Of 51 community members and 14 Indigenous health workers 46 (90%) and 14 (100%) respectively cited smoking as the cause of lung cancer. Nearly 80% of participants would seek health care early if they developed symptoms considered a warning sign. All participants use conventional medicine when they are ill and over 65% of community participants have a regular general practitioner (GP). Participants access traditional medicine or other alternative treatments but not in place of conventional medicine.

Culturally targeted health information were preferred by 25 (49%) community participants and 10 (71%) Indigenous health workers however 26 (51%) community members, 4 (26%) Indigenous health workers and one patient did not think it important to them personally that the resource was culturally targeted. Of 51 community participants and 14 Indigenous health workers 29 (83%) and 8 (73%) respectively found generic health resources received were somewhat to extremely useful in meeting their information needs.

The two patients recruited had similarities in their lung cancer journey. Both needed to leave home to access radiation treatment and also used traditional medicine complementary to prescribed cancer treatment.

A small proportion (15%) of participants reflected that there should be improved communication between patients, families and health providers and 14% believed Indigenous health workers could be more involved in preventative health and health promotion in the community. Indigenous health workers believed a lung cancer training resource would be helpful to increase their knowledge of the pathway a patient would follow for a lung cancer diagnosis.

Conclusion

The awareness of lung cancer risk factors and early diagnosis and treatment in Aboriginal and Torres Strait Islander communities are very important strategies to improve the lung cancer disparity between Indigenous and non-Indigenous Australians. Health professionals involved in the care of the lung cancer patient including Indigenous health workers need adequate resources to ensure the patient is supported through the journey from diagnosis, treatment and follow-up.

Culturally targeted health information can raise health literacy and sometimes aids in changing health behaviours, however, generic health information can also be effective for Indigenous Australians. This study found the use of culturally targeted versus generic health information was largely a personal choice and not necessarily associated with level of education or culture.

The Aboriginal and Torres Strait Islander culture (e.g. traditional medicine practices) marginally impacted on access to health care for participants of the research. Research participants did not choose traditional medicine over conventional medicine and attend the hospital or GP when ill.

Sub-optimal communication between doctors, local and regional health services, Indigenous health workers and patients was a common issue raised by participants from all communities. Effective, communication processes between health professionals and health services involved in the care of the Indigenous lung cancer must be sustained if lung cancer awareness strategies are to be successful in helping to improve lung cancer outcomes.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Publications during candidature

Abstracts accepted during candidature-

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Contributions by others to the thesis

I developed the research protocol, research design, research instruments and managed the ethical processes required. My academic supervisors, Professor Kwun Fong, Associate Professor Rayleen Bowman and Associate Professor Ian Yang have assisted me by providing feedback, suggestions, editing and proofing of written work and academic advice as required.

In conjunction with my advisors, I determined the study situation, population sample, and developed the interview schedules using pre-developed validated questionnaires which I modified to suit the aims of the research enquiry. The questionnaire used as the template for the interview schedules was developed by Ms Alison Hanks as part of her Bachelor with Honours research project which compared the lung cancer journey of urban and non-urban patients to a tertiary referral centre.

I approached the necessary Aboriginal Councils to seek support and permission to conduct research, managed the Human Research Ethics Committee (HREC) processes in two different Hospital and Health Services (HHSs) as well as the Public Health Act (QLD) 2005 (PHA) approval process and the expedited University of Queensland Medical Research Ethics Committee (UQ MREC) and finally the site specific application (SSA) approvals involving five Queensland Hospital and Health Service Research Governance Units (RGUs). This has included HREC monitoring requirements and amendments to the research protocol.

Ms Patsi Mawn, Senior Aboriginal Project Officer, Indigenous Respiratory Outreach Care (IROC) program accompanied me to communities, assisted with the recruiting and consent process.

I designed and managed the coding book for data analysis and completed the analysis myself with advice from Professor Kwun Fong.

My son, Michael Blake, assisted with the formatting of the thesis. My other son, Stephen Blake assisted with final editing and proofing providing me with an “outsider’s” perspective of the thesis content, concepts and structure.

Statement of parts of the thesis submitted to qualify for the award of another degree

None

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Lung cancer, Aboriginal and Torres Strait Islander, rural and remote communities, Queensland, health needs, cultural context

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Contents

Chapter 1: Introduction.....	1
Chapter 2: Literature review.....	6
2.1 A brief outline of Indigenous Australian population characteristics.....	7
2.1.1 The historical influence.....	8
2.1.2 Indigenous languages.....	9
2.2 Health of Indigenous Australians.....	9
2.2.1 Chronic disease in the Indigenous population.....	11
2.2.2 Closing the Gap on Indigenous health.....	11
2.3 Culture and health decisions.....	12
2.4 Reporting of Indigenous status and cancer registration.....	14
2.5 Epidemiology of lung cancer.....	16
2.6 Accessing cancer services.....	20
2.7 Health literacy and cultural appropriateness.....	21
2.8 Cancer care services.....	23
2.9 Summary.....	26
Chapter 3: Methodology.....	28
3.1 Research design.....	28
3.2 Study situation.....	28
3.3 Research instruments.....	29
3.3.1 Interview questions and relevance to research aims.....	29
3.3.2 Other instruments (See Appendices 2-4).....	31
3.4 Participants.....	34
3.5 Data collection.....	34
3.6 Study procedure.....	35
Chapter 4: Results.....	39
4.1 Participant demographics and social situation.....	39
4.2 Participant health status.....	40
4.3 What knowledge do participants have about lung cancer?.....	41
4.4 Would participants seek health care if they thought they had lung cancer?.....	43
4.5 Do Indigenous health workers understand the lung cancer pathway?.....	44
4.6 Do participants choose traditional medicine over conventional medicine?.....	44
4.7 Do participants know what support services can be accessed for lung cancer?.....	46
4.8 What are the main financial and social disadvantages when accessing medical care outside the community?.....	47

4.9 Are generic health resources rejected in favour of health information culturally designed and targeted to Indigenous Australians ?- what participants believe.	48
4.10 Are generic health resources rejected in favour culturally targeted ones? - Views of Indigenous health workers.....	53
4.11 Does the internet influence how participants access health information?.....	55
4.12 Is lung cancer a concern for participants or is another health problem more important?	56
4.13 How do participants view health services?.....	57
4.14 The patients' experience of their lung cancer journey.....	61
Chapter 5: Discussion.....	67
5.1 Lung cancer awareness: risks and symptoms.....	67
5.1.1 Indigenous health workers and awareness.....	68
5.1.2 Low incidence of lung cancer in communities	68
5.2 Health information.....	69
5.3 Access to health services and information.....	72
5.4 Influences on health care decisions	73
5.4.1 Stigma and nihilism	75
5.4.2 Patients need support to complete treatment	75
5.4.3 Health promotion is important.....	76
5.4.4 Influences on accepting treatment	76
5.5 Health priorities	77
5.6 Improving the lung cancer diagnosis and treatment pathway	78
5.6.1 The role of the lung cancer multidisciplinary team.....	79
5.7 The patient journey	80
5.8 Non-Indigenous rural and remote lung cancer outcomes	81
5.9 Assumptions and limitations	83
6. Conclusion.....	88
6.1 Recommendations	91
References	94
Appendix 1: Questions used for the interviews.....	102
Appendix 2: Flyer.....	115
Have you an hour spare to help your community?.....	115
Are you aware of the effects that lung cancer has on your community or family?.....	115
Appendix 3: Participant information sheet.....	116
Appendix 4: Participant Consent Form	118
Appendix 5: Clinical Cancer Care Framework	122

Appendix 6: Lung Cancer Clinical Care Framework	123
Appendix 7: Examination Lung Cancer Pathway of Care.....	124

Tables

Table 1: Age standardised rates for incidence, mortality, hospitalisation and 5 year lung cancer survival in Indigenous Australians	17
Table 2: 5 year crude survival by Indigenous status New South Wales, Queensland, Western Australia and the Northern Territory 1999-2007.....	19
Table 3: Relative survival of lung cancer by Indigenous status, Australia, 2001-2005 age adjusted to age distribution of Indigenous cases for lung cancer.....	19
Table 4: Proportion of Indigenous Lung Cancer Patients accessing health services in Queensland 2010-2011	25
Table 5: Key characteristics community members N=51	39
Table 6: Key population characteristics Indigenous health workers N=14.....	40
Table 7: Smoking behaviour community participants N=51.....	40
Table 8: Knowledge of lung cancer.....	42
Table 9: Lung cancer warning signs.....	43
Table 10: Community members and Indigenous health workers views on traditional medicine or alternative treatments.....	45
Table 11: Knowledge of support organisations	46
Table 12: Knowledge of support service or health discipline	47
Table 13: Community participants comment on generic versus culturally targeted health information	49
Table 14: What is the best style of media- DVD, poster, pamphlet? What community members believe.....	52
Table 15: Preferred type of media to inform patients – Indigenous health worker views.....	55
Table 16: Communication, service location and transport impact on patient experience	57

Figures

Figure 1: Health conditions as reported by community	41
Figure 2: Usefulness of generic health information to the participants.....	49
Figure 3: Preference for culturally targeted information: community participants by age and education.....	50
Figure 4: Culturally targeted information not important: community participants by age and education.....	51

Figure 5: More likely to use culturally targeted resources if available: community participants by age and income	51
Figure 6: Culturally targeted information not important: community participants by age and income	52
Figure 7: Are Indigenous health workers more likely to use culturally targeted resources over generic?.....	54
Figure 8: Do patients find generic resources helpful? - Indigenous health workers	54
Figure 9: Do participants learn about personal health on the internet?	56
Figure 10: Do Indigenous health workers use the internet to inform others about health?.....	56

List of Abbreviations

Abbreviation	Full Name
AODS	Alcohol and Drugs Service
ATODS	Alcohol Tobacco and other Drugs Service
AATSIHS	Australian Aboriginal and Torres Strait Islander Health Survey
AIHW	Australian Institute of Health and Welfare
HREC	Human Research Ethics Committee
HACC	Home and Community Care
IROC	Indigenous Respiratory Outreach Care
IHW	Indigenous Health Worker
IHLO	Indigenous Hospital Liaison Officer
MDT	Multidisciplinary Team
MREC	Medical Research Ethics Committee
PHA	Public Health Act
QCCAT	Queensland Cancer Control Analysis Team
QHPADC	Queensland Hospitals Patient Admitted Data Collection
QOOL	Queensland Oncology Online
OASys	Oncology Analysis System
RGU	Research Governance Unit
SSA	Site Specific Application

The term Indigenous or Indigenous Australian will be used interchangeably with Aboriginal and/or Torres Strait Islander people throughout the thesis.

Chapter 1: Introduction

Lung cancer is the most common cancer and cause of cancer death in the developed countries of the world.¹ In Australia, lung cancer ranks as the fifth most common cancer behind prostate, colorectal cancer, breast and melanoma.² Lung cancer in Australia is also the most common cause of cancer death.³

The incidence, mortality and hospitalisation rates for lung cancer are higher in the Indigenous population than the non-Indigenous population of Australia.³⁻⁵ Cancer incidence rates including lung cancer are higher yet for Indigenous Australians living in non-urban, low socio-economic areas.^{3, 4} Indigenous Australians are more likely to present at an advanced stage of disease and face lower survival rates than other Australians.^{6, 4, 7-9}

It is important that health providers identify reasons and seek solutions to the lung cancer disparity experienced by Indigenous Australians. It is known remoteness of residence (making access to services difficult), cultural beliefs and the level of health literacy potentially contribute to health disparities.⁹⁻¹¹ The health disparities are thought to be further influenced by marginalisation and racism, a consequence of colonisation, which has led to lower social determinants for the Indigenous Australian population.^{9, 12-14}

The aim of this study was to

- survey the level of lung cancer awareness in Aboriginal and Torres Strait Islander communities.
- identify cultural influences on health beliefs, health service utilisation and resources that contribute to barriers for the early diagnosis and treatment of lung cancer.
- identify where knowledge gaps for health professionals exist in the current pathway for suspicious lung cancer which potentially impact on access to health services.

The study was initiated as a result of a larger project undertaken by The Indigenous Respiratory Outreach Care (IROC) program in partnership with Lung Foundation Australia and General Practice Queensland (trading as CheckUp Australia).

The IROC program provides respiratory outreach services to Indigenous Queenslanders living in rural, remote and urban settings. The program is administered by the Aboriginal and Torres Strait Islander health unit and funded under the National Partnership Agreement on Closing the Gap in Indigenous health.^{15, 16}

The circumstances of where people are born, how they grow, live, work and age are an important way of measuring positive and negative influences on health^{17, 18} People can suffer chronic illnesses as a result of living in a sub-optimal social situation, experiencing racism, marginalisation or by participating in behaviours deemed risky.^{18, 19} In addition, access to health services can be negatively influenced by language barriers, lack of cultural security, spiritual beliefs, a low education level and low health literacy.^{10, 20, 21} Therefore, understanding the culture, history and social determinants of Indigenous Australians is important when researching Indigenous health issues including those of lung cancer.^{9, 13, 22, 23}

Indigenous Australians have a lower life expectancy than non-Indigenous Australians and experience poorer health and health outcomes.^{9, 22, 18, 24} In 2008, the Federal Government endorsed Closing the Gap program with a target finish of 2030 to address the disparities of health and social determinants.^{16, 22} Closing the Gap funding has enabled research into health areas including lung cancer to understand the causes and find solutions to the health disparity affecting Indigenous Australians.

The Closing the Gap program relies on the appropriate collection of Indigenous data which in turn relies on the self-identification of Indigenous status.^{22, 25} Accurate recording of Indigenous status provides a baseline for health data sets to ensure health determinants continue to improve.²⁵ However, Indigenous status statistics are assumed to be underestimated as not all Indigenous Australians will identify or be identified.²⁵ There are varied reasons for this which might include past experiences that had a negative impact on a person by identifying; not understanding the importance of identifying or feeling offence by being asked about Indigenous status. In some cases, people might incorrectly classify a person's Indigenous status on "how they look" or "where they live".²⁵

Indigenous Australians hold the view that health is a sense of wellbeing which involves culture, connection to the land, the environment, community, personal relationships and tradition.²⁶ The ability to carry out social and family responsibilities is a measure of good health and this is thought to be a reason why medical treatments such as surgery may be declined.^{17, 26, 27}

To better understand the causes of lung cancer disparities between Indigenous and non-Indigenous Australians a literature review was undertaken. The literature review provides the reader a brief outline of history, culture and social determinants of Indigenous Australians. It explores how health is viewed in Indigenous populations and how culture can influence decision making. Conceptualising issues faced by Indigenous Australians since colonisation can help explain why they continue to experience poor health and health outcomes including lung cancer outcomes. Epidemiology studies the pattern of disease and therefore a section of the literature review compares the incidence, mortality and survival statistics of lung cancer in Australia and Queensland then Queensland's Indigenous population.

Theoretical frameworks which support this research mostly encompass the social sciences specifically, health behaviour. Health behaviour theories frame the choice of methodology from why people choose to participate in research through to understanding how people's culture and attitudes influence their health decision making.²⁸

For an example, life threatening illnesses such as lung cancer can unconsciously or consciously raise thoughts of death.²⁹ The 'terror management theory' suggests that the threat of death can initiate behavioural responses and causes people to face their own mortality.³⁰ Unconsciously, a person facing the threat of death may activate self-preservation behaviour and retreat to the protection of culture or on a conscious level, increase healthier behaviours to reduce the risk of death.²⁹

The 'health resistance theory' suggests some people "actively resist health messages aimed at them by health professionals" because they might find them irritating or view them as nothing more than people pushing their own health beliefs.²⁸ The preconceived ideas can result in indifference towards health awareness, promotion, programs or other initiatives.²⁸ People may also react to health information as a threat to freedom or make ill-informed decisions through justifying their risky health behaviours.²⁸ This is partly demonstrated by health information on tobacco use which has caused a degree of stigma and nihilism for those people who continue to smoke.³¹

Stigma and nihilism have also been shown to influence people's decisions to seek medical help for symptoms of lung cancer.³¹ People may worry that smoking will preclude them from treatment or they will be treated negatively by health professionals.³¹ There is a divide between lung cancer patients who smoke and those that don't; the belief that the former being deserving of their cancer and the latter not.³¹

In consideration of the theoretical frameworks on health behaviour, the choice of mixed method research was the most appropriate for this research study. People will react differently dependant on their past experiences, their own personal views on health including fears and misconceptions. The use of qualitative data to supplement quantitative data can provide a deeper understanding of a research enquiry rather than using one method in isolation.³²

Using a mixed method research design, semi-structured interviews were conducted with community members, Indigenous health workers and people with lung cancer in three Aboriginal discrete communities. Data was collected on demographics, lung cancer awareness, social situation, access and experience of health services, use of traditional or alternative treatments and health information resources. The enquiry on health information resources was to learn more about the use of health resources reinforcing the need for lung cancer culturally targeted information.

When research or a project is undertaken within Indigenous populations it is very important that the community be included at every level of the research.^{14, 17, 33} Engaging the community enables a sense of ownership and will facilitate the research or project's success.^{14, 17, 33} Communities who participated in this study were visited prior to ethics submissions and invited to be involved in the research design, activities and feedback.

The decision on which Indigenous communities were able to be invited to participate in the research was somewhat restricted. Communities had to be a part of the IROC program, have a substantial Indigenous population and situated in an outer regional, remote or very remote area. This restriction had an effect on the sample size. Gatekeeper approvals for the research required from the Aboriginal or Torres Strait Islander councils and the complex ethics processes are detailed in Chapter 3. Seeking support from a Torres Strait Islander community did not eventuate and therefore there was minimal representation in the research by Torres Strait Islander people.

Descriptive statistics are used to display the research results and also compare results across communities. This is important as Australian Indigenous communities are not the same.^{13, 33} There are cultural differences, historical differences, language and socio-economic differences.^{13, 33} A multi-centered research design was used to explore if participant responses varied across communities or if common themes arose. Involving more than one site gave strength to the research, helped mitigate the small sample size and contributed to current knowledge in the area of lung cancer in rural and remote Queensland Indigenous communities.

The findings of the research reveal similarities in responses across communities and participating groups. Most significant was the preferences of culturally targeted versus generic health information which showed individual choice played a major role. Indigenous health workers make a valuable contribution to the health and wellbeing of Indigenous Australians and should be equipped to deal with patients undergoing investigations for suspected lung cancer. Communication was also a significant factor which impacted on how people feel about health services.

There may be other unknown or less distinct influences Indigenous Australians experience which contribute to the disparities of lung cancer incidence, mortality and survival between Indigenous and non-Indigenous Australians. Addressing causes and implementing health service changes will to a certain extent improve lung cancer outcomes for Indigenous Australians but we must continue to explore other novel approaches to the problem.

Chapter 2: Literature review

This literature review aims to provide a broad view of how history, culture and socio-economic characteristics have impacted the health of Indigenous Australians and explored disparities experienced by Indigenous Australians with cancer. Indigenous Australian's culture, health and social determinants differ from community to community. Studies on overall health as well as literature on cancer or lung cancer are reviewed.

A literature search relevant to themes of the literature review was conducted using the following electronic databases:

- Medline
- Jane
- CKN Discover
- Google scholar

Key words for inclusion criteria: lung cancer and/or lung neoplasm and epidemiology and burden and Aboriginal and Torres Strait Islander and rural or remote or regional and culture* or beliefs or tradition* and health and programs or resources and /or health promotion and/ or intervention and Queensland and/or Australia.

Other literature and resources searched included

- Queensland Health (QHEPS) <http://qheps.qld.health.gov.au>
- Queensland Cancer Control Analysis Team <https://www.qccat.gov.au>
- Australian Bureau of Statistics www.abs.gov.au
- Cancer Australia www.canceraustralia.com.au
- Lowitja Institute www.lowitjainstitute.org.au
- Health Informit www.healthinformit.ecu.edu.au
- Menzies School of Health Research www.menzies.edu.au

- State Library of Queensland www.slq.gov.au
- University of Queensland Health Sciences Library, Herston and The Prince Charles Hospital Library <http://www.library.uq.edu.au>
- Research Gate www.researchgate.net

Published and grey literature not specific to lung cancer or Indigenous Australians, was also reviewed if they addressed subjects on health information and access and utilisation of health services for people living in rural and remote areas. A small proportion of articles involving research in other Indigenous populations of the world were included. Articles considered of high value for this review were studies conducted in Queensland, involved Aboriginal and Torres Strait Islander peoples and addressed cancer or lung cancer.

2.1 A brief outline of Indigenous Australian population characteristics

Population characteristics such as geographical spread, population size, age structure, religious affiliation, education, language, as well as social determinants, can shape people's standard of health and affect their access to health services.^{17, 18} Indigenous Australians experience lower social determinants on every measure than non-Indigenous Australians.²³

A group of non-government organisations which included Oxfam, GETUp and Australians for Native Title and Reconciliation (ANTAR) started an advocacy campaign to raise awareness of the Indigenous social determinant gap.²² The campaign led to the 2008 Closing the Gap program which was supported by all major political parties of the day.²² The Australian Government then headed by Prime Minister, the Honourable Kevin Rudd MP, endorsed the program with a target finish of 2030.²² The aim of Closing the Gap is to improve Indigenous Australians key health and social determinants within a generation so their life expectancy reaches equality with other Australians.¹⁴

Life expectancy was nearly twenty years less for Indigenous Australians when Closing the Gap program was implemented and by 2011 was 11.5 years less for Indigenous males and 9.7 years less for Indigenous females.^{12, 22, 24, 34} Many Indigenous Australians live in remote areas and comprise only 3% of the total Australian population.³⁵ One percent of the Aboriginal and Torres Strait Islander people reside in major cities, 2% in inner regional areas, 5% in outer regional areas, 12% in remote areas and 45% in very remote areas.³⁶ Queensland's estimated population at the 2011

Census was 4,332,739 people of which 188, 954 or approximately 4%, identified as Aboriginal or Torres Strait Islander or both.³⁵

Thirteen percent of Indigenous Queenslanders live in Deed of Grant in Trust communities (DOGITS – “State owned land granted in trust for the benefit of Aboriginal people or for Aboriginal purposes”) which are usually located in more remote areas.³⁷ An estimated 15% of Queensland’s 24,386 Torres Strait Islander peoples live in the Torres Strait region. Torres Strait is located on the tip of the mainland of Cape York and islands between the Cape York Peninsula and Papua New Guinea.^{5, 35}

From the 2011 Census data, the median age for Indigenous Australians was 21 years compared to 37 years for non-Indigenous Australians. In Queensland, the median age of the Indigenous population is 20. Indigenous Australians, therefore, have a younger age structure than non-Indigenous Australians with 38% of the population aged 15 years or less. Age structure has an impact on health statistics and must be considered when comparing age related variables to ensure comparison data is a true representation of Indigenous and non-Indigenous Australian health issues.^{38, 39}

2.1.1 The historical influence

Colonisation of Australia by the British in 1788 and subsequent government policies have resulted in the Indigenous struggle to achieve equality with non-Indigenous Australians.¹³ Over two centuries have passed since the British arrived in Australia or as sometimes referred to as the ‘*invasion*’.⁴⁰ Over this time Indigenous Australians were forcibly removed from their lands and separated from their families which resulted in the loss of traditional ways and values.^{13, 23}

Colonisation is seen to have caused most of the adversity faced by Indigenous Australians. Colonisation has resulted in a loss of identity and pride, lower social determinants, poor health and a level of racism and marginalisation in Indigenous Australians.¹³ Prior to colonisation, Indigenous Australians had a strong culture based on kinship, connection to land and spiritual beliefs. Although Aboriginal and Torres Strait Islander peoples are Indigenous to Australia they have different histories but have faced similar challenges in areas of inequality, racism, dispossession of land and loss of culture.^{13, 23}

Before the British arrived, Australian Aboriginals lived in small semi nomadic groups and there were over 500 different languages.^{13, 23,37} Torres Strait Islander peoples lived in small island communities. The increasing contact with Europeans changed their culture considerably. Christian missionaries influenced their lives and destroyed their traditional cultural religious practices.¹³ The Australian Bureau of Statistics reported in 2010 that from the 2006 Census, 73% of Indigenous Australians identify as Christian and 1% identify with the Indigenous traditional religion (mostly from rural and remote regions of Australia).³⁸

2.1.2 Indigenous languages

The 2011 Census reports that 83% of Indigenous Australians speak English as their first language and 11% speak an Indigenous language at home. Indigenous languages spoken as first language are highest in the Arnhem Land and Daly River region followed by the Western Desert.⁴¹

Although more young Indigenous people are completing year 12, there is still a significant gap in the education attainment of Indigenous Australians compared to non-Indigenous Australians. In 2008, 21% of Indigenous persons aged 15 to 64 years completed year 12 or equivalent compared to 53% of non-Indigenous persons aged 15 to 64 years.⁴² According to the 2011 Census, 37% of Aboriginal and Torres Strait Islander peoples aged 15 years and over had completed Year 12 or equivalent and /or certificate 11 or higher qualifications. Therefore, educational attainment has increased 7% from 2006.⁴¹

The demographic landscape of Indigenous Australia illustrates a diversity of factors and influences which impact on health and wellbeing. Research findings of studies conducted in different Indigenous communities may not be generalisable.

2.2 Health of Indigenous Australians

Social class or status and health outcomes are associated.^{12, 43} The more elevated people are in the social hierarchy, the healthier people can expect to be. Unfortunately, Indigenous peoples both in Australia and other countries' usually have poorer health than non-Indigenous peoples.¹² Australian health data suggests that Indigenous Australians have worse health outcomes than other Indigenous populations of developed countries evidenced by life expectancy. However, this could be due to the fact Australia maintains very comprehensive health data sets compared to those in other developed countries^{12, 24}

The theory of people having better health the higher their socio-economic situation ('social gradient theory'), may not be so applicable in the case of the Indigenous Australian population. Experiencing adversity such as marginalisation and racism can also contribute to poorer health.¹² Conversely, social factors such as connection to land, community, kinship and culture may have a positive influence on health regardless of socio-economic status.¹² Although adversity can cause chronic stress in an individual which can then lead to disease, positive factors such as social support, self-belief, confidence and worthiness can provide resilience to developing disease.¹²

The relationship between socio-economic circumstance and health is complex.¹² Access to clean water, nutrition and housing determinants are not the only influences on achieving good health. When planning health interventions the social structure of a community and potential causes of inequities should be considered so that interventions can be targeted and designed appropriately.^{12, 18, 9}

The Aboriginal and Torres Strait Islander Health Survey (AATSIHS) conducted in 2012-2013 involved 7700 households including those in discrete Indigenous communities. The survey was answered by 5900 persons in non-remote areas and 3400 persons in remote areas.¹⁹ The survey found nearly forty percent of Indigenous Australians aged 15 years and older consider themselves in very good or excellent health and only seven percent believed their health was poor.¹⁹ Indigenous Australians are half as likely to report excellent or very good health compared to non-Indigenous Australians.^{19, 44}

Not all Indigenous Australians would face a lower standard of health than non-Indigenous Australians. Dugdale and Watlemaro (2000) argue that a minority of people within a community may have poor health and participate in risky health behaviour.⁴⁵ Within the same community there may be a larger number of Indigenous Australians who experience good health and self-esteem. Australia's overall health is not measured on the health of the poorest and nor should the health of Indigenous Australians be measured on the most disadvantaged group amongst them.⁴⁵ The findings of Dugdale's and Watlemaro's study on health statistics in an outer regional Indigenous community suggests that excess morbidity and mortality may be confined to a decreasing minority within a community. Other studies suggest the problem may lie more with family background and remoteness of residence rather than race.⁴⁵

2.2.1 Chronic disease in the Indigenous population

Smoking causes chronic disease and is a major risk factor in developing cancers including lung cancer. Smoking rates in Indigenous Australians fell 8% over the last decade, and the rate of taking up smoking also declined.¹⁹ However, Indigenous Australians are still two and a half times more likely to be current daily smokers than non-Indigenous Australians where smoking rates also continue to decline.¹⁹

Diabetes and high blood sugars also present health challenges for Indigenous Australians. The AATSIHS found these conditions were three and five times higher in Indigenous Australians over 25 years than non-Indigenous Australians.¹⁹ Circulatory disease is the highest cause of death for Indigenous Australians, followed by cancer and accidents, suicide and assaults.⁴⁴ Of all cancer types; lung cancer is the major cause of cancer death in Indigenous Australians.^{3,4}

Indigenous societies report socio-economic disadvantage, marginalisation and discrimination and so Indigenous Australians tend to participate in risky behaviours.³⁷ Psychological stress is nearly three times higher in the adult population of Indigenous Australians compared to the non-Indigenous population. Excess alcohol, illegal drug use, obesity, smoking and a sedentary lifestyle are more pronounced in the Indigenous Australian society.^{19,37}

2.2.2 Closing the Gap on Indigenous health

The Closing the Gap program aims to bring Indigenous social determinants to an equal standing with non-Indigenous Australians.²² Pholi et al. 2009, raised concerns about the Closing the Gap approach that are worthy of contemplation. Firstly, it is the government that develops the policies and sets the key performance measures to report outcomes on Closing the Gap. Failing to allow for self or collective determination of Indigenous Australians means they have limited control and power over their path.²²

Secondly, the approach used by the government in Closing the Gap is not new, and similar approaches have not worked in the past. There was a period prior to 1967 when protection and assimilation of Indigenous Australians was monitored through the collection of data.²² Pholi et al. argues that the Closing the Gap program relies too much on the data which measures how well Indigenous social determinants have improved. Therefore, if targets set by the government are not met, programs and interventions to increase Indigenous social determinants and life expectancy will

seem a wasted effort and opportunities lost on a hopeless cause.²² An ongoing conversation involving Indigenous Australia and the Federal Government on whether Closing the Gap is meeting its aims needs to be supported intelligently without political or power plays.²²

A third concern raised by Pholi et al. is the use of statistics to measure inequality in the Indigenous population. Statistics might be viewed as reducing Indigenous Australians to a “numerical problem” which is patronising and removes the will to determine and manage their own affairs. The ability of Indigenous Australians to manage their own path is what should be measured.²²

The health of Indigenous Australians is a highly complex area with wellbeing an important component. It is suggested by scholars both in Australia and overseas that conventional methods of analysing social determinant data may not reflect the Indigenous populations’ actual circumstances or how they view themselves.¹⁷

In Canada and New Zealand there are programs that engage their Indigenous peoples in the social sciences and demographic research with the aim to develop other methods of collecting and analysing data which is more relevant to the Indigenous population.¹⁷ Australia has not at this stage reassessed data frameworks relevant to Indigenous Australians. ¹⁷The limited baseline data available is also a barrier to planning strategies to improve and monitor social determinant levels in Australian Indigenous communities.¹⁷

Indigenous Australians have many cultures within one; face different types of adversity, and levels of socio-economic disadvantage. These factors all play a role in determining the health of a community and can be potentially used to develop frameworks to support the collection of Indigenous data on wellbeing.^{17, 37}

2.3 Culture and health decisions

Indigenous Australians believe good health not only involves the physical body but involves a sense of wellbeing that includes culture, connection to the land, the environment, community and personal relationships and tradition.^{23, 26} The Indigenous definition of being healthy includes the ability to continue with social and family responsibilities. Indigenous Australians might be reluctant to seek aggressive cancer treatments such as surgery or chemotherapy if they are unable to continue with personal responsibilities given the lifestyle impacts or they might view other social and economic aspects of their life as more important than health.²⁶

People's views on health can be influenced by their culture which may also influence the decision to seek health care. For example, cancer can raise feelings of shame and fear for an Indigenous Australian. These feelings can cause Indigenous Australians to avoid doctors, ignore symptoms until they are severe and not participate in screening programs.¹⁰ Therefore, we should be aiming to prevent lung cancer by raising awareness of risk factors and increasing patient support to facilitate early diagnosis and treatment.⁴⁰ Well rounded health promotion or prevention activities considerate of culture and language can help mitigate fatalistic attitudes and reluctance to seek treatments.¹¹

Health professionals who have an awareness and understanding of Indigenous Australians' culture are better equipped to provide information on cancer in a culturally sensitive, relevant manner. This potentially will increase the likelihood of patient compliance with treatment.^{10, 11}

However, while cultural awareness is said to be an important element to improving health outcomes for Indigenous Australians, understanding some cultural differences or professing to be culturally aware is not enough to effectively communicate and deliver health care to Indigenous Australians.²¹ There are another two elements to being culturally aware; safety and security. Cultural safety is also important. This might include such actions as involving family in decisions about treatment or giving time to the patient to seek permission to have treatment.²¹

Cultural security takes the concept of awareness and safety further. A health service which provides cultural security understands Indigenous men and Indigenous women do not like being grouped together (cultural awareness). The health service may have gender specific waiting rooms and exits (cultural safety).²¹ For complete cultural security the service would also provide female and male doctors, and have in place processes for staff to follow when an Indigenous Australian seeks health care.²¹ Health service organisations should support their staff to learn about the culture of Indigenous Australia and how it can impact on health outcomes.²¹

Providing cultural security as described is probably not realistic. It would be difficult for all health facilities to provide gender specific waiting rooms and exits. The likelihood that males and females could be seen by a doctor specific to their gender is also an unlikely scenario. However, there are elements of cultural security which can be addressed; understanding how Indigenous Australians view health, what family or community obligations an Indigenous Australian faces and providing health information most suited to their individual needs.

Whether an Indigenous Australian accepts medical treatment can be driven by how consent is sought. In the general population, individuals have the autonomy to consent to their own medical treatments however, in the Indigenous Australian culture, permission is required from the right person within the family network. Indigenous Australians can be expected to seek the permission of extended family or someone with authority such as an Elder. Communities might take a dim view of a person who does not follow this process of consent. The effect of seeking permission from others in the community can take time and delay lifesaving treatment.²⁰

Language and cognitive impairment can also affect health decisions and treatment uptake. If communication is reliant on family or interpreters, doctors cannot be certain that patients with language or cognitive challenges have understood enough to make an informed decision.^{20, 46}

Cultural beliefs and influences are entwined in the health care of Aboriginal and Torres Strait Islander peoples and can affect decisions to seek treatments. Increasing health literacy and understanding cultural beliefs in a health context might be a key to improving the health outcomes of Indigenous Australians.¹¹

Aboriginal and Torres Strait Islander peoples have inhabited Australia for many thousands of years but Australian society relative to history inhabits a newly developed nation.⁴⁷ We can expect Australia to continue to change in regards to population characteristics, influence from other cultures and socio-economic factors. Australia is a multicultural nation yet Indigenous Australians and other minority groups face prejudice and ongoing challenges in their lives.⁴⁸ Strategies to deliver health service commensurate with societal changes and which consider cultural differences must continue to be explored so outcomes can improve.

2.4 Reporting of Indigenous status and cancer registration

There is no global accepted definition of an Indigenous population although approximately 390 million people in over 90 countries are considered Indigenous to their country.⁴³ The United Nations believes a single definition would either be “over or under inclusive” and not make sense in all communities.⁴³ Australia and other countries have employed the process of ‘self-identification’ of Indigenous status. There is, however, a set of characteristics which is accepted as fundamental to being identified as Indigenous.⁴³

1. “Indigenous people demonstrate a historical connection to the land prior to colonisation”

2. “Indigenous people consider themselves distinct from the current population of the ancestral land”
3. “There is a distinct culture and language”
4. “The Indigenous population are likely to have a distinctive geographical spread and form a minority part of the society”.
5. “Culture has been retained”⁴³

“In Australia a person is considered to be of Aboriginal and/or Torres Strait Islander if he or she:

1. is of Aboriginal and /or Torres Strait Islander origin
2. identifies as Aboriginal and/or Torres Strait Islander
3. is accepted by an Aboriginal and/or Torres Strait Islander community”.²⁵

The accuracy of Indigenous status data can be affected by the decision of a person to self-identify.²⁵ Domestic and international studies show that people who have one Indigenous and one non-Indigenous parent will vary in their decision to identify.²⁵ A study in New Zealand found people identified as Indigenous in one circumstance and not in another especially children of individuals who marry outside their Indigenous group.²⁵ Researchers also found in New Zealand that people who married outside their Indigenous group reported better socio-economic outcomes which then had an influence on the variability to identify as Indigenous.²⁵

The Australian Bureau of Statistics (ABS) conducted a series of research projects to understand factors involved in self-identification in data collection contexts.²⁵ The ABS released a paper in 2012 outlining the views of Indigenous Australians. Factors found to positively influence the decision to self-identify as Indigenous included being proud of having an Indigenous heritage, or believing there would be a personal benefit or a benefit to Indigenous Australians as a whole.²⁵

Factors which negatively influenced self-identification was the belief that the person or their community would be adversely affected, taking offence at being asked in certain circumstances or the memory of a bad experience.²⁵ Health services acknowledge that data needs to be reliable to ensure the health outcomes of Indigenous Australians continues to improve and so the effort to increase Indigenous status reporting continues.¹⁵

Indigenous cancer incidence data is not only reliant on self-identification of Indigenous status; it is also reliant on the hospital identification of status and the accurate reporting of cancer incidence and mortality to state cancer registries.^{7, 49} Although there is a comprehensive cancer registration system

in each state of Australia it is assumed that a proportion of Indigenous Australians diagnosed with cancer are registered but their Indigenous status remains unidentified.⁵⁰

The Queensland Cancer Control Analysis Team has made headway into improving cancer registration by developing a comprehensive cancer data collection which links to many data sources including the Queensland Cancer Registry. There are ongoing efforts to improve the recording of Indigenous cancer cases.⁵¹

The “Oncology Analysis System (OASys) is a statewide clinical database which houses diagnostic, treatment and outcome data on invasive cancer reportable to the Queensland Cancer Registry and Queensland Oncology Repository”.⁵¹ OASys also ensures Indigenous status as reported is recorded. However, due to the probability that not all Indigenous Queenslanders identify as such, a level of underestimation of cancer incidence and mortality data is expected and statistics should be considered accordingly.^{15, 50}

2.5 Epidemiology of lung cancer

Over the last two decades lung cancer has remained the most common cancer and the most common cause of cancer death globally.¹ As of 2008, fifty five percent of cases occurred in the more developed countries with the highest incidence rate in Northern America and the lowest in Middle Africa.¹

In Australia, lung cancer is the fifth most common cancer and the most common cause of cancer death in both men and women.^{2, 7} Australia and New Zealand have the ninth highest lung cancer incidence when compared to other regions of the world.

Queensland is one of the fastest growth areas of Australia with the population increasing faster than the national average to 30 June 2008 due to interstate and overseas migration, an ageing population, increased births and temporary visitors.^{52, 53} The population growth has impacted on lung cancer statistics in Queensland.⁵³ Although new lung cancer cases have increased due to population growth and ageing, the actual incidence age standardised rate has decreased since 1982.⁵³

This is thought to be due mostly to the rate of male lung cancer steadily decreasing since 1982 in line with decreasing use of tobacco. However, the female lung cancer incidence rate has been gradually increasing over the same period due to the higher use and pattern of use by females.^{7, 53, 54}

Likewise, the mortality rate has also decreased for men since 1982 (73 per 100,000 men in 1982 to 50 per 100,000 men in 2009) but has increased nearly two fold for women (13 per 100,000 women in 1982 to 25 per 100,000 women in 2009).⁵³

Queensland’s lung cancer incidence rate is 29 cases per 100,000 people per year compared with the whole of Australia at 26 cases per 100,000 people per year. Globally, the incidence rate is 23 cases per 100,000 people per year. In 1982 there were 1008 lung cancer cases in Queensland compared to 2094 in 2009.⁵³

Mortality rates in Queensland are slightly higher than the Australian age standardised mortality rate. Australia shares the same mortality rate as the world (19 cases per 100,000) and in Queensland it is slightly higher at 21 cases per 100,000.⁵³

Indigenous Australians are 1.9 times more likely to be diagnosed and die with lung cancer than non-Indigenous Australians. While lung cancer is the fifth most common cancer in Australia, it is the most common cancer in the Indigenous Australian population as well as the leading cause of cancer death.^{2, 55} The higher incidence of lung cancer in Indigenous Australians is thought to be due to risk factors such as smoking, high alcohol consumption, high levels of chronic infections and living in rural and remote, low socio-economic areas.⁵⁵

Age standardised incidence rates for lung cancer over years 2004-2008 were 79.8 per 100, 000 for Indigenous Australians compared to 43 per 100,000 for non-Indigenous Australians. Mortality rates for years 2007 – 2011 also were higher for Indigenous Australians (63.6/100,000 vs. 33.2/100,000).⁵⁵ (See Table 1)

Table 1: Age standardised rates for incidence, mortality, hospitalisation and 5 year lung cancer survival in Indigenous Australians

Lung Cancer	Incidence^b 2004-2008	Mortality 2007-2011	Hospitalisation 2006-07 to 2010-11	Survival 1999-2007
Indigenous	79.8	63.6	12.3	7.4
Non-Indigenous	43.0	33.2	7.9	10.7

Source: Australian Institute of Health and Welfare (AIHW): Australian Cancer Database 2009-2007, AIHW National Mortality Database and AIHW National Hospital Morbidity Database.⁴

^b Incidence refers to the number of new cases diagnosed in the given time period

Indigenous Australians with lung cancer are less likely to survive five years past their diagnosis date than non-Indigenous Australians (1999-2007: 7.4 per 100,000 compared to 10.7 per 100,000). Hospitalisation rates in 2006-2007 to 2010-2011 for lung cancer were also higher for Indigenous Australians (12.3 per 100,000 compared to 7.9 per 100,000).⁴

Lung cancer incidence, mortality, survival rates and hospitalisation rates differ between age groups and remoteness of residence in Indigenous Australians. Incidence is higher across all age groups, remoteness areas and in both males and females compared to non-Indigenous Australians. Incidence is highest in those aged 45 years and older.⁴

Five year survival is lower after a lung cancer diagnosis in Indigenous people aged 50 to 69. Hospitalisation rates are higher in all remoteness classifications i.e. inner regional, outer regional, remote and very remote areas. Hospitalisation rates are higher yet for Indigenous Australians younger than 75 years with lung cancer.⁴

Relative survival is the chance of a person diagnosed with cancer being alive at a certain point in time compared to the expected survival of the general population. Age, gender and year of diagnosis are taken into account. Relative survival data can tell us the experience of survival of a group of people diagnosed in a specific time frame and assess the effectiveness of treatments.⁷

In Australia, fourteen out of 100 people will survive five years after receiving a diagnosis of lung cancer. The relative survival for males diagnosed with lung cancer from 2000- 2007 was 11.3 % and 15% for females.⁷ In Queensland, over the time period, 2005-2009 one year relative survival was higher in females (41.9%) than males (35.7%) and remained higher for females over a 5 year period, 15.6% and 12.1 % respectively.^{7,53}

There is a lack of life table data on Indigenous Australians which is needed to measure relative survival and so five year crude survival rates collected from Western Australia, Queensland, New South Wales and the Northern Territory were used to calculate survival of Indigenous Australians diagnosed with lung cancer over the years 1999-2007.⁷

Five year crude survival measures the percentage of people alive five years after their diagnosis date. Male and female crude survival rates for lung cancer were found to be lower for Indigenous Australians than non-Indigenous Australians. However, it is unknown how the crude survival rates

were affected given the younger age structure of Indigenous Australians who are consequently diagnosed at a younger age than non-Indigenous Australians.^{7,4}

Table 2: 5 year crude survival by Indigenous status New South Wales, Queensland, Western Australia and the Northern Territory 1999-2007

	Indigenous	Non-Indigenous
All cancers	40%	52%
Lung cancer	7%	11%

Source: Australian Institute of Health and Welfare, Cancer Australia. Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. 2013

Condon et al (2014) has also produced relative survival analysis using cause specific survival analysis of Indigenous cancer patients. The ‘cause specific survival’ like ‘relative survival’ measures the proportion of people with cancer still alive over a given time period. Using death data from national cancer registries to determine cause of death was from a diagnosed cancer; the relative survival analysis found survival to be lower for Indigenous Australians for all cancers combined and for some individual cancers.⁵⁶

The data also uncovered evidence that survival was lower for Indigenous cancer patients living in rural and remote areas than non-Indigenous patients who also resided in rural and remote areas. Indigenous cancer patients living in more urban areas also faced lower survival. The Indigenous relative survival analysis for lung cancer over years 2001-2007 was significantly lower than non-Indigenous cases (age adjusted to age distribution of non-Indigenous cases).⁵⁶

Research has also found that the survival difference for Indigenous Australians with cancer compared to non-Indigenous was mostly during the first year after diagnosis.^{6,56}

Table 3: Relative survival of lung cancer by Indigenous status, Australia, 2001-2005 age adjusted to age distribution of Indigenous cases for lung cancer

Indigenous (% of cases, 95%CI)			Non-Indigenous (% of cases, 95%CI)		
Cases	One Year	Five Year	Cases	One Year	Five Year
500	29.4 (25.4-33.5)	9.1 (6.3-12.5)	42139	43.4 (42.9-43.9)	16.7 (16.3-17.2)

Source: Condon et al: Cancer survival for Aboriginal and Torres Strait Islander Australians: a national study of survival rates and excess mortality. Population Health Metrics 2014, 12:1

Cancer incidence in Aboriginal and Torres Strait Islander populations comprises only 1% of all cancer incidences in Australia.⁵ There is evidence however, that suggests a higher incidence of fatal

cancers occurs in the Indigenous population and Indigenous cancer patients present late. These two factors contribute to the cause of poor outcomes.⁵⁶

Remoteness of residence also contributes to poor cancer outcomes but whether non-Indigenous cancer patients living in similar demographic and socio-economic circumstances have similar outcomes needs to be more fully investigated.

2.6 Accessing cancer services

Indigenous Australians living in rural and remote areas of Queensland can face challenges in accessing cancer care. This includes the whole pathway from diagnosis to treatment and follow-up. Cultural security, financial concerns, attitudes or beliefs can influence people's decisions about seeking care and treatment. These factors could explain why Indigenous Australians often present with an advanced stage of cancer.^{57, 27, 58, 59}

Language has also been shown to be a factor in treatment and survival disparities between Indigenous Australians and non-Indigenous Australians.⁶⁰ Indigenous languages are reportedly more commonly used in remote areas of Australia and more prevalent in the Northern Territory where four out of five Indigenous people live in a remote area.⁵

A Queensland study found Indigenous cancer patients were less likely to receive a range of cancer treatment, waited longer for surgery and had poorer survival than non-Indigenous patients. Indigenous patients were 1.7 times more likely to have three or more co morbidities (95% CI 1.4-2.1) at diagnosis, 1.2 times more likely to have distant metastatic disease and more likely to have regional disease than non-Indigenous patients. The presence of regional and metastatic disease can exclude patients from aggressive cancer treatments. Indigenous cancer patients were also at a 30% higher risk of cancer death despite adjusting for stage at diagnosis, cancer treatment and the presence of co morbidities.⁵⁹

A further study looking at lung cancer survival of Indigenous and non-Indigenous patients in Queensland found survival was significantly lower for Indigenous patients compared to the non-Indigenous patients (median survival, 4.3 v 10.3 months; hazard ratio, 1.48; 95% CI 1.14-1.92). Of the 158 Indigenous patients, 72 (46%) were treated with chemotherapy, radiotherapy or surgery compared with 152 non-Indigenous patients where 109 (72%) received chemotherapy, radiotherapy or surgery.⁶¹

The difference in the survival rates could be explained by the higher presence of co-morbidities in the Indigenous patients. However, although adjustment was made for co-morbidities that affected performance status and lung function the number of Indigenous patients who did not receive treatment was 35% lower than non-Indigenous patients. Low treatment rates were attributed to whether patients or general practitioners (GPs) make decisions not to consult specialists, cultural views on lung cancer or difficulty accessing lung cancer specialists.⁶¹

The presence of chronic disease which can negatively impact on Indigenous patients' access to adequate cancer treatment indicates that health education is important for health professionals to increase their knowledge in risk factors, early signs and symptoms and cancer treatments. Relevant health information suited to patients' will provide them the knowledge and confidence to seek cancer care and continue with treatments.^{56, 60}

Other reasons that may delay Indigenous Australians seeking or completing cancer care is the culture about seeking permission for medical treatment from family, Elders or others who have authority within the tribal group. As previously discussed, this consent process can take time.²⁰

Culture is affected by historical, socio-economic factors and government policy which in turn influences people's perception of health, health seeking behaviour and decision making. Health professionals need to adapt communication methods and styles to meet the needs of Indigenous Australians to enable them to make informed decisions.^{20, 34, 56}

2.7 Health literacy and cultural appropriateness

A sound education helps people develop knowledge and skills such as problem solving and reasoning.¹⁸ Health literacy is the ability of individuals to gain access to, understand and use information that improves health. Health literacy is low in people with limited education, the elderly, immigrants and prisoners.^{18, 62}

According to the Australian Bureau of Statistics in 2008, 59% of the population aged from 15 to 74 years did not have an adequate level of health literacy to be able to meet the complexity of health and health systems.⁶³ Health literacy differs from general literacy in that it represents a range of skills involving health promotion and protection, disease prevention, health care maintenance and systems navigation. Skills such as the ability to read and comprehend health information in print media, food and product labels, graphs, sign consent forms, fill out health forms and understand

rights and responsibilities is all part of health literacy.^{62, 64} Although different from general literacy, people who have a higher education level are usually more proficient in health literacy.⁶³

Health information resources are one strategy used by health units, organisations and government to help people develop their health literacy. Resources come in many forms and are targeted to different consumer and professional groups. Pamphlets, posters, DVDs, booklets, TV commercials, public health campaigns and charity drives are types of health resources available to the public. Organisations such as the Heart Foundation, Lung Foundation Australia and Cancer Australia provide information and support to both consumers and health professionals. Conferences and public forums also build health literacy.

Cultural influences on health and illness can affect how a person relates to his or her doctor and their ability to act on or understand the doctor's instructions.¹¹ Culturally targeted health information resources may help Indigenous Australians develop their health literacy by providing information that is relevant and appealing to them.

Indigenous Australians reportedly prefer visual media that is easy to read, colourful and includes pictures of local or well-known Indigenous Australians. Mediums such as traditional art, song, dance and storytelling can also be effective in the delivery of health messages.⁶⁵⁻⁶⁷ It is important, however that culturally targeted, and generic health programs and interventions are evaluated to provide evidence of what works best to deliver health messages to Indigenous Australians and minority groups who are mostly affected by low health literacy.^{11, 68}

A study in the Northern Territory evaluated dementia awareness targeted resources for Indigenous peoples that included a DVD, flip chart and poster. Indigenous patients and dementia educators found the resources were useful in raising awareness but not effective if used in isolation. No comparison with general resources was made. The flipchart was found useful to trigger discussions between the health professional and patient and patients preferred the DVD over other resources.⁶⁷

Gould et al, 2013 undertook a systematic review and narrative synthesis exploring if multimedia anti-tobacco messages should be targeted to Indigenous populations. The review reported that highly graphic media works well in delivering anti-smoking messages.⁶⁸ The review also found that culturally targeted anti-tobacco resources were preferred amongst Indigenous populations both in Australia and overseas.⁶⁸ However, an intervention such as a mass media Indigenous anti-tobacco

campaign is an expensive proposition, especially if outcomes from the financial investment would be unknown.⁶⁸

The need for more evaluation and comparison studies between generic, targeted and culturally neutral resources was identified within the review, in order to confirm which anti-smoking resources are most effective for Indigenous people.⁶⁸ The review cited one study where the Maori people of New Zealand were less responsive to culturally holistic targeted campaigns compared to generic fear campaigns.⁶⁸

Health programs and resource development are shown to be most successful if Indigenous community members are involved in their design and implementation which gives them a sense of ownership and control.^{9, 69, 70} Projects involving the development of health information resources or programs should not be implemented in a patronising way. The needs of individuals and communities need to be considered as expecting Indigenous Australians to conform to change rather than working in collaboration with them is most likely to end in failure.⁶⁹

Research and evaluation on the health information needs and the way health messages are delivered to Indigenous Australians will enable more effective health prevention and promotion strategies to be developed. Government funding for health depends on the evidence base to support the need for an intervention. Australia's population continues to evolve as a multicultural society and social determinants of Indigenous Australia are likely to improve through the commitment of *Closing the Gap* program.¹⁶

2.8 Cancer care services

There are many support services which assist patients to cope with their diagnosis of lung cancer. Allied health services such as nutrition and dietetics, physiotherapy and occupational therapy are necessary to ensure the patient remains as physically fit to be able to endure aggressive cancer treatments.

Social workers, cancer care coordinators, Indigenous health workers and Indigenous hospital liaison officers can offer support socially and help patients and families navigate the lung cancer pathway. Disciplines such as psychiatry, psychology and palliative care are important services as they further support patients through the mental anguish and treat adverse effects of cancer such as pain and depression.

Organisations such as Lung Foundation Australia and Cancer Council Queensland, Home and Community Care (HACC) also play a role in the wellbeing of patients with lung cancer by providing information and practical help.

The expanse of Queensland creates difficulties in the delivery of specialised cancer treatment services that are equitable across the population especially in more remote areas. Most rural and remote patients are required to travel to larger cities to undergo diagnosis and treatment. Supportive care can also become fragmented as patients travel back and forth between treatments.⁷¹

Queensland's health system comprises seventeen financially independent Hospital and Health Services (HHSs). Hospital and Health Services who cannot deliver certain health services are able to form service line agreements with other HHSs to ensure their populations have access to appropriate health care. Queensland Health was successful in its submissions to the Commonwealth Government Health and Hospitals Fund to have regional cancer care centres established to improve access to cancer services in rural and remote Queensland.⁷² Currently, cancer centres operate in Townsville and Cairns, located in northern Queensland. Other cancer centres within Queensland (Hervey Bay, Bundaberg and Rockhampton) are expected to be in operation by 2016.

Despite the establishment of regional cancer centres in Queensland, people in very remote areas such as Cape York or North West Queensland need to travel over a 1000 kilometres to access specialist cancer care. Indigenous Australians who live in outer regional areas can find access just as challenging as those in remote or very remote areas due to factors such as lack of public transport, culture or fear of leaving the community.

To help mitigate the lack of cancer services in outer regional, remote or very remote areas Townsville Cancer Centre initiated a model of care using telehealth in 2007. Delivering cancer care by telehealth has enabled Indigenous patients from communities in North Queensland and the Gulf of Carpentaria to receive specialist cancer care including chemotherapy which has reduced the need for some patients having to travel to Townsville or other major cities.⁷³ There are also improvements in diagnostic testing as more regional hospitals and workforces continue to expand.

Complex lung cancer surgery is available at the Townsville Hospital in North Queensland, The Prince Charles Hospital (TPCH), Royal Brisbane and Women's Hospital (RBWH) and the Princess Alexandra Hospital (PAH) in Brisbane. Private facilities also offer lung cancer surgery at Greenslopes, Mater Private and Wesley Hospitals in Brisbane.⁷⁴⁻⁷⁷ Success in lung cancer

awareness and earlier diagnosis for Indigenous people with suspected lung cancer should see an increase in surgical treatments and may provide a useful measure of the effectiveness of health programs.⁷⁷

Allied health services which support lung cancer patients or other cancer patients are limited in rural and remote Indigenous communities and are mostly on a visiting capacity. Allied health professionals who provide a service to an Indigenous community may not have the expertise required to treat cancer patients. It is important therefore that lung cancer multidisciplinary teams ensure processes are in place for patients to access the appropriate support service. This has been demonstrated as a workable model of care in Townsville through the use of telehealth.^{73,77}

A study conducted in Queensland on health service utilisation by Indigenous cancer patients concluded that patients used a range of health services while receiving treatment (Table 4). The most commonly used services were the Indigenous health worker and allied health services. The study compared gender, age, socio-economic status, area of remoteness and type of cancer. Lung cancer patients were found to use three health services on average.⁷⁸

Table 4: Proportion of Indigenous Lung Cancer Patients accessing health services in Queensland 2010-2011

Indigenous health worker	Information sources	Support services	Community services	Allied health workers/services	Others
16 (84%)	13 (68%)	6 (32%)	10 (53%)	13 (68%)	54(21%)

Source: Bernardes et al: Health service utilisation by Indigenous cancer patients in Queensland: a descriptive study. *International Journal for Equity in Health*. 2012, 11:57

Bernardes et al cited a lack of available information on non-Indigenous cancer patients' use of cancer support services apart from one study on gynaecological cancer and one on breast cancer.⁷⁸

In comparison to the gynaecological cancer patients, Indigenous cancer patients utilised more community based health services but similar levels of internet use, lower use of telephone help lines and higher use of information booklets. Physiotherapy was used more widely by breast cancer patients treated in public hospitals.⁷⁸

The study suggests there is no significant difference on health service utilisation by Indigenous cancer patients by cancer type, age, socio-economic status and place of residence but does identify the need for more research on health service utilisation by cancer patients as a whole.^{78, 79}

Cultural safety is important to Indigenous Australians when accessing health services.²¹ Many cancer support services in Queensland are concentrated in areas with a low population of Indigenous Australians.⁷⁹ Studies of 121 services found only 11 (13%) were classified as Indigenous friendly and their main support was information. A service was considered Indigenous friendly if they provided a service to 10 or more Indigenous patients in the previous year or if the service had staff designated for Indigenous Australians. Only 46% of services participated in cultural awareness training and less than 9% had consulted with an Indigenous organisation.⁷⁹ Indigenous patients identified barriers to access as lack of knowledge about the service, lack of culturally targeted health information and being too shy to use the service. Costs were also cited by the Indigenous patients as being a barrier.⁷⁹

Specialised lung cancer diagnostic services, and cancer treatment services are not easily accessible to Indigenous rural and remote communities. Socio-economic and cultural considerations add further challenges along with the need to travel for cancer treatments. These challenges can affect the Indigenous patient's decision making on accepting, commencing and completing treatments for cancer. The management of cancer requires a specialised workforce as well as specialised facilities.⁷⁷

The solution to this quandary for Indigenous Queenslanders lies in health services exploring models of care which lessen the burden of travel for diagnostic, treatment and support services whilst incorporating their culture into the service delivery.³⁴

2.9 Summary

Indigenous health is a complex area. The relationships which exist between culture, socio-economic factors, history, demography and social determinants must be considered before implementing health programs and interventions to solve health disparity.⁹ If the relationships are not considered there is a risk scarce health resources are misdirected effectively lowering the chance of successful outcomes.

Indigenous cancer patients including those with lung cancer face significant incidence, mortality and survival disparities than non-Indigenous cancer patients.⁴ There is a stigma associated with lung cancer thought to be due to public anti-smoking campaigns. The campaigns have unintentionally led to beliefs that people diagnosed with lung cancer are deserving of their fate.³¹ Death is at the forefront of people's minds when lung cancer is mentioned; the premise that lung cancer is not

curable and the belief that death is certain.²⁹ Indigenous Australians spiritual beliefs could result in stigma and nihilism being more pronounced in Indigenous lung cancer patients.

Indigenous Australians who hold with traditional beliefs could believe the lung cancer is caused by some event in the past and it is now “payback”. Spiritual beliefs which involve sorcery or black magic can be very strong in Indigenous communities.³¹ Remoteness of residence, cultural security, health literacy and difficulty accessing appropriate lung cancer diagnostic treatment and support services can also influence lung cancer outcomes.^{9, 79}

The literature review has revealed many potential barriers and influences faced by Indigenous Australians seeking health care. Lung cancer is a high fatality cancer and often is stigmatised. Indigenous Australians have poorer outcomes than non-Indigenous Australians and whether less perceptible influences exist is unknown. Cancer care providers need to identify barriers to lung cancer services to ensure health funding benefits and improves outcomes for Indigenous patients.

Chapter 3: Methodology

This study uses a mixed method research design involving three participant groups in three Indigenous communities in Queensland. The study focuses on surveying the level of lung cancer awareness, cultural influences on health decisions, use of health information resources and access to services. This chapter will describe the research design, research instruments, study situation, sample group, study procedure and data analysis.

3.1 Research design

A mixed method research approach using semi structured interviews for collecting data was the chosen design for this study. A combination of closed questions (quantitative data) and open ended questions (qualitative data) was used. This approach was considered more suitable for the population sample.

Interviews and focus groups are a good method for research where participants may have low literacy, language challenges and where sensitive subjects are being investigated. Face to face interviews were thought the most effective method of data collection given the sensitive nature of the subject and expected diverse education levels of potential participants. McGrath's study on informed consent and Shahid's study on bush medicine utilised interviews and focus groups in Indigenous populations located in the Northern Territory and Western Australia.^{20, 27} Interviewing is also useful to obtain in depth information. Being face to face with the respondent allows the researcher to develop trust. In addition, body language and non-verbal reactions can be observed to supplement information from the interview responses.⁸⁰

3.2 Study situation

Communities invited to participate in the research were considered suitable on the following criteria:

1. The Indigenous Respiratory Outreach Care Program provided an outreach service to the community.
2. The geographical location was outer regional, remote or very remote as per the Australian Bureau of Statistics ASGC remoteness classification.⁸¹
3. The communities were sufficiently distant from each other in order to provide a wide sample of geographical area, Hospital and Health Service, culture and access to health services.

3.3 Research instruments

Research instruments included the interview schedules, flyer, participant information sheet, the consent form, revocation of consent and third party authority. (See Appendices 1-4). Interview schedules were developed for the three groups and differed slightly in content according to what information was the focus of the group.

Each interview schedule was specific to the participant group and themed accordingly: Themes included:

- Demographics
- Current health status
- Lung cancer awareness
- Support services
- Financial and social impact of treatment
- Information resources
- Reflection

3.3.1 Interview questions and relevance to research aims

Patients

The interview schedule for patients was the most lengthy of the interview schedules. Its focus was on the whole gamut of the lung cancer pathway so gaps in care and the impact both socially and financially on the patient might be identified. The questions were also designed to elicit information about awareness of lung cancer (risk factors, symptoms) access to care, family responsibility and support and willingness to seek health care.

Indigenous health workers (IHWs)

The focus of this interview was on the awareness of lung cancer pathway, symptoms, risk factors and health information resources. The aim of the questions in this interview was to provide information about what would help IHWs assist their patients navigate the lung cancer pathway. Subjects addressed were lung cancer awareness, identifying risk factors, symptoms suspicious of

lung cancer, diagnosis, treatment and supportive care. The interview questions did not include personal information on current health situation or family responsibility.

Community members aged 18+ years

This interview schedule was designed to survey awareness of lung cancer, access to services, knowledge of local support services and use of information resources. Although not cancer specific, questions on access to health services and peoples perspective of the health service and its utilisation were included.

All interviews enquired about health information resources with an emphasis on preference, method of delivery and effectiveness of generic versus culturally targeted. Responses to these questions were intended to elicit information about what works best to deliver health messages and to determine whether lung cancer resources should be targeted to Indigenous Australians.

The final two questions were also common to all interview schedules. The first enquired what health issue was most important to the participant. The enquiry would help understand health priorities in the community and assess whether lung cancer is ever a concern. Communities that are unaware of the risks of lung cancer might not realise that lung cancer in their community may be a hidden problem. The other question enquired about the participant's view of the health service and how in their opinion it might be improved. The premise of this question was to obtain information to identify deficiencies in the delivery of or access to health services.

Questions regarding lung cancer awareness and health resources were based a lung cancer awareness tool developed by Cancer Research UK and similar questionnaires used in other respiratory disease surveys.⁸² These included the questions used in research conducted by Menzies School of Health Research on respiratory diseases and awareness. Remaining questions were sourced from a study comparing the lung cancer pathway of urban and rural patients in Queensland to two tertiary centres.⁸³

Due to a limited budget and time the interview schedules were tested in Brisbane. Elders from a community in Brisbane and Indigenous project officers were asked to undertake the interview to test the following:

- Flow of questions
- Length of time it took the participant to complete the interview process
- If the interview was a pleasant experience as opposed to raising anxiety levels.
- If the participant found findings from the interview would contribute to better lung cancer services or health services for the community.

3.3.2 Other instruments (See Appendices 2-4)

A community flyer was developed with the following considerations

- The flyer was designed to appeal to people’s sense of community spirit by heading the flyer with “Have you an hour spare to help your community?”
- Using familiar, informal language such as the term ‘yarn’ to depict friendliness and including a picture of the researcher.
- Explaining the purpose of research in an easy to understand format.
- Inviting the groups separately on the flyer.

The participant information sheet developed from a template within the lung cancer awareness toolkit⁸² included:

- The HREC approval number
- The title of the research study
- The names of the research team
- Sponsors and funding bodies involved in the research

Questions a person might ask when invited to take part in research followed by a short response which included essential information formed the body of the participant information sheet.⁸²

- Why have I been asked? – explains the purpose of the research
- Do I have to take part? – informs participation in the study is voluntary
- What do I have to do? – informs participant of their role
- Is my information private? – informs participant that personal details are private and data is deidentified when data collection is completed
- What happens to the information that is collected? – explains how data is used and what measures are taken to ensure confidentiality.

The participant information sheet also provided the potential participant the contact details of the researcher and independent contact so any concerns could be addressed should the need arise.

Consent forms were provided to the participant once the information sheet was read and any questions addressed. The consent form was also developed from a template within the lung cancer awareness toolkit.⁸² A third party authority consent form was included in the event a participant requested someone to speak on their behalf.

Each consent form also had the provision for revocation of consent. The revocation of consent was for participants who felt unable or unwilling to continue their involvement in the research. The revocation of consent further reinforced the voluntary nature of participation. The revocation of consent if invoked by the participant provided assurance that withdrawal from the study would not harm any relationship with the Hospital and Health Service, local health service or the Indigenous Respiratory Outreach Care program. No participant revoked consent.

3.4 Ethics

Although this research was conducted in only three Aboriginal communities in Queensland, five communities were originally given ethics approval. The ethical process involving all communities invited to participate in the research will be outlined.

The ethical process for research involving Indigenous populations is very complex in Queensland. Five communities were approached to be involved in the research and are referred to as community A, B, C, D and E to maintain confidentiality. Multicentre ethics review for general research studies is undertaken by one allocated Human Research Ethical Committee (HREC) but research involving Aboriginal and Torres Strait Islander peoples must be reviewed by individual Hospital and Health Service HRECs. In this study, two HRECs were involved in reviewing the ethics application for five communities. Each was accredited to review Indigenous research and for some communities this meant ethical approval had to be undertaken outside the Hospital and Health Service to which they belonged. The applications were also assessed by University of Queensland Medical Research Ethics Committee (MREC).

Site specific applications assess the proposed governance surrounding the research in regards to funding and costs that might be incurred by the Hospital and Health Service and are mandatory requirement for conducting research in Queensland. Site specific application (SSA) for each of the HREC approved communities is undertaken by the actual Hospital and

Health Service Research Governance Units (RGUs) in which the community is located. Therefore even though an ethics application was reviewed by an external HREC to the Hospital and Health Service area where the invited community is located, the SSA was reviewed by the local governance unit within the Hospital and Health Service area where the invited community is located.

All required HREC, SSA and PHA approvals were obtained for applications pursuant to community A, B and C. SSA approval for research to be conducted in Community D and E was unsuccessful. The approval process was halted by the inability of the research team to obtain local Queensland Health staff's required signatures. Despite negotiations with the required signatories, no final response was offered by the Hospital and Health Service. It was not possible to include the sites of Community D and Community E within the timeframe of the project and negotiations were ceased.

A Public Health Act (PHA) 2005, a requirement in Queensland when patient information for purposes of research is accessed without the patient's consent. Part of the research required patient information available through the Queensland Hospitals Patient Admitted Data Collection (QHPADC) and patient medical records available through the relevant Hospital and Health Service data custodians.

HREC approval numbers for Community A, Community B, Community C, Community D and Community E are as follows:

- HREC/13/ QTDDS/ 20 Community A and Community B
- HREC/13/QTHS/ 40 Community C, Community D and Community E
- MREC/ 2013001256 Community A Community B and Community C

SSA approval from the individual Hospital and Health Service Research Governance Units were obtained for the sites of Community A and Community B.

- Community A SSA/ 13/QCQ/28
- Community B SSA /13/QTDD/67

One RGU gave SSA approval for Community C on the provision that Indigenous Health Workers (IHWs) were not involved. A research ethics amendment was submitted to recruit the IHWs through the community flyer was eventually granted.

- Community C SSA/QTHS/220

There was a further amendment to the research protocol for an additional site which would allow an urban Indigenous patient to be a participant in the research. A local RGU approved the site specific application.

- HREC/13/QTDD/20/AM01 (amendment HREC approval number)
- SSA/14/QPCH/138 (approval from Research Governance Unit).

3.4 Participants

As the research focuses on surveying lung cancer awareness and cultural influences on health decisions, a good cross section of participants was needed. To be eligible to join the study, the participant had to identify as Aboriginal, Torres Strait Islander or both Aboriginal and Torres Strait Islander and be over the age of 18 years. Children and people who could not speak English or could not give consent were excluded.

The participant groups included:

- a. Indigenous community members aged 18 years and older.
- b. Indigenous health workers (IHWs)
- c. Indigenous patients who had been investigated for suspicious lung cancer or who had lung cancer in the past or who currently had lung cancer.

3.5 Data collection

Data for this study was collected by a combination of questions and discussion through a face to face interview after obtaining consent from the volunteers. See Appendix 1.

3.6 Study procedure

The study adheres to the Australian Code for the Responsible Conduct of Research and Protocols for Consultation and Negotiation with Aboriginal People.^{33, 84} To begin the consultation process and gain support for the research, Aboriginal shire councils were contacted by phone. A letter of introduction with details of the research was then sent to the councils' chief executive officer or mayor. Key stakeholders from the Hospital and Health Service were also contacted to inform them about the research. Stakeholders included chief executives of the Hospital and Health Service and directors of nursing of the local hospital.

The introduction letter contained the aims of the research and the benefits to the community. A template supplied for the reply letter of support asked that an appropriate community contact be assigned. Support letters or emails were received from all involved Aboriginal shire councils and Queensland Health key personnel. Communities who offered support and agreed to participate were then visited to further discuss the research proposal. The community contact at each site was given a copy of the research protocol and research instruments and invited to give feedback prior to ethics submissions.

The research study was advertised for two weeks in the community through the use of the flyer. The flyer was distributed in public areas of the participating communities.

Recruitment techniques included approaching people in the street, visiting community services such as a rehabilitation centre, employment service, community meeting places and using a snowballing method. When approaching people in the street to ask if they wished to participate in research, a simple "hello" and general chat broke the ice. People seemed curious to know what the research involved.

Community contacts and Queensland Health site contacts assisted with the logistics of the research activity including providing a suitable venue. However, interviews were generally conducted in locations where the participant felt most comfortable. Venues ranged from a room within the council offices, a hospital meeting room, community meeting places, community services, outside under a tree or in a park.

First contact with potential patient participants was to be made through an Indigenous health worker or a medical officer in accordance with the ethics approvals. Otherwise patients self-identified

through the community flyer would be approached. This was deemed the most appropriate method on cultural and ethical grounds for the recruitment of patients in order to protect privacy. There were several patients in the communities who were being treated for lung cancer at the time of the fieldwork which resulted in one patient agreeing to be interviewed. The patient did not identify themselves through the flyer but was asked to participate by an Indigenous health worker from the community. Because there was only one patient from the communities, during the course of the project ethics approval was also sought for a volunteer Indigenous patient from an urban area of Brisbane.

The consent process was carefully followed to ensure the participant was aware of their right to withdraw or not answer questions or feel pressured in any way. This was important to gain trust and not breach any ethical boundaries. It was explained to the participant that a digital voice recorder would be used for verification purposes. If the participant refused or did not look comfortable about the use of a voice recorder (observed through body language) the recorder was not used. Eighteen participants refused to have the interview recorded.

At the completion of the interview, responses were reviewed with the participant and participants then had the opportunity to ask questions. This also provided an opportunity to raise awareness on lung cancer. The interaction between researcher and participant at the end of the interview contributed to building relationships, respect and reciprocity. Completed interviews and other data were secured in a business case whilst on location in the community and in transit. All research data is now stored in a secure environment within Queensland Health for a period of 15 years.

3.7 Data Analysis

Data was analysed by frequency distributions in terms of the following

Demographic Characteristics	<ol style="list-style-type: none">1.Indigenous Status2.Language3.Age4.Income5.Education attainment6.Marital Status7.Government Support
Current Health Status:	<ol style="list-style-type: none">1.Smoking history and status2.Co morbidities
Social Situation	<ol style="list-style-type: none">1.Family responsibility and support2.Employment
Access to Medical Treatment and Support Services	<ol style="list-style-type: none">1.Referral2.GP details3.Knowledge of referral4.Symptoms5.Delays6.Number and Type of Doctors7 Location of doctors8.Diagnostic Tests9.Time to diagnosis10.Knowledge of support services11.Type of treatment sought western vs. alternate12. Use of support services
Financial and Social Impact of Treatment	<ol style="list-style-type: none">1.Financial barriers to access treatment2.Leaving community to access treatment
Information Resources	<ol style="list-style-type: none">1.Design preferences2.Effectiveness3.Use by participant

Cross tabulations were then made in respect to

1. Age
2. Education attainment
3. Socio-economic characteristics
4. Cultural influence
5. Lung cancer awareness and knowledge

At the completion of the data collection, interview schedules were sorted into communities and then participant groups. Each interview question had already been allocated a code when the schedule was being developed. This helped decrease the time needed to enter and analyse the data which was then entered into an excel spreadsheet organized by community and participant group.

If participants answers to the questions requiring a narrative response the amount of times that particular word or idea presented itself was counted. The counts were then described in percentage of the participant group. All narrative responses were categorised by issues relating to lung cancer knowledge, cultural influences and beliefs, the patient experience and access to lung cancer medical and support services. The quantitative data was kept separate from the qualitative data or narrative response data, analysed separately then findings merged to assess if there were other relationships between the responses. When all the data from the communities had been coded and entered into the spreadsheet, comparisons between communities and participant groups were made and further analysis on any similarities conducted.

Voice recordings were only accessed if there was unclear responses and validation was needed otherwise the voice recordings have been encrypted and stored on a password protected USB in a secure Queensland Health office. Participants were identified on the audio by their allocated code number. After completing the data analysis, all names and communities were removed from interview schedules with the relevant code to identify the participant remaining.

All research data and signed consent forms have been securely stored in a Queensland Health secure office.

Chapter 4: Results

The results are presented using descriptive statistics and follow the themes of the interview schedules. Research findings are organised by participant group. From a total of 67 participants there were 51 community members aged 18 years and over, 14 Indigenous health workers and two patients. Patient responses are not included in the community and Indigenous health worker data; they are displayed separately. The patients' lung cancer journeys are compared not only from an experience perspective but from a geographical one as well.

4.1 Participant demographics and social situation

Demographic information is important to ensure the population sample is as representative as possible across the communities. Participant age, income, Indigenous status, gender, education and employment status were collected.

Table 5: Key characteristics community members N=51

Gender	Female:	Male:	
	33(65%)	18 (35%)	
Indigenous Status	Aboriginal:	Torres Strait	Both
	49 (96%)	2 (4%)	0
Language spoken at home	English	Indigenous	Other
	51 (100%)	0	0
Age Bracket	<30 yrs.	31-50 yrs.	> 50 yrs.
	8 (16%)	21 (41%)	22 (43%)
Marital status	Married or defacto	Single	Divorced
	32 (61.5%)	15 (29%)	4 (8%)
Education attainment	< Grade 10	Grade 10-12	>Grade 12
	16 (31%)	25 (49%)	10 (20%)
Employment Status	Full time	Part time/casual	Not working
	26 (51%)	8 (16%)	17 (33%)
Income in \$ N=45 (6 declined to answer)	<20000	20001-40000	>40000
	18 (40%)	14 (31%)	13 (28%)

Table 6: Key population characteristics Indigenous health workers N=14

Gender	Female:	Male:	
	8 (57%)	6 (43%)	
Indigenous Status	Aboriginal:	Torres Strait	Both
	12 (86%)	0	2 (14%)
Language spoken at home	English	Indigenous	Other
	14 (100%)	0	0
Age Bracket	<30 yrs.	31-50 yrs.	> 50 yrs.
	3 (21%)	7 (50%)	4(29%)

4.2 Participant health status.¹

Community participants were asked questions on their health to determine what health conditions could take priority in the community. Questions on smoking behaviour were asked to determine if anti-smoking campaigns have had an effect on people in these communities.

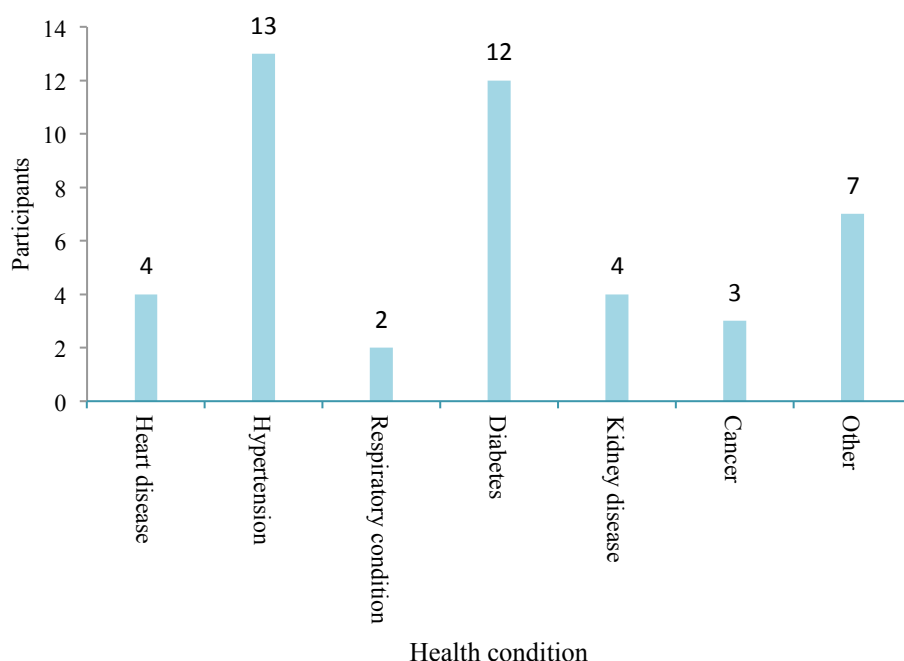
Table 7: Smoking behaviour community participants N=51

Current smoker	23 (46%)
Past smoker	15 (29%)
Never smoker (less than 100 cigarettes in their life time).	13 (25 %)
Average age smoking commenced	15.5years

The most common health condition amongst participants was hypertension followed by diabetes. Other health conditions included haematological conditions, depression and sleep apnoea.

¹ Indigenous health workers excluded

Figure 1: Health conditions as reported by community



4.3 What knowledge do participants have about lung cancer?

Community participants (N=51) and Indigenous health workers (N=14) were asked about their knowledge of lung cancer and what might cause it. As both the community participants and Indigenous health workers were asked questions in this category their responses have been displayed side by side. Questions about lung cancer knowledge required a narrative answer and themes which emerged are listed in Table 8 and the count of how many times they were raised recorded. Of the 51 community members and 14 Indigenous health workers 26 (51%) and 6 (43%) respectively said they knew nothing or not much about lung cancer. Death was mentioned by 9 of 51 (18%) community participants and 4 of 14 (28%) Indigenous health workers and smoking by 16 of 51 (31%) community participants and 4 of 14 (28%) Indigenous health workers.

Table 8: Knowledge of lung cancer

Theme identified	Number of times theme mentioned	
	Community members N=51	Indigenous health workers N=14
Little knowledge: where the words “nothing or not much” is mentioned	26 (51%)	6 (43%)
Death (kills you) where the word death or kill is used	9 (18%)	4 (28%)
Smoking where the word smokes or smoking is used	16 (31%)	4 (28%)
Disease of lung or the words it affects your lungs	6 (12%)	3 (21%)
Family or someone known has died from lung cancer	8 (16%)	0
Breathing difficulties/ lung damage	4 (8%)	1 (7%)
Spreads through body	1 (2%)	0
Information on cigarette packets	3 (6%)	0

Of 51 community participants and 14 Indigenous health workers, 46 (90%) and 14 (100%) respectively cited smoking as the cause of lung cancer. The next most common response was toxic fumes which included gas, petrol, paints, pesticide and this was cited by 4 (8%) community participants and 4 (28%) Indigenous health workers. Other causes mentioned by participants were passive smoking, genetic causes, environment, occupation, diet, pollution, alcohol, drugs, asbestos or chronic disease (asthma, emphysema, general poor health or stress).

Participants were read common lung cancer symptoms (listed in Table 9) and asked if they thought the symptom could be a warning sign of lung cancer. Of 51 community members and 14 Indigenous health workers, 100% could recognise one or more symptoms that may be a warning sign of lung cancer. Some participants could name other conditions that might cause these symptoms for example: heart attack, tuberculosis, asthma, arthritis. The participants thought however, the symptoms could be reasonably associated with lung cancer.

The symptom least considered a warning sign was ‘shoulder pain for no reason’ by 23 (45%) community participants and 8 (16%) Indigenous health workers.

Table 9: Lung cancer warning signs

Possible warning signs
Weight loss
Cough that won't go away
Cough that is worse or painful
Coughing up blood
Ache or pain in chest when breathing
Shortness of breath
Shoulder pain for no reason
Lump in neck

4.4 Would participants seek health care if they thought they had lung cancer?

Of 51 community members and 14 Indigenous health workers 35 (69%) and 9 (64%) respectively, said they would go to the doctor as soon as they could if they developed any one of the listed symptoms in Table 9. Once informed that the symptoms were possible warning signs of lung cancer but could be indicative of another condition, 40 (78%) community participants and 12 (86%) Indigenous health workers indicated they would seek health care earlier.

Participants in both groups who would wait for up to two weeks or more said their decision would be based on the persistence or severity of symptoms and the chance symptoms would resolve themselves. An Indigenous health worker who wouldn't seek health care at all cited time involved and other more pressing personal problems. One community participant said that even if they thought lung cancer was a possibility they would delay going to the doctor as it could turn out to be nothing.

Community participants were asked questions about where they accessed medical care and whether they used the Indigenous health service. When needing medical treatment 33 of 51 (65%) community participants reported having a regular GP. The remaining 18 (35%) attended the hospital for medical treatment. The Indigenous health worker service was accessed by 38 (75%) community participants with the remaining 13 (25%) participants choosing not to use the service due to privacy reasons.

4.5 Do Indigenous health workers understand the lung cancer pathway? ²

Of 14 Indigenous health workers, 4 (28%) knew of someone in their community who had been referred to a respiratory specialist with symptoms suspicious of lung cancer however none were familiar with the phrase ‘lung cancer diagnostic pathway’. To help patients navigate the sometimes complex pathway to diagnosis and treatment, it is important that Indigenous health workers have an understanding of what appointments and investigations a patient may experience.

Indigenous health workers were uncertain about what diagnostic tests a patient needed if lung cancer was suspected. Participants could not be specific about types of X-rays or scans. Of 14 Indigenous health workers 7 (50%) mentioned spirometry or “breathing test”, 5 (35%), x-ray, 4 (28%) blood test and 3 (21%) CT scan.

When asked if a training resource for Indigenous health workers would be helpful to learn about lung cancer 14 (100%) Indigenous health workers answered “yes”. The following were the most preferred style of lung cancer learning resource chosen by the Indigenous health workers.

- A learning package with easy to read information, drawings and quizzes.
- Tutorials by respiratory physicians.
- A training module which would include in depth reading and assignments.
- A combination of the above.

4.6 Do participants choose traditional medicine over conventional medicine?

Of 51 community participants and 14 Indigenous health workers 1 (2%) and 5 (36%) respectively did not wish to answer questions on the subject of traditional medicine citing cultural lore as the reason.

Of 51 community participants and 14 Indigenous health workers 100% reported they used conventional medical treatment when ill. However, of the 51 community participants and 14 Indigenous health workers 17 (33%) and 6 (43%) respectively used some form of traditional medicine at various times but not on a regular basis. Acupuncture, massage, chinese herbs and naturopathic medicines were mentioned as other alternative treatments used by participants.

² Community members excluded

Gumbi Gumbi was the most mentioned traditional medicine. Participants said they accessed it through Elders. Gumbi Gumbi a rare native plant of Australia used by participants mostly for skin conditions, sores, boils, arthritis and back pain, and internally for conditions such as sore throat or as a general detox.

Table 10: Community members and Indigenous health workers views on traditional medicine or alternative treatments

"I use Gumbi Gumbi for my diabetes treatment. I also use a Chinese drink for control of diabetes".

"You can use this for cancer as well. I think it works. I break Gumbi Gumbi into a liquid drink to help lower blood sugars".

"A person I know also goes to doctor but takes whatever it is from the trees, takes it in liquid form every morning with medications. Apparently ...is not supposed to be living so long due to cancer".

"Some people do but they still go to the doctor. Elders can't tell us anymore about traditional medicine cause culture has been lost but I know it is plants".

"You are pushing the barrier with privacy so I can't say much. If people are comfortable using alternative treatments and it works for them then it is their choice".

"Patients take over the counter medications or herbal remedies e.g. evening primrose and marijuana in different forms but maybe no tell the doctor and therefore at risk of it reacting with medications. They are likely to try anything to get relief but maybe not tell anyone. Even if the doctor asks they may not say. I have used the gum off the tree for tummy upsets and there used to be grey mud for cleaning the bowel but that's not around now".

"Traditional medicine and western medicine complement each other".

"You can get herbs from the wild but I don't do any black magic stuff. I was bought up a Christian".

"I heard an Elder say that years ago (back in the day) he made a mixture from a plant oil to cure STIs and it worked. He put in in the water to dose the hard working men (he didn't tell them)".

"Grandparents did not pass info on but the medicine man can only heal the tribal caused sickness. This is still practised today. If people use traditional medicine they may not own up to it for privacy reasons".

"Yes refusing to take modern medicine in the age group that don't trust modern medicine. They say 'no don't need this- as I am going to beach to use salt water".

"Gumbi Gumbi. I can access it from the Elders and they relay it or get it from relatives".

“Yes I know someone who uses Gumbi Gumbi for liver cleansing. My makes it and it cures everything”.

Some participants knew of very old people (over 80 or 90 years) with chronic disease using traditional medicine in conjunction with conventional treatment. Participants believed it was the traditional medicine that has extended the elderly people’s lives. Some participants thought old people were more likely to use traditional medicine and also reported knowing people with cancer using traditional medicine. They claimed that these people lived longer than predicted.

Two participants from different communities said that many elders once used traditional medicine instead of conventional medicine but believed they now go to the doctors. In one community two participants felt that the culture of using traditional medicine had been lost. Some participants said they would like to use traditional medicine but didn’t know how to access it.

There were several novel treatments which may be considered as home remedies rather than traditional medicine. These included shark fin for stomach cancer, cobwebs to bring phlegm up, garlic on toast and eucalyptus oil for colds and salt water, the use of vegemite to prevent mosquito bites, ‘Vicks’ taken internally for coughs and colds or a teaspoon of ‘metho’ to keep healthy.

4.7 Do participants know what support services can be accessed for lung cancer?

People affected by lung cancer need supportive care to help them through their journey and prior knowledge of organisations and services therefore would be beneficial. Most participants were aware of the organisations listed in Table 11. The less known organisations were Lung Foundation Australia and Cancer Council Queensland.

Table 11: Knowledge of support organisations

Organisation	Community members N=51	Indigenous health workers N=14
Home and Community Care (HACC).	18 (35%)	13 (93%)
Alcohol Tobacco and Drugs Service (ATODS).	17 (33%)	14 (100%)
Lung Foundation Australia (LFA)	12 (23%)	9 (64%)
Cancer Council Queensland. (CCQ)	15 (30%)	12 (86%)

Participants knew of most allied health or health discipline available in the community and acknowledged they were of a visiting capacity. In two communities, participants said the Indigenous hospital liaison officer role was done by Indigenous health workers. Across all communities there was some confusion between the role of psychologist and psychiatrist until an explanation was given. The participants were then able to answer with some certainty whether the service was available in their community. Several participants were unaware of the role of an occupational therapist.

Table 12: Knowledge of support service or health discipline

Support Service or health discipline	Community members N=51	Indigenous health workers N=14
Nutrition and dietetics	48 ((94%)	14 (100%)
Physiotherapy.	42 (82%)	13 (93%)
Occupational therapy	32 (63%)	10 (71%)
Social work.	42 (82%)	13 (93%)
Psychology	36 (71%)	13 (93%)
Psychiatry	35 (69%)	12 (86%)
Indigenous health worker	48 (94%)	n/a
Indigenous hospital liaison	15 (29%)	6 (43%)

4.8 What are the main financial and social disadvantages when accessing medical care outside the community?

Specialised services are not always available within close proximity to rural and remote Indigenous communities and accessing treatment can mean the patient and family can face financial and social disadvantage. Inadequate public transport, no access to a car and loss of employment income for carer's or family can add strain to the patient journey.

Of 51 community participants 33 (65%) had a current drivers licence and 38 (74%) had access to a car. Of the 51 participants 49 (96%) had accessed medical treatment outside the community at some time. 21 (41%) used their private car and 28 (57%) used other forms of transport. Travel was organised by the local health service for 24 (49%) participants.

Of 49 participants 28 (57%) were usually accompanied by a family member or carer and 25 (51%) said they or their family member had to take time off paid work. Of the 49 participants 28 (57%) would choose to stay at relatives or friends as the preferred accommodation.

For the 49 community participants who had travelled away from their community for medical treatment travel costs mostly involved food, petrol, parking and accommodation. Indigenous health workers thought a mixture of both the travel and accommodation costs e.g. meals or petrol would bear most of the burden for patients.

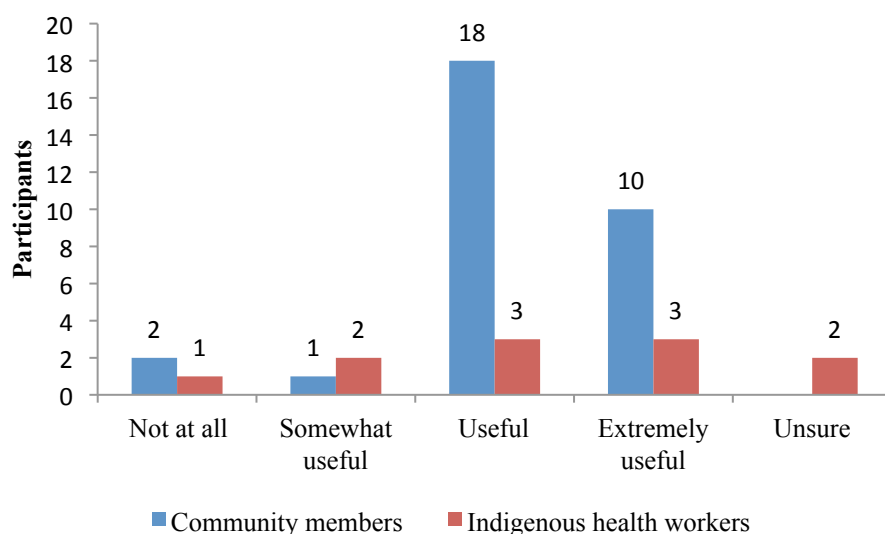
4.9 Are generic health resources rejected in favour of health information culturally designed and targeted to Indigenous Australians ?- what participants believe.

Health information comes in varied forms of media and design. The questions on information resources provided insight into how important culturally targeted resources are to Indigenous Australians and if they would access generic resources.

Of 51 community participants and 14 Indigenous health workers, 25 (49%) and 12 (86%) respectively had in the past been given culturally targeted health resources. The most common resource received was a pamphlet.

Of 51 community participants and 14 Indigenous health workers 29 (83%) and 8 (73%) respectively found generic health resources received in the past were somewhat to extremely useful in meeting their information needs (See Figure 2).

Figure 2: Usefulness of generic health information to the participants.



Of 51 community participants and 14 Indigenous health workers, 25 (49%) and 10 (71%) respectively would prefer to use culturally targeted resources whereas 26 (51%) community participants and 4 (26%) Indigenous health workers did not think it important to be given culturally targeted information as long as what they received correct information. The main theme arising from the participant quotes is the importance to tailor information to the individual.

Table 13: Community participants comment on generic versus culturally targeted health information

<i>"Just get information you need. I just want the right, correct and best information".</i>
<i>"I can read and write".</i>
<i>"Just want information".</i>
<i>"Same information put in another way".</i>
<i>"Any information is important".</i>
<i>"Should be designed for everyone".</i>
<i>"They say the same thing".</i>
<i>"I would use anyone of them- they are helpful".</i>
<i>"I will read any information".</i>
<i>"I prefer general, I do a lot of reading and I understand".</i>
<i>"I would use it no matter how it is designed. I am reasonably educated and can read and write. People who can't read may need pictures".</i>
<i>"Non-Indigenous people have cancer too. It is about the quality of the information that is important".</i>
<i>"I understand both sides".</i>

The level of education, income and age group did not appear to influence community participants’ answers on whether they would be more likely to use resources designed for Aboriginal and Torres Strait Islander peoples. The graphs on page 50 - 52 (See Figure 3 to 6) display the community participants by age, education and income likeliness of using culturally targeted resources.

Figure 3: Preference for culturally targeted information: community participants by age and education

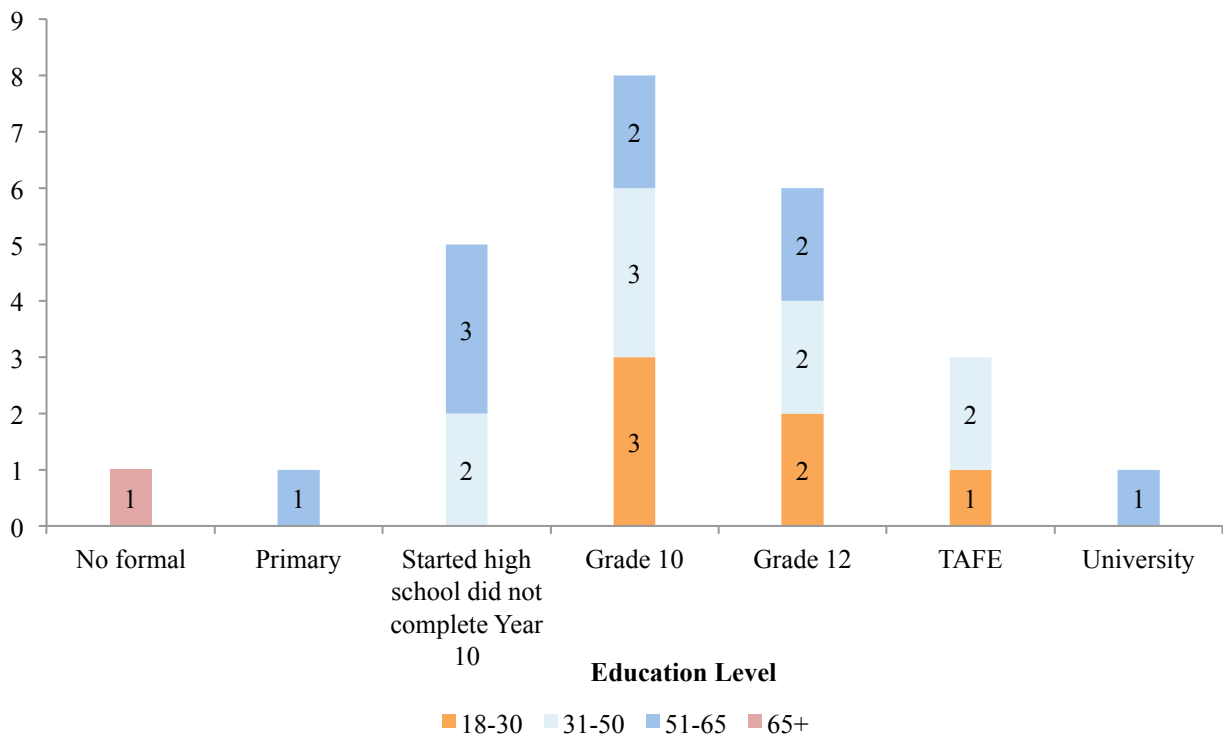


Figure 4: Culturally targeted information not important: community participants by age and education

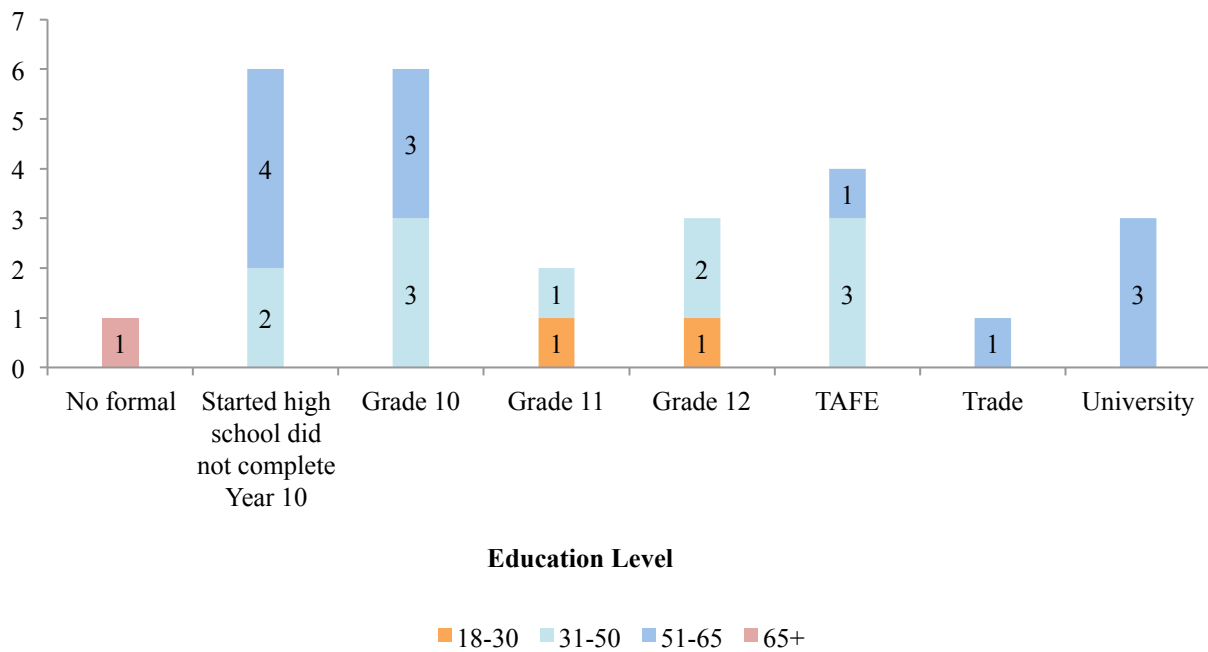


Figure 5: More likely to use culturally targeted resources if available: community participants by age and income

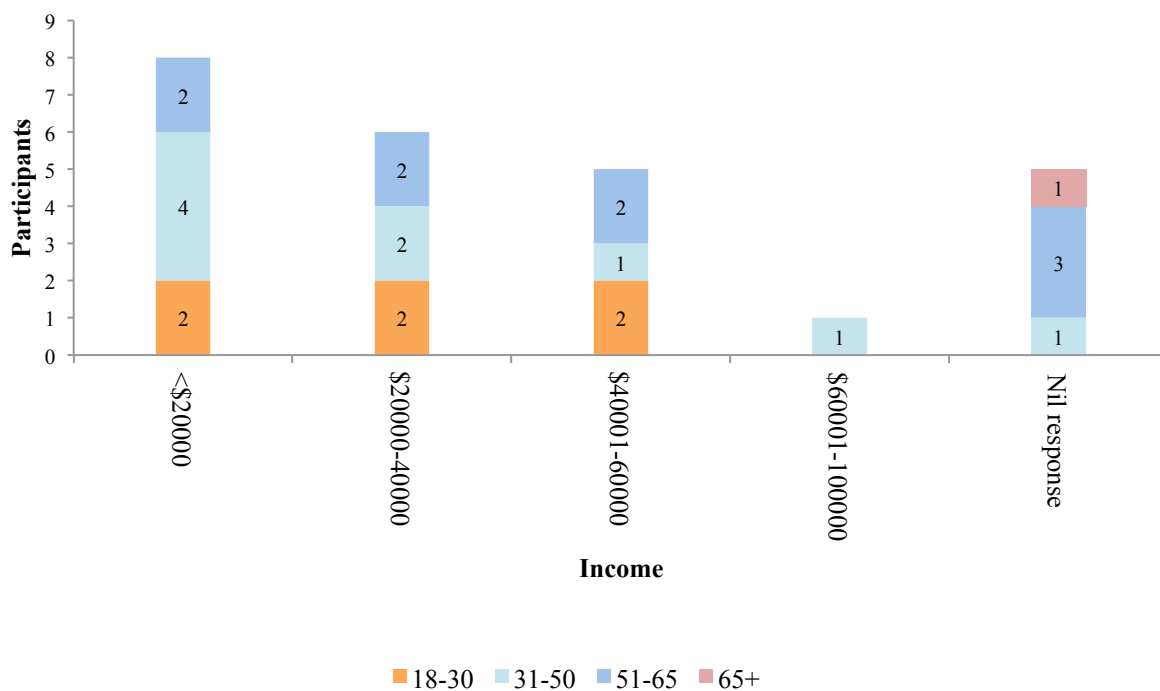
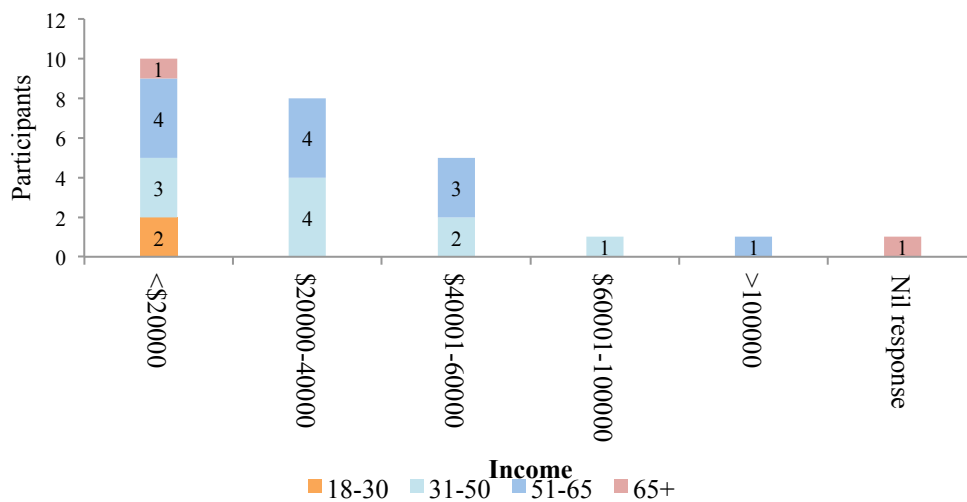


Figure 6: Culturally targeted information not important: community participants by age and income



The three styles of information resources commonly preferred by community participants were:

- Pamphlets
- DVD which tells a story
- Flipchart or booklet

Table 14: What is the best style of media- DVD, poster, pamphlet? What community members believe.

“Interesting and you get the facts”. (Information DVD)

“Poster is interesting. Pictures break it down and DVD story more interesting than DVD with information only”.

“Because it gives me a choice to decide what is more appropriate to my diagnosis”. (A variety of resources)

“You can sit down and look at poster. The DVD that tells a story is interesting. Working in the hospital for a long time you realise people can't read”.

“I like it because what I got was well presented and it explained it to you well”. (information package)

“I can relate to the internet better”.

“I don't watch DVDs I would rather sit down and read”.

“They are right there and they are bright. Grab me grab me, read me read me”. (pamphlets)

“Pamphlets are easy to carry and stick in your pocket”.

“I am not a person to muck around with DVDs”.

“Posters done in a way that draws attention - colours, indigenous people or someone you know if you want to know more”.

"I prefer a good talk with the doctor. All information is good information but sometimes pamphlets don't give enough".

"You can watch it on DVD and then it gives you all the information you need to know about and what to do". (Booklet)

"Parents can read (Pamphlets) to kids and watch DVD".

"It is how information is presented and at what time would be how you work out what is preferred. And it depends on the audience".

"Posters are big and printed out. DVD's are good. I like story ones".

"I prefer to read".

"Easy to read. Watching a DVD you have to rewind and think and interrupt people. Having something to read while someone is talking to you about it is good". (Pamphlet or booklet)

"I prefer talking. Face to face is more important to get information".

"Pamphlets are good because they are full of information and have contact numbers".

"See it, tells you what is happening". (story DVD)

"Talking one on one. Person can explain it to you face to face".

"Looking at the film I can't ask questions".

"I like talking. There should be more talking so people can open up and get answers straight away".

"I like something I can take with me and read".

4.10 Are generic health resources rejected in favour culturally targeted ones? - Views of Indigenous health workers

Questions on information resources were also asked of Indigenous health workers. The questions asked about their preferred resource for informing their patients.

Of 14 Indigenous health worker participants 11 (78%) would be somewhat to definitely more likely to use culturally target resources for patients (See Figure 7). However, 7 (50%) believed patients who received generic resources found them somewhat to extremely useful to meet their information needs (See Figure 8).

Figure 7: Are Indigenous health workers more likely to use culturally targeted resources over generic?

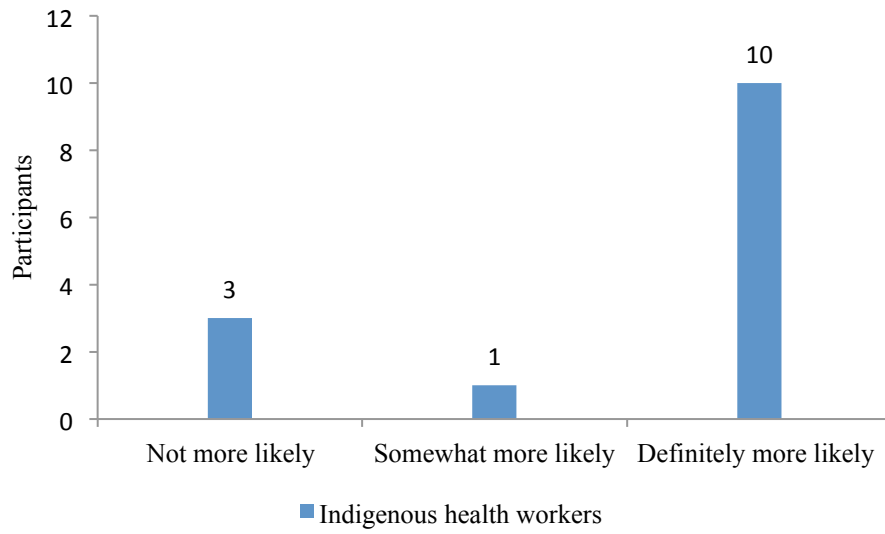
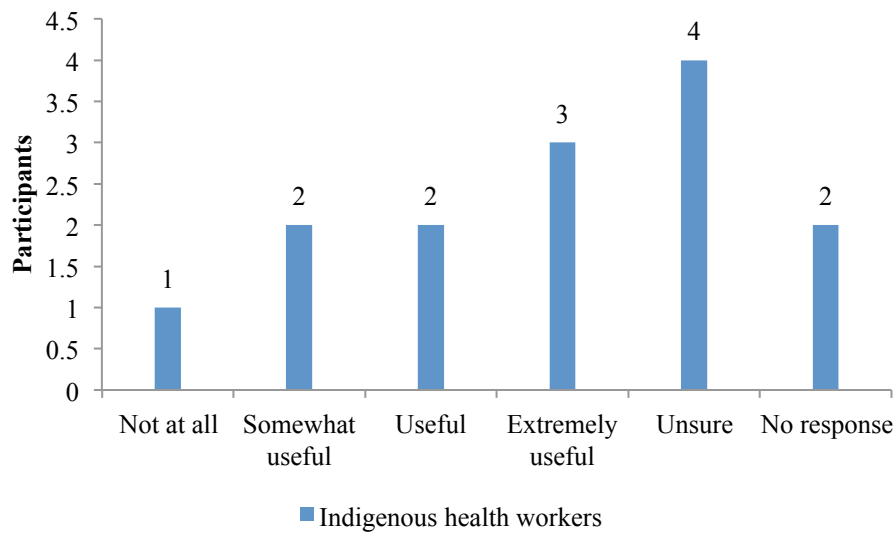


Figure 8: Do patients find generic resources helpful? - Indigenous health workers



Indigenous health workers believed the DVD which tells a story was the most useful resource for patients however the poster and pamphlet also were believed to be useful.

Table 15: Preferred type of media to inform patients – Indigenous health worker views.

“I like the internet. Good guidelines for me to give the information to clients. Our people don't like big words and lots of jargon so I can break it down to give them the relevant information”

“I like to read from a pamphlet, I can understand and learn from reading. DVD would be interesting when people have been through it and you know what to expect. - i.e. a patient experience cause they have been through the process already”.

“Whatever most helps with gaining information and understanding individual needs” (variety of resources)

“Story about what they are going through and how they are coping with disease” (patient experience- DVD)

“Full scale model of lung would be good”

“Variety is a good way to get message and information out there”

“Actually seeing it. Doing it by visual means is a better way of getting it across to them” (DVD)

“I like different things to do research”

“People learn in different ways mainly by pictures” (Pamphlets and booklets)

“Reading all information is useful”

“Different people learn different. People can like visual, audio or both”

4.11 Does the internet influence how participants access health information?

Questions on the use and access to the internet can provide information of the impact of technology in respect to health information needs. Technology advances and increased access to the internet will more than likely influence people’s preferences over time.

Of 51 community participants 7 (13%) knew of the internet but had no knowledge in how to use it however, 37 (72.5%) had some knowledge or were confident in using it. The remaining 7 (13%) participants did not know of the internet.

Of the 51 community participants 40 (78%) had access to the internet and 33 (65%) owned one or more devices to access the internet. The internet was sometimes to frequently used to learn about health by 17 (42%) of 40 community participants (See Figure 9).

All Indigenous health workers participants owned one or more devices to access the internet and 12 (86%) frequently used the internet to learn about their own health or inform others about health (See Figure 9 and 10).

Figure 9: Do participants learn about personal health on the internet?

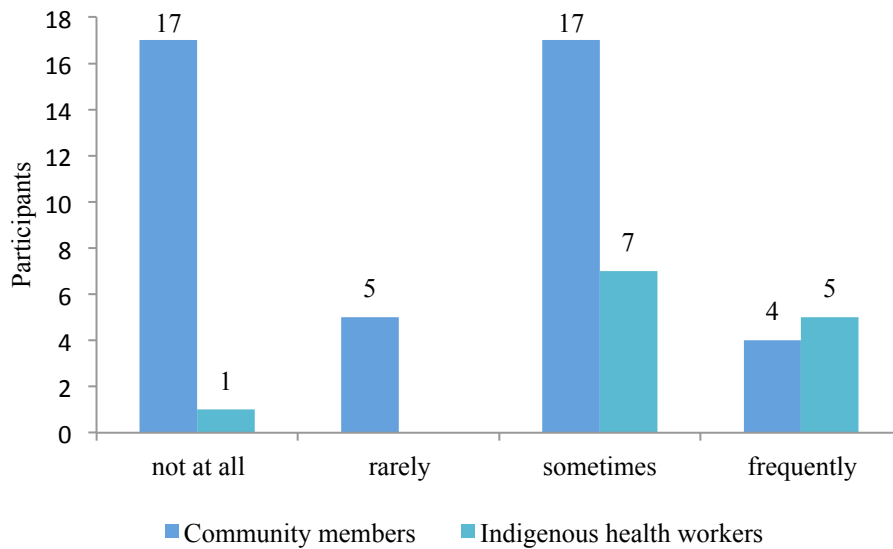
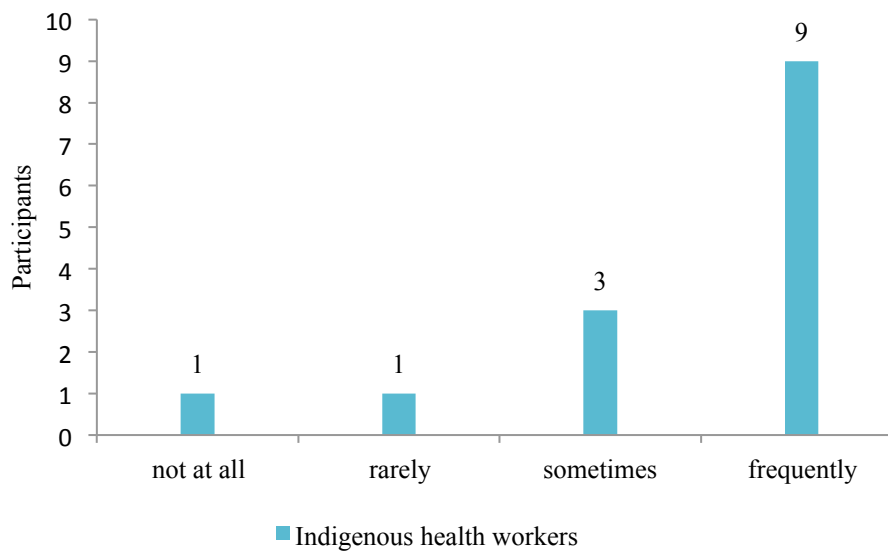


Figure 10: Do Indigenous health workers use the internet to inform others about health?



4.12 Is lung cancer a concern for participants or is another health problem more important?

Both the community and Indigenous health worker participants were asked what illness they worry most about getting or their family getting. The aim of this question was to explore the health priorities of communities. The enquiry was not focused on a specific participant group so responses are collated. Of a total of 65 participants, 24 (37%) named cancer as their main concern. The

question required a narrative answer with no prompts. Types of cancer mentioned included bowel, liver and lung. The top three other health concerns were diabetes (highest response), heart disease and general health.

Other health concerns mentioned were eye health, lupus, stroke, infections, kidney disease and dialysis, sexually transmitted infections and substance abuse.

4.13 How do participants view health services?

The final question on the interview schedule asked participants about their experience of health services and what could have been done better. This question assists the health services to understand the views of consumers within their Hospital and Health Service. Of 51 community participants 26 (51%) said they were happy with their experience of the health service both in the community and outside the community.

Communication between patients, families and health providers was reported as needing improvement by 7 (14%) community participants and 6 (43%) Indigenous health workers. Of 51 community members and 14 Indigenous health workers, 4 (8%) and 3 (21%) respectively believed Indigenous health workers should engage more with the community and there should be more preventative health.

Other improvements to the health service were around the need for better patient information, difficulty with public transport, costs of medications and costs of food and transport when leaving the community to get health care. Another improvement suggested were responsibilities of the family being considered when treatment is being planned.

Main themes emerging from communities on health service improvement were (1).Improved communication including patient information and (2) preventative health in the community.

Table 16: Communication, service location and transport impact on patient experience

“I prefer to stay locally to get treatment. It is difficult to go outsidebecause to arrange transport, parking and train only goes once a week to Brisbane. If I had to go to Brisbane for lung treatment I would not go neither would others especially Indigenous. Getting down to Brisbane is very hard”.

“More communication between parties. Not having to tell your story over and over. The medical profession should have more understanding of your limitations and what you need to get treatment. That is, asking about your needs and limitations - especially costs and take into consideration your circumstances when deciding on treatment”.

“There should be a better breakdown of information. It can be given too quickly. Health professionals should be more sensitive on how information is given to patients so as not to alarm or make them fatalistic especially Indigenous because they think the worst case scenario”.

“Make medication for cancer treatment free or cheaper. The Hospital Indigenous Liaison Officer should be more informed. When I went to Brisbane the HLO didn't know where (Community) was. We should look at ways to decrease isolation for patients outside of their community like having local elders visit. Our people think that cancer is a death sentence and they might not have treatment - fear of leaving and going to the big city. What am I in for? Where am I going to stay? Things are better now since specialists come to..... (Community). Also doctors should not beat around the bush they should give factual information”.

“The cost of food for a week. The health service didn't cater for me as a parent when my child was in hospital”.

“Travel is hard”.

“Just waiting but that happens in every hospital”.

“Travelling - we need another road to leave..... (Community) Waiting for appointments, hospital bus only goes to (regional hospital) 3 times a week”.

“Transport up and down could be better”.

“Waiting time for surgery and services should be more culturally aware”.

“Pretty happy with health service. The liaison person needs to know when someone is coming from the hospital to help with follow-up. More cultural awareness should be given to non-Indigenous people”

“Aboriginal health team needs to be in the community where they used to be. People used to go to them when they were away from the health service. They shouldn't be under, they should have their own Aboriginal leader. Should be out in the community more. They can do more preventable stuff if they were out away from the hospital”

“Health workers need to go out in community and promote themselves and not sit in the hospital setting. No privacy on days when specialists are here. Indigenous health worker should be in the community not at the hospital. More preventative health is needed”.

“There is plenty of information available but I think more community help should be made available especially if family members work and aren't available to provide the support. More practical help is needed”.

“It would have been easier if I was told about my son having cancer. My son didn't even know”.

When I travelled to Brisbane with children I had a lot of help from the hospital. But there is no liaison inand I think there should be one. Our people when they go to especially young mums having babies aren't treated so good. They would like their partners to be with them but it is not set up for that”. (Referring to regional hospital)

“Indigenous health workers should do more outreach in the community because people don't like going to hospital. Health people (IHW) should talk more in the community like showing pamphlets There is not much support outside the community in except for the IHLO. You have to fend for yourself”.

“Health workers should do more in the community like regular health promotion and especially with diabetes, the effects of alcohol and awareness of health in general”.

“There should be more attention given to patients, it is too rushed. You have to get in and get out. There should be more doctors and more time to sit and talk so patients can open up. They aren't thorough unless it is something really serious. Indigenous Health Workers should be out in the community more especially to help people get to the hospital. The ambulance service could also be used for hospital transport”.

“Old people have to go to..... for dialysis. We need more machines (In community)”.

“More dental health is needed. Only those with a health care card can see the dentist here otherwise you have to leave the community and go to..... There should be more time for talking when you see the doctor, like a meet and greet otherwise I am happy with the health service”.

“I think they did a fantastic job and I use that experience to advise my family. I kept strong through exercise and prayer”.

“No I think they do a really good job”.

Indigenous health workers – views on how services can be improved

“Taxi vouchers flight details and gathering all the information about travel. Making sure paperwork is done and contact people in Brisbane. All transport and getting people down for appointments”.

“Not really - services- nothing to be improved. My(Relative) does own dialysis in.....(community). I think that targeting young community members on health is needed”.

“More health promotion. One on one contact. We should visit homes more but alcohol and dogs are a barrier to this”.

“It would be better if nursing staff or doctors would use more easily grass root explanations to patients”.

“Information for patients should be grass roots. More time should be spent with patients to show them you care for their health. The health service trusts in their workers to build up relationships with clients/ patients but if the worker goes away or leaves, the patient tends not to continue with treatments. When a new arrival of an IHW comes there should be a few months of hand over time otherwise patients lose faith in the health service. People don't follow up their treatment so family needs to be involved to offer support. People cannot make a choice on the spot they need time to think about and talk to the family”.

“Transport because very soon we will have no bus service”.

“If patients are hospitalised in major hospitals - discharge summaries should include them being discharged to hospital who referred them. Patients shouldn't be discharged to family; better information should be given to hospital so there can be better follow-up. It would be better if they were transferred by ambulance and no private care therefore no financial burden. Major hospitals should take into account where patient comes from. No out of district transport can be arranged by”.(Community)

“Appointment times can cause trouble especially if patients have to travel for early appointments in Brisbane from..... (Community). And also waiting for appointments to come through”.

“For people who have to go to major hospitals for diagnosis - transport, family support and family left behind who need to be cared for. They like the whole family to be there but it is too costly for the patient. There are not enough cancer support services in”.(Community)

“Regular home visits by Aboriginal Health Worker and recalls for social and emotional wellbeing and how they are coping”.

“When patients get to Brisbane a lot of complaints because often patients don't know what they are going for. Patients from here are shy. With the actual treatment they are not informed enough. When the patient comes back they do not know why they had treatment and it is hard to follow up. Not enough communication between health services at different locations. Patients waiting and breakdown of communication”.

“There is not a process for follow-up for patients that come back and we don't know what they are being sent down for. Once they go for diagnosis and come back there should be a liaison and we could be better advocates for example with cancer, they go off and then come back and wait to die. Follow-ups could be home visits”.

4.14 The patients' experience of their lung cancer journey

At the time of the research only one patient volunteered to participate. Whether this was because there were no other people with lung cancer or who had ever been suspected with lung cancer remains unknown. In community C, there were two patients however the GP declined to contact them as they were undergoing medical treatment.

As only one patient from the participating communities was able to be recruited for the study (defined as a non-urban patient) an ethics amendment was submitted and approved to allow an additional site located in a major metropolitan area. A patient (defined as an urban patient) was recruited. Both patients' responses from the interview have been presented as an account of the lung cancer journey so comparisons can be made.

Non-urban patient

A patient aged over 50 presented to the local GP with what was believed to be worsening symptoms of emphysema and asthma. The patient had a past smoking history of 42 pack years (one pack year equals 20 cigarettes smoked every day for one year) and co morbidities which included hypertension, chronic obstructive pulmonary disease and diabetes. Due to co morbidities, the patient has been unable to work and is on a government pension. The patient has limited family support and no close friends but does volunteer in the community for 1-2 hours per week. The patient's understanding of lung cancer is that it could kill and is caused by smoking. The patient recognises symptoms such as haemoptysis, cough, weight loss and chest pain as signs of disease and would seek medical care as soon as possible if experiencing any of these.

On first presentation to the GP the patient had suffered a sudden onset of whole body aching. The patient had also been experiencing cough, weight loss, shortness of breath, chest pain, general body ache, and lethargy and memory problems. The patient's regular GP immediately referred the patient to a larger regional hospital. No diagnostic investigations were ordered by the GP.

The patient received the diagnosis of lung cancer more than 4 months after investigations were completed. The patient was told there was a spot on the lungs and the first treatment would be a watch and wait approach. The patient felt scared and did not keep appointments, instead waiting till symptoms became worse.

“I did not keep my appointments. I was told I had a spot on my lungs. I was scared. First treatment was watch and wait cause it was so small. I waited till symptoms got worse instead of going when I was supposed to”.

During the course of initial consultations, the patient consulted a respiratory physician, radiation oncologist and traditional healer. The patient attended the local hospital, regional hospital and a Brisbane hospital as well as the traditional healer in the local community. The patient declined to see a surgeon as it was important to speak to family about what treatment was allowed.

“I was offered surgery but didn't want to see surgeon. Talked to family about it and type of treatment I could have”.

The patient was aware of organisations such as Home and Community Care, Lung Foundation Australia and Cancer Council Queensland however was not aware that support or help could be obtained from them. The patient did receive support from social work, the Indigenous health worker and the Indigenous hospital liaison officer during the course of treatment.

The patient also used traditional medicine during treatment and believed this was the reason the cancer had not grown at the time of a repeat scan. The patient has been offered further traditional medicine (Gumbi Gumbi) but has not been able to travel to access it. The patient described the experience of a family member who took traditional medicine over conventional medicine and lived a long time. The patient however uses conventional medicine as the mainstay of health care.

“I used it a couple of times (.... traditional medicine). I believed it helped in some way cause when I went for my second scan the cancer was still there but hadn't grown. I have been offered more traditional medicine but haven't been up there in the bush to get it”.

“My (Relative) used it but he had alot of traditional ways that he didn't pass on. I don't think he took his heart meds”.

When travelling away from the community for appointments and lung cancer treatment, the patient's travel was organised by the local hospital. The patient was accompanied by a family member and they stayed in a motel. The patient found the cost of travel the most expensive part of the treatment especially getting from the accommodation to the hospital by taxi.

Lung cancer, heart disease and kidney disease are the main health concerns of the patient. The patient worries about family developing these conditions.

The patient believed getting around Brisbane was the most difficult aspect of the lung cancer journey and being given night appointments for radiation.

“Getting around the city of Brisbane is very difficult. When I was getting radiation they would give me night appointments”.

The patient found it difficult to apply cream to the radiation area with no help.

“I didn't have enough help to put on cream to radiation area”.

Overall the patient felt the information provided by the health professionals and support was as expected.

“I was given information and support as I would expect especially as I came from the bush. I was lucky to have family members in Brisbane”.

The patient was given information resources on lung cancer in the form of a pamphlet and DVD. Information was general in design and the patient found it extremely useful. The patient stated that it was not important that resources be designed for Aboriginal and Torres Strait Islander peoples because of the ability to read and write.

The patient liked a variety of media *“Because it gives me a choice to decide what is more appropriate to my diagnosis”*. The patient also stated that *“There should be more DVD's for people to understand more about lungs and videos are a very good resource for people to learn about lungs and lung cancer”*.

Although having access to the internet, confident in its use and owning a personal computer, the patient never uses the internet to learn about health.

The account of the patient journey highlights some barriers faced. Time is needed to consult with family, and the cost of taxis to and from accommodation to radiation treatment, the lack help with caring for the radiation treatment site were barriers mentioned. The patient believed enough

information was given and supportive care needs were met. The patient also highlighted how family was important for support when away from the community.

Urban Patient

A patient aged over 60 presented to the GP with an acute sore throat, lethargy and worsening cough. The patient was a current smoker having commenced at 16 years and was undergoing management of hypertension. The patient had previously presented to a regional hospital some months prior with respiratory symptoms of cough and shortness of breath but did not receive the appropriate follow-up by the usual GP.

“I had gone to hospital about 3 months before with breathing problems and told I had emphysema and they would get in touch with my GP for followup. But I never heard again and thought it must have been ok”.

“After that last time at hospital I got sick again and I went to the chemist. The chemist told me about a doctor that was open on the weekend and I should go to the doctor. I had a sore throat; I was tired and coughing up phlegm” I couldn’t see the (Usual GP Service) cause they weren’t open. The GP, he was from another country, sent me for a chest x-ray and there was a black shadow then I had a CT. The GP said he thought I had early stage lung cancer and referred me to(Respiratory Physician)”.

“I was disappointedlet me down by not following up Redcliffe. I went there when I found out I had lung cancer and told them “you let me down”.

The GP was not the patient’s regular doctor but was concerned regarding the abnormal X-ray so a CT scan was ordered. The patient was advised by the GP that the investigations were indicative of early stage lung cancer and a referral to a specialist centre was required. The patient at this stage was not in a good state of mind feeling shame and assigning blame due to being a smoker.

“It’s a death sentence. You blame yourself cause you didn’t do the right thing”.

The patient was seen within a week of the referral and underwent bronchoscopy and the diagnosis confirmed. The patient was advised by the specialist that a treatment plan would be developed at a multidisciplinary team meeting. The patient accepted the recommended treatment plan and commenced chemotherapy and radiation.

Although the patient lived less than 40 kilometres from the hospital leaving home to stay closer to the hospital for cost and convenience was necessary for the radiation treatment. The patient stayed with a relative and used taxi vouchers to get to and from appointments. The cost of sundry items such as food caused the most financial burden.

The patient was satisfied with the general information resources given to understand lung cancer side effects but would have liked to have seen culturally targeted ones. *“I have never seen any”*. The support of the dietitian was also acknowledged Without good information and support from the dietitian the patient felt doubtful if treatment would have been completed. By receiving information on how food could taste metallic after radiation the patient was able to better cope.

“If I wasn’t told about food tasting like metal when having radiation I don’t know if I could keep going”.

The patient was aware of Cancer Council Queensland but only because pamphlets came from there, but did not know of any other support services offered. The patient was given phone numbers of contacts within the hospitals but thought it not very good when an answering service informed that the hours were 8-4 Monday to Friday; therefore having no knowledge where to seek advice after hours.

“There was not enough weekend support – no one to talk to. When you ring the contact numbers – cause they work Monday to Friday till 4”.

The Indigenous health service representative did not come to any treatment appointments and therefore the patient believed the support should have been better.

“(IHLO) just came to one appointment and said I am so and so, said a few more things then I never seenagain”.

Although the patient attended all appointments and investigations without being accompanied by family or friends did have strong family support at home.

“I kept a positive belief – wasn’t going to let me down”.

When the patient was first diagnosed help from the traditional healer was sought. Gumbi Gumbi as a tea was consumed daily until treatment commenced so as not to cause an interaction. The patient commenced Gumbi Gumbi tea once treatment was completed and continues to drink it on a daily basis.

“I take Gumbi Gumbi as a tea. I took it when I first got sick then stopped when I started treatment in case it reacted. When treatment was finished I took it again and I am still having it every day. My (Relative) is a strong advocate of it knew a lady with breast cancer who never went to the doctor and her brother had cancer. He took Gumbi Gumbi and still smokes. So they both took Gumbi Gumbi and they are still alive”.

Regardless of living within the metropolitan area there were still barriers faced when accessing lung cancer care. Costs associated with transport to attend radiation caused the patient to move closer to the radiation centre. There were also a feeling of being let down by Aboriginal services including medical staff and Indigenous hospital liaison staff. The patient stated that “a positive belief” helped with the experience of the lung cancer journey.

Chapter 5: Discussion

The following is a discussion and synthesis of the knowledge derived from the literature review to the findings of the interviews in order to meet the aims of the research.

5.1 Lung cancer awareness: risks and symptoms

Awareness of lung cancer is a priority for Indigenous Australians as they are 1.9 times more likely to receive a diagnosis of lung cancer and die from their lung cancer than non-Indigenous Australians.⁴ Lung cancer is the most common cancer in both Indigenous males and females and the most common cause of cancer death.⁴ Socio-economic status, literacy, education levels, remoteness of residence, higher prevalence of co morbidities, higher smoking rates and late presentation are the known causes of the lung cancer disparity.^{4,70,9, 44}

The study found lung cancer awareness in the participating communities was relatively low in regards to risk factors (other than smoking) and symptom recognition (other than cough). Of 51 community participants and 14 Indigenous health workers, 26 (51%) and 6 (43%) respectively answered ‘not much’ or nothing’ when asked what they knew about lung cancer.

The words “smoking” “death” or “it kills you” was mentioned by 25 (49%) of 51 community participants, 8 (57%) of 14 Indigenous health workers and 2 (100%) patients. Therefore, smoking or death was associated with lung cancer by over half of 67 participants in three rural and remote Aboriginal communities in Queensland.

The question on warning signs of lung cancer was well answered. All 67 participants could recognise at least one symptom associated with a diagnosis of suspicious lung cancer. It is unknown if participants actually knew of the symptom or whether they used some intelligent guessing.

Although smoking was acknowledged as a cause of lung cancer by 62 (92%) of 67 participants almost half of the community participants were current smokers (46%). This suggests that participants do have an understanding of the risks of smoking and the severity of being diagnosed with lung cancer. However, it does not explain why nearly half the community participants continue to smoke (Indigenous health workers were not asked about their smoking behaviour).

5.1.1 Indigenous health workers and awareness

Indigenous health workers, although aware of the severity of lung cancer did not have any knowledge of what the lung cancer diagnostic pathway could mean. Knowledge of the term ‘diagnostic pathway’ would not be considered crucial however, as a part of the interview, it was interesting to uncover whether Indigenous health workers had a concept of the meaning of the phrase which is routinely used within cancer care services both in Australia and internationally.

Only five of the Indigenous health workers thought of chest x-ray and three mentioned CT scans as diagnostic of lung cancer. No mention of bronchoscopy was made although seven Indigenous health workers were familiar with “breathing tests”. This knowledge may have been gained from the Indigenous Respiratory Outreach Care program community visits. During IROC visits, some Indigenous health workers have had the opportunity of seeing spirometry performed as well as receiving education on the procedure. Indigenous health workers participants clearly had knowledge gaps which would prevent them from being of assistance to patients facing a diagnosis of suspicious lung cancer or have confirmed lung cancer

Participants appeared to know about the dangers of smoking such that one could postulate that public health awareness campaigns on the risks of smoking and its association with developing lung cancer have been effective. However, lung cancer awareness does not necessarily equate to people changing their health behaviours. There are theories on health behaviour that can in part explain why health promotion activities or messages may not be effective. One theory is delivery effectiveness. For example, people might think health professionals or governments are attempting to remove personal freedoms by pushing organisational health ideology or agendas. People can therefore react positively or negatively to health programs.²⁸

5.1.2 Low incidence of lung cancer in communities

At the time of this study’s fieldwork, there were few participants who mentioned knowing someone in their community affected by lung cancer and only one patient volunteered to be interviewed. It was possible that privacy issues may have prevented people from coming forward or sharing knowledge about the cancer status of a community member.

Although during 2002-2011, 395 cases of lung cancer by Indigenous status were recorded in Queensland, over the same period there were four lung cancer cases reported by Indigenous status in Community A, three in Community B and seven in Community C ⁵¹

The possible perception by residents and health professionals that low incidence in their community equates to lung cancer being of little concern may potentially contribute to lack of awareness and subsequent failure to act on warning signs. It may even contribute to the complacency of the dangers of smoking.

When participants were informed of that Indigenous Australian's have a higher risk of developing lung cancer there was palpable concern shown. Informing Indigenous Australians of the higher risk might help raise their awareness and encourage them to take health messages about risks and symptoms seriously.

5.2 Health information

A way to raise awareness of any health condition is through public health campaigns and providing relevant information to patients and families or carers. A significant amount of the interview was addressing the use of health information resources. This enquiry on health information was to support the premise that culturally targeted lung cancer resources are more suitable than generic resources for Indigenous Australians. Questions on health information resources and design were also intended to elicit information on what works best to deliver health messages.

Studies conducted about health promotion and education have shown that Aboriginal and Torres Strait Islander peoples prefer visual media, and information that is easily read, colourful and pictorial. Art, song and dance have been used to convey health messages in a culturally targeted way.^{66, 67, 85}

This study found that nearly half of the participants stated that culturally targeted health information was not important to them personally. These participants offered varying reasons from "*we are all the same*", "*all I want is good information*", and "*the opportunity to have a choice*". The patient participants both found the generic lung cancer information very useful but interestingly the patient from the urban centre had never seen culturally targeted resources for Indigenous Australians.

It could be argued that the education level of the participants influences what type of information resource people are more likely to use. On analysing cross tabulations of community participants' age, education and income, the highest categories of education were (1) commencing high school but not finishing year 10 and, (2) completing year 10. The highest category of income was in the bracket of < \$20,000 per annum. There was no significant correlation with education, income, or age regarding community participants' preference for culturally targeted resources. Over half (58%) of the participants also found generic health information resources useful to extremely useful on the likert scale in meeting their information needs.

Assessing the health information needs should be viewed as a principle component of monitoring patient experience and effectiveness of awareness campaigns or health interventions. Although belonging to a particular community, Indigenous Australians are not the same and will likely have varying health information needs. Different levels of education, personal beliefs, preferences and preferred ways of learning will affect how people view health messages.

Literacy levels for example, may be lower or higher in some communities compared to others. Indigenous Australians' literacy and education levels continue to improve although a significant gap still exists compared to non-Indigenous Australians.⁸⁶ To reiterate; health literacy is not always dependant on general literacy levels. Understanding health terms and navigating the health system is complicated and every strategy should be considered to help people deal with these complexities in unison with the provision of suitable health information.

As the principle researcher on this study I was expecting participants to be fully supportive of culturally targeted health resources and even dismissive of generic resources. Responses to questions about health information design preference revealed that culturally targeted health information was not as crucial to some participants. The finding surprised me as well as some of my colleagues and highlights the importance of not stereotyping or exaggerating Indigenous requirements because of what is popular opinion or learned through media^{21, 45, 87-89}

Although research findings are contrary to what is expected they should not be discarded or assertions on the quality of research made. Instead, it is important to consider these results and to ascertain whether if any unexpected findings are the result of societal changes or just an anomaly related to small sample size, influence of western culture or the participant's perception of the line of enquiry. Variations and commonalities in responses across the communities emerged from this

research enquiry. Conducting the research in more than one community therefore gave strength to the study.

If culturally targeted resources have a place (and it seems they do as evidenced by various studies), it is important to understand what actually makes a resource culturally appropriate. An identified need along with the involvement and advice from Indigenous people at different stages during resource development will add towards the effectiveness or use of the resource. Ensuring Indigenous language is incorporated and having content and images which are relevant to the population will further enhance engagement.⁶⁷ A lung cancer resource should be relevant to an Indigenous Australian's emotional, clinical and supportive needs to support a culturally appropriate approach.⁹⁰

However, one could argue that developing culturally targeted health resources will become unsustainable both in money terms and capacity, particularly in the Australian multicultural environment. If health economies are to be considered, health units involved in resource development may need to adopt different design methods to deliver effective health messages without compromising cultural sensitivities. The amount of money invested in health information resources in Queensland was unable to be substantiated through scholarly and grey literature searches but anecdotally if all media forms are taken into account the budget must be substantial.

It might eventuate that key design principles preferred by Indigenous Australians (easy to read, pictorial etc.) could be adopted for all health information resources thus rendering them 'culturally neutral' and suitable for a wider range of audience.

As noted by the Gould et al study on culturally targeted anti- tobacco information, regardless of their effectiveness, there still remains limited evidence supporting the need for the sole use of culturally targeted messages and generic ones can be just as effective.⁶⁸ Also, there is a paucity of studies comparing culturally neutral, generic health information and culturally targeted to assess if the financial investments are returning the wanted outcomes.⁶⁸ One study which did evaluate a targeted holistic Maori campaign in New Zealand involving the QUIT program found a generic fear campaign was more effective.⁶⁸ The use of highly graphic imagery in the study reviewed by Gould et al was deemed most effective by both Indigenous and non- Indigenous viewers in delivering the anti- tobacco health message.⁶⁸

5.3 Access to health services and information

Telehealth has enabled health services to be delivered across distances and technological advances like smart phones, personal computers and tablets are more affordable and available to many Australians regardless of residence. Health services are increasingly using internet applications to deliver health messages and preventative programs.⁹¹

Western culture continues to influence Indigenous Australian populations and this was demonstrated in this study by the substantial use of the internet and how many participants own devices to access the internet. Participants with access to the internet were mostly confident in its use particularly social media and Google, and owned capable devices to access the internet. Participants also access the internet to learn about their health and Indigenous health workers use the internet to inform patients about a health condition.

The accessibility to the internet in the communities shows there is a paradigm of everyday communication and learning and it is continuously influenced by technological advances. Many areas of life have been impacted by the introduction of the internet and health is one. Software applications that provide tools, processes and communications have supported electronic health (ehealth) delivery including telehealth.⁹² Wireless and mobile communication technologies have virtually eliminated barriers of distance between clinicians and patients.⁹² There are also many health applications for patients to monitor their own chronic disease (e.g. asthma, diabetes) or learn about health.⁹²

We are using technology in our everyday lives. Not only do we have personal computers and smart TVs, there is also an increasing use of mobile communication in the form of smart phones and tablets. The internet and internet devices are also more affordable.

Connectivity to the internet is happening in more remote areas of Australia. A parliamentary committee has acknowledged that some remote Indigenous communities have unreliable internet connectivity.⁹³ In order to address chronic disease which contributes to the gap in mortality between Indigenous and non-Indigenous Australians, technical barriers to high quality internet connectivity which encompasses telehealth must be addressed.⁹³ The committee has recommended the Queensland Government advocate for the implementation of the National Broadband Network (NBN) in remote Indigenous communities as a matter of priority.⁹³

Using internet programs such as YouTube, apps and social media is a strategy for health services to raise awareness of risk factors of lung cancer in a culturally appropriate way. However, despite a culturally targeted lung cancer resource being well received, it does not necessarily lead to a change in health behaviour. Being aware of risk factors and symptoms also does not always lead to seeking, commencing or completing lung cancer treatments.

5.4 Influences on health care decisions

Research investigating Indigenous Australians' access to health care suggest that cultural security, leaving the community, distrust of conventional medicine and traditional spiritual beliefs influence Indigenous Australians health decision making.^{21, 94} However, in the three communities who participated in this research these factors appeared to play a very small role.

No mention was made of issues regarding cultural security such as fear of leaving the community, not trusting doctors or conventional medicine. Traditional medicine is used secondary to conventional medicine. When participants were made aware of symptoms which could be suspicious of lung cancer, 40 (78%) community participants and 12 (86%) Indigenous health workers said they would seek medical advice from the GP or hospital as soon as they could with only five community participants choosing to wait more than two weeks. This response was similar across the three communities.

When faced with a diagnosis of suspected lung cancer or confirmed lung cancer Indigenous Australians could turn to traditional medicine to either complement or replace conventional treatments with traditional or alternative treatments.^{21, 94} Research exploring traditional medicine and attitudes to conventional medicine has shown that Indigenous Australians worry about toxicity of conventional treatments, have a more holistic view of health and can experience a disconnect with physicians if they do not feel culturally safe therefore are more likely to use traditional medicine.^{10, 95, 96} Traditional medicine is widely used in Indigenous communities of the Northern Territory and the role of traditional healers has been recognised by the Northern Territory Health Service.⁹⁴

Participants were asked questions on the use of traditional or alternative treatment to determine the probability that they would use these treatments in place of more aggressive cancer treatments like surgery, chemotherapy or radiotherapy. The use of traditional medicine is considered sacred by

some Aboriginal people and to discuss the use and access can be against cultural lore. There is an air of secrecy about its source and use.^{10, 97}

Only four (6%) of the 67 participants did not wish to respond to questions on traditional medicine and it is unknown whether remaining participants chose to hold back information. One participant said he used traditional medicine before going to the doctor but would also consult a doctor if symptoms worsened or persisted.

The most mentioned traditional medicine was Gumbi Gumbi, a native plant (*Pittosporum Phylliraeoidesa*), that has been used for thousands of years by Aboriginal Australians for traditional bush medicine purposes.⁹⁸ A scientific study on the medicinal potential of Gumbi Gumbi validates the use of the plant by Aboriginal Australians as it has proven antibacterial and antifungal properties and is of low toxicity.⁹⁹

The patients who were interviewed used Gumbi Gumbi complementary to their conventional treatment. Research studies conducted in the Northern Territory and Western Australia that looked at the use of traditional medicine concluded Indigenous Australians do seek conventional medicine when ill but would also use traditional medicine if it were easier to access, particularly people who live in urban centres.^{27, 95, 96}

There are both similarities and differences in this study with other research findings on the use of traditional medicine. The study found Gumbi Gumbi was the most mentioned type of traditional medicine in all three communities. In the Northern Territory and Western Australian studies, other forms of traditional medicine were referred to with a strong emphasis on supernatural beliefs and causation of disease. The use of traditional medicine, although wide spread, was used complementary to conventional treatments which was also a finding of this study. People also acknowledged other forms of alternative treatments such as acupuncture.^{27, 95}

Doctors and other health professionals should discuss traditional medicine or other therapies as it is probable that they will seek advice from a traditional healer within their community.²⁷ Acknowledging traditional medicine may also help the patient feel that their cultural beliefs are respected which can encourage them to comply with medical advice and make informed decisions about the use of conventional treatments.²⁷

5.4.1 Stigma and nihilism

Stigma of lung cancer and nihilistic attitudes can be factors which effect health seeking behaviours.³¹ The guilt felt by patients because of smoking may lead them to believe they will not be treated.³¹ Similar to all lung cancer patient, Indigenous lung cancer patients too are likely to experience stigma and nihilism. These emotions may manifest themselves with greater intensity in Indigenous lung cancer patients due to spiritual influences such as belief in ‘payback’.¹⁰

Attitudes of stigma and nihilism toward a diagnosis of lung cancer have been studied widely and can have detrimental effects on lung cancer outcomes.³¹ Responses to the lung cancer awareness questions showed nihilism and stigma were definite attitudes in participant’s thoughts. This was demonstrated by the number of participants who associated smoking and death with lung cancer. The urban patient’s felt shame and guilt because of smoking which was an indication that nihilistic thoughts were present.

Stigma was further demonstrated through the reaction of people when invited to participate in the interview, with some citing – ‘oh I smoke’ as if that should automatically exclude them from an opinion. Some smokers had to be reassured that their smoking behaviour was not under judgement. The unintended consequence of anti-smoking campaigns is that patients are facing stigmatism about having lung cancer.³¹ This consequence highlights the need for quality lung cancer information and a careful consideration of how it is delivered to avoid negative attitudes that can have profound effects on health decision making.

5.4.2 Patients need support to complete treatment

It is important to ensure people with lung cancer have access to relevant support services that can prepare and help them cope with treatment both physically and mentally. Indigenous Australians may be shy and will not actively seek support.⁷⁹ If not referred at the appropriate time lung cancer patients may not complete cancer treatment. The urban patient was certain that without the advice and support of the dietitian, radiation treatment would not have been completed.

Lung cancer multidisciplinary teams (MDTs) are best placed to liaise with the local health service and the Indigenous health worker service to ensure patients not only have knowledge of what support is available to them but can also access the service at the appropriate time. Treating teams need to ensure patients have an understanding of their treatment options and be informed of

potential side effects and prognosis. This will assist the patients' decision making on commencing and completing lung cancer treatment.

A study by Cramb et al. (2012) found if Indigenous cancer patients completed treatment and remained alive in the first year post diagnosis they would have survival outcomes similar to those of non-Indigenous cancer patients.⁶ This suggests support and relevant information is crucial to Indigenous cancer patient's likelihood of commencing and completing treatments.

The role of nihilism, general poor health due to co morbidities and socio-economic factors play a role in the patients outlook on life and their ability both physically and mentally to complete their lung cancer journey.⁶

5.4.3 Health promotion is important

More emphasis on healthy living through health promotion activities in the communities seems to be an obvious strategy to decrease the risk of cancer including lung cancer and therefore contribute to better health outcomes.

Indigenous cancer patients are more likely to have three or more co morbidities which can affect what treatment they can receive. Indigenous Australians suffer a higher prevalence of diabetes and kidney disease than the general population.⁵⁹ Hypertension and diabetes were the most common health conditions in the communities. Cancer is a devastating diagnosis but can be treated and outcomes improved if people do not have other diseases which contribute to risk and poor outcomes.

Although increasing health promotion in the community was mentioned by few participants, this response emerged in three communities which therefore suggests that health promotion activities about lung cancer could be accepted. Indigenous health workers should be involved more in promotional activities as they have previously instrumental in improving outcomes in cardiac rehabilitation and mental health.⁹

5.4.4 Influences on accepting treatment

The choice to accept medical care can depend on other logistical considerations like travel and costs of treatment. This issue of travel and associated costs of petrol was raised by participants from all

three communities. Some participants experienced isolation when accessing medical care outside the community, complained public transport was inadequate and responsibilities of families were not being considered when appointments were organised. The travel between accommodation and the hospital was also raised by some participants as being the most difficult part of their whole experience.

Participants were generally happy with the experience of their health service either in their community or away from the community. The main themes emerging from this enquiry involved the need for effective communication between treating teams, the patient and the community, and more engagement of Indigenous health worker in the communities.

Another area of service improvement mentioned by community and patient participants was the need to discuss illness and treatment with family members before having to make decisions.

Indigenous Queenslanders from rural and remote areas are faced with a unique array of factors that can influence health decision making. Hospital and Health Services, clinicians and other health professionals need to support Indigenous Queenslanders to encourage them to complete treatments through care coordination, providing relevant information that meets their needs and increasing health promotion activities in communities.

5.5 Health priorities

Health priorities of communities provide an insight into how individuals view health and what is foremost on the mind to sustain their own health or that of their family. Participants were asked what illness they worried most about getting or someone close to them getting. The purpose of this question was to determine whether lung cancer is seen as a concern. There might be a misconception in communities that lung cancer is not a problem because awareness is low and risks are not well known.

Cancer was not the main health concern in the communities. Although 35% of 67 participants mentioned cancer as their first health concern, they were generally not specific about the type.

The subject of lung cancer, which could be perceived by some as a sensitive subject, also did not appear to raise the participants' anxiety as was expected. The most mentioned health concern was diabetes across all communities. Usually health concerns were related to what illness the participants, their family, or friends had experienced.

5.6 Improving the lung cancer diagnosis and treatment pathway

Much of the disparity of poorer cancer outcomes including those of lung cancer in rural and remote areas of Australia lie within the realm of diagnosis and treatment.¹⁰⁰ Before any improvement can be made there is a need to put in place processes to mitigate the known causes of delays to diagnosis, through to treatment and on to follow-up.

The Clinical Cancer Care Framework (See Appendix 5) has been developed as a result of the Australian Health Ministers' Advisory Group agreement in 2002 to create National Service Improvement Frameworks for chronic diseases which includes cancer.¹⁰¹ The frameworks are joint initiatives of both the Federal and State Governments. The frameworks are tools for health professionals and consumers to bring an integrated approach to the delivery of health care.¹⁰¹ The Clinical Cancer Care Framework shows what pathway patients with suspected or confirmed cancer are expected to undergo regardless of their place of residence. The framework was developed through a wide consultation with clinicians was recently endorsed by Queensland Health's Executive Management Team.¹⁰¹

Each type of cancer has a typical diagnosis, treatment and follow up pathway including lung cancer. The lung cancer pathway which is aligned to the Clinical Cancer Care Framework was examined to flag potential road blocks an Indigenous Queenslanders from rural and remote communities might face based on the findings of this research study (See Appendix 7). To develop a pathway exclusively for Indigenous lung cancer patients would make no difference to the clinical aspect of their care. However, modifications to the support aspect of the current lung cancer pathway may help Indigenous Queenslanders overcome potential barriers to seeking, commencing and completing lung cancer diagnosis and treatment. The most effective modification to the current lung cancer pathway is to recognise the role of the Indigenous health worker and Indigenous hospital liaison officer in the different stages of the pathway.

Areas of lung cancer service delivery which could be improved to mitigate or remove barriers to best practice are not beyond the scope of the Hospitals and Health Services. The support and implementation of service improvements will benefit all Indigenous lung cancer patients regardless of residence and also help non-Indigenous lung cancer patients.

Two areas of importance which should be flagged for improvement are communication and care coordination. By using existing videoconferencing facilities, local medical officers and Indigenous

health workers can be included in the lung cancer multidisciplinary team meeting discussions. Care coordination could also be improved through telehealth so GPs, other treating teams (where patient is being medically managed for co morbidities), Indigenous health workers, the patient and their family are fully informed and care streamlined.

The use of telehealth oncology clinics to provide patients with follow up closer to home may see a new model of shared care. Not only does the use of telehealth minimise costs to the health service and patient, it also benefits the patient's emotional and cultural wellbeing.

5.6.1 The role of the lung cancer multidisciplinary team

The lung cancer multidisciplinary team (MDT) as a key enabler of integrated cancer care, should ensure appropriate and timely investigations, recommend treatment plans based on evidence, assess where treatment can be delivered and consider the needs of the patient.¹⁰² The lung cancer MDT also has an obligation to the patient and local health service to ensure the communication processes are effective.¹⁰² Lung cancer MDTs should regularly review processes, have clear objectives around diagnosis, treatment and survivorship, strong leadership and benchmarking exercises to enhance their effectiveness.¹⁰²

Comments from community participants highlighted the issue of effective communication, needing time to consult with family and the feeling of being rushed by doctors. Indigenous health workers also alluded to experiencing lack of communication once the patient had left the community for medical treatment. Inadequate communication processes can have an adverse effect on patients as they may experience a sense of isolation when leaving and on return to their community.

Implementing effective communication processes between the multidisciplinary team, regional and remote hospitals and other health professionals involved in the patients care will greatly improve the delivery of lung cancer to rural and remote Indigenous patients. Health services should be made aware of the Clinical Cancer Care Framework and use this to develop clearly defined lung cancer referral, diagnosis and treatment pathways for their health population. There may also be a place for a rapid referral process for suspected lung cancer as is practised in other countries such as the UK and Canada.

The extension of cancer care coordination to the metropolitan area may provide an unmet need for Indigenous patients who do not have the support, means or health literacy to navigate the lung cancer pathway therefore making them a greater risk for poorer outcomes.

Patients living considerable distances from major tertiary referral centres might face financial and social challenges so it is important that appropriate diagnostic investigations are coordinated and time to treatment optimal. Lung Foundation Australia has identified (anecdotally) that lung cancer patients receive more timely access to appropriate treatment if allocated a specialist lung cancer nurse who works within the multidisciplinary team.¹⁰³

Indigenous health workers require the appropriate education on lung cancer to be able play a valuable role in helping patients navigate the lung cancer pathway, Education programs for Indigenous health workers need to be continuous and not one off.⁹ If knowledge and skills are to be fostered within cancer care for Indigenous Australians then improvements should occur in cancer support services.

5.7 The patient journey

The disparities experienced by Indigenous Australians in lung cancer incidence, mortality and survival compared to non-Indigenous Australians are caused through a complex, interplay of socio-economics, culture, remoteness of residence, education and associated low levels of health literacy, marginalisation and racism.^{9 12, 14, 104} While Indigenous lung cancer disparities continue to be addressed it is vital that evaluation of patient experience is used to inform future solutions. As only two patients were recruited for this study it is not possible to draw any generalisations or offer any insight to what other Indigenous lung cancer patients may experience but rather offer up some similarities of what two patients from different geographical and demographical areas experienced.

The patient from the non-urban area encountered difficulty with taxi costs, appointment times and personal care whilst being treated in Brisbane. The patient was fearful and delayed appointments and the seeking permission from Elders or family was apparent as a cultural influence as was the consultation with a traditional healer and use of traditional medicine. The urban patient although living less than 40 kms from the major hospital still had to move from home to be closer to treatment, accessed traditional medicine and experienced feelings of fear and self-blame. The patient was disappointed with the lack of support shown by the Indigenous hospital liaison service.

Research suggests that Indigenous Australians who do not have English as their first language have a greater incidence of not being offered the full range of lung cancer treatments.¹⁰⁴ The patients who participated in this study had a very good command of English. Research on lung cancer has also found that Indigenous cancer patients are less likely to have the range of treatment available for cancer, waited longer for surgery, had more co-morbidities and poorer survival than non-Indigenous patients but we should be aware that other factors will have influence on the recorded statistics.¹⁰⁴

The urban patient was willing to undergo the prescribed conventional cancer treatment however, the non-urban patient although offered surgery, refused after speaking with family members. The patient did not display any regrets over this decision and received radiation treatment instead.

Although the patient participants came from different geographical areas and had different presentations of lung cancer they did have similarities in their journey. These similarities included the desire for in good information, to feel supported when away from their home and to receive a level of care that demonstrates good communication and liaison between treating facilities. Each of the patients had unique influences on their lung cancer journey which ranged from cultural, logistical and emotional.

5.8 Non-Indigenous rural and remote lung cancer outcomes

It is acknowledged that Indigenous Australians have higher cancer incidence and mortality rates and poorer outcomes particularly in high fatality cancers such as lung cancer.^{55, 70} This has been shown to be more evident in rural and remote areas.^{7, 37, 70}

So how do lung cancer outcomes in the non-Indigenous rural and remote population compare with Indigenous rural and remote population lung cancer outcomes?

Statistics show non-Indigenous Australians who live in rural and remote areas also have excess mortality through cancer and face disadvantage compared to their city counterparts.¹⁰⁰ In Queensland, statistics sourced from Oncology Analysis System (OASys), Queensland Cancer Control Analysis Team show over years 2007-2011 the incidence of lung cancer in remote areas (ASG outer regional, remote and very remote) was 130 for Indigenous Australians and 1,407 for non-Indigenous Australians.⁵¹

A study of cancer diagnosis in Western Australia found non-Indigenous Australians from rural and remote areas also have a higher risk of dying from their cancer within 5 years than people who live in urban areas.⁴⁰ Patients often present late and this is thought to be due to the Australian characteristics of “optimism, stoicism and machismo”.⁴⁰ Australians are generally described as optimistic when dealing with symptoms suspicious of cancer and tend to believe symptoms are due to more minor illness.⁴⁰ Men often think they can manage illness on their own (stoicism) and want to be regarded as tough (machismo) which will cause them to delay seeking medical care. Self-doubt can also influence decisions to seek medical care when symptoms may not be consistent.⁴⁰

Difficulty accessing health services, travel and the fact symptoms do not interfere with activities of daily living are suggested influences on health care decisions.⁴⁰ The socio-economic status including level of education, cultural background and different view of health have also been suggested as contributing to poor outcomes in non-Indigenous Australian rural and remote populations.^{100, 105} People might delay medical care based on their own belief system or because of their family or work responsibilities.⁴⁰ Research has also found that rural patients want more information and better communication between treating facilities and GPs.¹⁰⁶

If you have cancer and live in a rural and remote area you are statistically worse off than people with cancer who live in inner regional areas and major cities. This is due to socio-economic status, belief systems, access to services, and a different view of health.¹⁰⁰

Indigenous and non-Indigenous Australians, regardless of residence, also face the stigma and nihilistic attitudes toward a lung cancer diagnosis.³¹ Therefore, non-Indigenous Australians living in rural and remote areas can face very similar challenges to health as the Indigenous Australian population.

An international study on health beliefs and culturally diverse populations found beliefs on causation of disease were largely independent of education and race. When offered a list of natural and supernatural causes of particular health conditions people of different races including European Americans rated supernatural causes such as ‘payback’ as important.³¹

Perhaps in considering health outcomes too much emphasis is placed on categorising people by race and not enough is thought about the underlying human conditions such as fear of death, shame, embarrassment or even over optimism that symptoms will resolve. The areas which should be concentrated on by health services are better access to specialist lung cancer care for early

diagnosis, better communication between health facilities and increasing GP and community knowledge of risk factors and early symptoms. Rapid access referral to lung cancer multidisciplinary teams is also a much needed strategy to decrease delays in diagnosis and treatment.

All individuals regardless of background are different but there are commonalities in regards to health and wellbeing; everyone wishes to have their views and personal wishes respected, they want to receive good information and they expect that their doctor and other health providers will engage in effective communication.

There is enough knowledge to understand the causes of rural and remote disadvantage in lung cancer outcomes including those of Aboriginal and Torres Strait Islander peoples. Coory et al (2013) cites causes of disparities are mostly in diagnosis and treatment and therefore fixed funding should be allocated to research and evaluate possible solutions over continuing to fund research to discover causes.¹⁰⁰

5.9 Assumptions and limitations

Seven sites were invited to participate in the research based on inclusion criteria. Five of those sites offered support for the research protocol. Of those five, three were given full ethical and governance approval. It was disappointing not to receive support from a community in the Torres Strait which significantly impacted on the aim of the research.

Having no real representation of Torres Strait Islander peoples in the research turned this research project into one with a focus on Aboriginal Australians. We know Torres Strait Islander peoples have a different culture and different historical influences that have impacted their social determinants than Aboriginal Australians.^{13 37} A representative sample of Torres Strait Islander peoples would have added more insight into health challenges in respect to lung cancer awareness for this population group.

The term “researched out” was given on more than one occasion as a possible reason for low interest in support for research in some Indigenous communities. The reasons given by communities who did not wish to offer support or participate was not clear. As no correspondence was received explaining their position assumptions from phone calls or unreturned phone calls could only be

made. There were indications communities and health services were research fatigued, had different priorities and believed the costs and planning would be burdensome.

The ethical process required for Indigenous research is highly complex compared to similar research in the general population. As Indigenous communities have unique ethical considerations it is deemed more appropriate for ethics applications to be submitted to a local HREC, credentialed to evaluate Indigenous research proposals and who are more aware of a community's needs.

The ethics approval processes involved gatekeeper support from Aboriginal and Torres Strait Islander councils, four HRECs, four research governance units and a PHA approval (Qld) 2005. The process therefore proved very convoluted and complex. Although HREC approval was granted for five sites, governance approvals could not be obtained despite much negotiation. No reason was formally given about why the HHS would not support research in two communities but it was intimated that cost and other priorities were the reason. This was disappointing as both communities were keen to participate in the research.

Another research governance unit placed a restriction on the research for one community where Indigenous health workers could not be recruited or participate in work hours due to perceived cost to the local health service. The process of obtaining all ethical and governance approvals including University of Queensland as an expedited review took almost 13 months. The length of time to obtain ethics prevented further sites being considered and a delay in the research commencement date.

Time involved also impacted on the continuity of maintaining interest of participating communities. The ethics process for an additional site which allowed the recruitment of an urban patient took approximately four months. Fortunately, ethics and governance approval for the amendment was "just in time" for a patient to be recruited and data included in the research.

Semi structured interviews were the method of choice for the collection of data. A significant focus of the interviews was on lung cancer awareness, access to health services and use of health information resources to ensure the aims of the study were met. Questionnaires could have been used instead of personal interviews however given the population group several assumptions were made which decided on the interview approach.

There was a degree of expectation that people would choose not to participate in interviews because the subject of lung cancer could raise fear of death or association with cultural beliefs such as payback.⁹⁵ Challenges participants may have with literacy, the advantage of being able to observe body language and other non-verbal reactions which can supplement responses to questions helped in making the decision to use interviews.⁸⁰

Interviews and focus groups are a good method for research where participants have low literacy, where English is not the first language, and where sensitive subjects are being investigated. Interviewing can provide in depth information.⁸⁰ The decision to avoid using focus groups was made on the premise that in similar studies involving Aboriginal and Torres Strait Islander peoples. In similar studies the participant rate was very low and this was assumed to be due to the shyness of the participants and the need for maintaining privacy especially considering the subject of lung cancer which might be associated with beliefs about “payback”.⁹⁵

On analysing the quantitative and qualitative data some response patterns emerged. There was a small degree of consternation amongst peers regarding validity and generalisability because of the seemingly small sample size compared to population of the participating communities.

Similar research conducted in other Australian states including Western Australia, Northern Territory and South Australia conducted interviews involving 34 participants to 157 participants. Very few were on cancer and none on lung cancer. In the Garvey et al study on insights into Aboriginal people’s view of cancer, not all participants were Indigenous. A study which investigated health service utilisation by Indigenous cancer patients had the highest participant numbers (N=157) in Queensland but this was conducted in hospital settings in major cities.^{20, 27, 34, 78, 87, 107-109}

A study by Campbell et al 2013, on smoking behaviour did recruit 593 Indigenous Australians in eight Queensland Indigenous communities through door to door surveys administered by Indigenous interviewers recruited from each community.¹¹⁰ The consultation period was over several months and the household surveys were conducted over six months.¹¹⁰ Therefore, considering the methodology used in this study, one can argue that the participant numbers recruited are acceptable if not better than originally expected.

When the protocol was developed, the sample size expected was 10-20 community members, 4-10 Indigenous health workers and 1-6 patients in each community. There were 20 community members

and six Indigenous health workers recruited in community A, 20 community members and seven Indigenous health workers in community B and 11 community members and one Indigenous health worker in Community C. The patient and Indigenous health worker groups were not as well represented as one would have hoped for.

Descriptive statistics were used to describe the interview data collected and summarise the shared responses or response patterns which have emerged. Findings from this mixed method research design based on sample size and population characteristics should be used with caution in making any generalisation or conclusions to other Indigenous communities.

Sample bias is a valid concern within the confines of small participant numbers and numerous other factors which may affect responses.⁸⁰ For instance, many people within the community are related and they could have shared experiences of health services or possibly responded to questions in a way they felt pleased the researcher.

Recruitment of participants was expected to be a challenge. It was foremostly reliant on the flyer announcing the upcoming research and sent to the communities two weeks before the intended fieldwork. Although the flyer was visible on notice boards in the communities it was an ineffective means of attracting participants. There were so many other notices which seemed to engulf the flyer. Not one participant mentioned having seen the flyer and no participants identified themselves as being one of the participant groups on the flyer.

I believe the pre organised recruitment through a snowballing technique was the most effective means of recruitment. In one community a place of business allowed one interview, and then other participants were sent along by the first participant and so on. This was very efficient but could also have introduced some unintended sample bias. Approaching people in the street was also quite effective especially if a general conversation was started with a person and time was not a consideration. If given the reason behind the research people were generally happy to participate as they believed their community would benefit.

So why do people such as those who were approached in the street give up their time to participate in the research?

Response behaviour theory has been used to examine personal interview surveys in two countries with distinct cultures; Australia and Hong Kong.¹¹¹ Self-perception was thought to influence the Australian participants' choice to volunteer for survey interviews. The "*self-perception theory*

“suggests that in liking an object, people observe their own positive behaviour. It is also suggested that culture influences participation in survey interviews and the standard practise of self-introduction and invitation to participate may not work equally in different cultural groups. The “self-perception theory “used an introductory script to test the response to participation: “*We would like to get the opinion of helpful people like you. Would you please answer a few questions*”? ¹¹¹

The “self-perception theory” supports the approach used to recruit participants in this research study. Potential participants were asked to give their opinion for the purpose of improving lung cancer services in Aboriginal and Torres Strait Islander communities and used similar wording on the flyer (See Appendix 2). It is unknown if a different approach may have helped increase participation rate. An “exchange approach” for example may have increased participation. The approach involves participants being offered some sort of motivation such as a voucher, a commitment or an involvement which uses their connection to the community or a social group.¹¹¹

An air of suspicion of what would be asked in interviews was also apparent across communities. The body language of some people in the 18-30 age groups, especially young men, demonstrated disinterest. There are people who do not wish to divulge personal information or opinions so suspicion and disinterest should be expected.

Indigenous Australians need to be included from the outset of any project or health intervention whether it is research based or not.⁶⁹ Collaboration and inclusion gives Indigenous community members a sense of ownership and projects or health interventions are more likely to succeed.⁶⁹ This is why I visited the communities and key stakeholders to consult on research design prior to ethics applications being submitted. However despite efforts to engage, the subject of lung cancer did not raise a noticeable level of interest.

6. Conclusion

The ‘Lung cancer in rural and remote Aboriginal and Torres Strait Islander communities in Queensland’ project was a rewarding research journey both professionally and personally despite the unforeseen challenges. My first preparation was cultural awareness training which I had completed on several occasions during my employment with Queensland Health. I was soon to discover that research involving Indigenous peoples requires a deeper level of cultural awareness than what can be offered in a day’s training. There are different cultures in different communities and each population has been affected or influenced by governments of the day, environmental factors, and other intangible elements unique to individual people.^{13, 22, 33}

Research involving Indigenous Australians must be conducted in a manner which does not put participants at risk of further adversity.³³ The ethical protocols and procedures put in place protect both the researcher and the participant.³³ There was not enough time allocated within the project plan to acquire gatekeeper permissions and support, gain ethical clearances, and communicate widely with stakeholders, to finally receive ethical approval and research governance approvals without delaying agreed project timelines. Almost a year passed before fieldwork was able to be commenced and data collection was ongoing until July 2014.

Protocols for Indigenous research state the importance of involving the community in the research from the outset and at every level and definitely prior to seeking ethical and governance approvals. The communities must be supportive if the research is to be successful. Keeping the communities involved and visiting communities is the most optimal way to gain support.³³

An introductory letter or a phone call is formal but relationships need to be built over time so an environment of trust and mutual respect is achieved. It is also important that the right people within the community are contacted. This is where I found difficulty. My own reservation and the concern that I would inadvertently conduct myself in a culturally insensitive manner only proved to add barriers to seeking out the best contacts in the communities.

It was only when I commenced fieldwork I realised how important it is to gain support from community groups such as ‘health action groups’ or ‘women’s and men’s groups’. I believe a longer period of consultation at the planning stage would have been worth the extra budget cost.

I also found preconceived ideas partly imposed on me by colleagues (including those involved in mandatory cultural training) restricted my approach to community members as I felt acutely aware

that I could upset or alienate people by my words or actions. Some colleagues were worried about the findings of the research and the sample size. Qualitative research often involves small participant groups. Other qualitative studies involving Aboriginal communities had similar if not smaller sample sizes and these studies are well cited in literature as evidential of a research problem.

The findings from this study reinforce other research findings and also raise further questions for research. I would find it particularly interesting to have included North West Hospital and Health Service and Torres Strait and Cape Hospital and Health service as these areas have the most Indigenous communities, Indigenous languages are in more use and due to the remoteness accessing tertiary level services would likely be more challenging. The areas have different histories, cultures, languages and are located in the most remote regions of Australia.

On reflection, the research design might have included not only Indigenous Health Workers but Indigenous nurses, doctors and allied health workers. Indigenous health workers often are not privy to patient outcomes from doctor's visits and therefore may not be informed enough to be involved in the patient journey. This is unfortunate as the Indigenous health workers are at the forefront of the health services situated in Indigenous locations, and can be the first health professional an Indigenous Australian approaches with a health concern.

In hindsight, more open ended questions should have been included on the interview schedule to gain a deeper understanding of health seeking behaviours and cultural influences which impact on health decisions. This line of enquiry may have given a greater insight into other reasons Indigenous Australians face poor health outcomes including lung cancer outcomes

“Does the influence of western culture influence how Indigenous Australians view health?” The communities who participated in this study were relatively close in comparison to large regional or tertiary level services with the average distance being 146 km even though one community was not accessible by road. The participants of the research were therefore relatively close to a regional centre, had access to modern technologies and services.

Religious beliefs are also thought to influence traditional Aboriginals living with Christian influences stemming from colonisation.²⁷ Shahid's et al (2010) study on bush medicine also concluded the influence of western culture on traditional practises.²⁷ Therefore if research was conducted in communities less exposed to western culture and technology such as very remote outer

islands of the Torres Strait Islander or areas of Cape York and Gulf of Carpentaria then responses to the interview questions are likely to be very different. Lessons learned in this study and applied to a repeat study would also likely result in different conclusions. The data collected and analysed for this study should be taken in context of the sample population and be viewed accordingly.

While this study did have several limitations, overall it provided information regarding the level of lung cancer awareness in the community, health seeking behaviours which might be influenced by culture (e.g. traditional medicine, seeking consent) and the knowledge gap Indigenous health workers have in regards to the lung cancer pathway. Using this knowledge, recommendations on have been developed so health professionals and health services can identify areas for further research and seek solutions to the lung cancer disparity which exists in the Indigenous Australian population compared to the non-Indigenous population.

6.1 Recommendations

The following recommendations have been developed as a result of this research study.

1. Research activities in Indigenous communities must include a suitable consultative period and involvement of local Indigenous people. This will help build relationships, foster trust and give the community a sense of ownership resulting in increased participation.
2. Barriers to health care can be largely mitigated at a local level. Encouraging people to learn and be responsible for their health through improved health literacy can be supported by health promotion, prevention and provision of basic health checks in the community. Investing in and acknowledging the Indigenous health worker and Indigenous hospital liaison workforces is important to ensure Aboriginal and Torres Strait Islander people have access to continuing advocacy during the lung cancer journey.
3. Communication processes between local health services and regional and tertiary hospitals need improving. Multidisciplinary teams (MDTs) have a responsibility to ensure communication between treating teams is effective.
4. Cancer care coordinators help patients navigate the lung cancer pathway but this service is generally offered once a confirmed diagnosis is made and when the patient commences treatment at the tertiary centre. How much communication occurs between the Indigenous health worker, Indigenous hospital liaison officer and cancer care coordinator should be explored. Collaboration between these health professionals at the beginning of the lung cancer pathway could contribute to improved patient outcomes. Indigenous health workers and Indigenous hospital liaison officers should also be involved in lung cancer multidisciplinary meetings to act as the patient advocate and be more aware of the treatment path of their patients.
5. The research findings suggest that cancer care coordination should not be limited to patients from rural and remote areas. There is an identified need for care coordination to be offered to all patients regardless of residence to ensure people who have low health literacy, linguistic challenges, cultural needs and other special needs do not face poorer lung cancer outcomes than other lung cancer patients.

6. Investing in lung cancer awareness campaigns will be beneficial not only to the community but also for Indigenous health workers and other health professionals. This will ensure they are equipped with the knowledge and resources to assist and support patients and families navigate the often complex lung cancer pathway.

7. Smoking is recognised as the major risk for lung cancer and as Indigenous Australians have a higher smoking rate than non-Indigenous Australians, a concentrated effort should be placed on early anti-smoking education particularly amongst the younger population. A school based program could be considered. Access to subsidised nicotine replacement therapies and community health support should be made available to young adult and older Indigenous Australians. Activities that are novel and community based could be trialled, for example, a community ‘stop smoking challenge’ that has a worthwhile incentive to participate.

8. Although culturally targeted resources are preferred by many Indigenous Australians it is not proved that conventional resources are unsuitable. More work is required to evaluate the effectiveness of health information resources both generic and culturally targeted. Information needs of Aboriginal and Torres Strait Islander peoples will change in line with improved education and access to technology. Evidence is required to ensure resources are relevant and effective in health promotion and prevention and commensurate with changing population characteristics, socio-economic factors, culture and education.

9. Further research on lung cancer in Indigenous communities is needed in Queensland to investigate the level of lung cancer awareness and other factors which influence decision making in health. This would be of particular benefit to those communities in the Torres Strait and Cape Hospital and Health Service areas where there are higher populations of Indigenous peoples. The extent of lung cancer as a hidden problem in Aboriginal and Torres Strait Islander communities is unknown and it remains unknown whether people with symptoms suspicious of lung cancer are diagnosed or offered the full range of diagnostic and treatment options.

10. Research on solutions to achieving early diagnosis and treatment of lung cancer should be undertaken and evaluated. Solutions might include rapid referral processes for GPs and testing the feasibility of expanding care coordination roles to urban areas.

10. Implementing rapid referral processes, developing MDT communication tools and encouraging GP and IHW involvement in patients' treatment and follow-up, will contribute to strengthening patients' chances of early diagnosis, uptake of treatment and completion of treatment.

11. The ethics approval process for research involving Aboriginal and Torres Strait Islander peoples needs review by the Office of Health and Medical Research. An HREC established for all Indigenous specific research including multicentre studies should be considered. Each HHS and Indigenous community could be represented. Continuing with processes will risk research being conducted in a rushed manner which may result in the abandonment of valuable projects.

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Appendix 1: Questions used for the interviews

PART A: Demographics		
A1	Are you Aboriginal, Torres Strait Islander or both?	<input type="checkbox"/> Aboriginal <input type="checkbox"/> Torres Strait Islander <input type="checkbox"/> Both Aboriginal and Torres Strait Islander
A2	Do you speak any other language besides English?	<input type="checkbox"/> Yes Dialect _____ <input type="checkbox"/> No
A4	What is your age bracket?	<input type="checkbox"/> 18 yrs-30 yrs. <input type="checkbox"/> 31 yrs-50 yrs. <input type="checkbox"/> 51 yrs-65 yrs. <input type="checkbox"/> Over 65 yrs.
A6	How much income do you get in a year?	<input type="checkbox"/> Less than \$20 000 <input type="checkbox"/> \$20 001 to \$40 000 <input type="checkbox"/> \$40 001 to \$60 000 <input type="checkbox"/> \$60 001 to \$100 000 <input type="checkbox"/> Over \$100 000 <input type="checkbox"/> Declined, no response
A7	What is your level of schooling?	<input type="checkbox"/> No formal education <input type="checkbox"/> Primary school <input type="checkbox"/> Started high school but did not finish grade 10 <input type="checkbox"/> Grade 10 (or equivalent) <input type="checkbox"/> Grade 12 (or equivalent) <input type="checkbox"/> Trade certificate/ apprenticeship <input type="checkbox"/> TAFE, technical or other similar course (i.e. diploma) <input type="checkbox"/> Undergraduate university degree (bachelor) <input type="checkbox"/> Post-graduate university degree (masters, doctorate) <input type="checkbox"/> Unsure <input type="checkbox"/> Declined, no response
A8	Are you married or do you have a partner?	<input type="checkbox"/> Single (never married) <input type="checkbox"/> Married, or living as married <input type="checkbox"/> In a significant relationship but not living together <input type="checkbox"/> Widowed <input type="checkbox"/> Separated, divorced or no longer living as married <input type="checkbox"/> Declined/no response

		<input type="checkbox"/> Pensioner concession card <input type="checkbox"/> DVA treatment card - Gold <input type="checkbox"/> DVA treatment card - White <input type="checkbox"/> DVA treatment card - Orange <input type="checkbox"/> Commonwealth Senior Health Card <input type="checkbox"/> Health care card (Australian Government issued) <input type="checkbox"/> Taxi card/ Dept. of Transport disability card <input type="checkbox"/> Other, <i>please specify</i> <input type="checkbox"/> Unsure <input type="checkbox"/> Declined/no response
A9	Do you have any government concession cards?	

PART B: Current Health Status

		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Declined/no response
B1	Do you smoke?	
		<input type="checkbox"/> Yes GO TO B3 <input type="checkbox"/> No GO TO B7 <input type="checkbox"/> Declined/no response GO TO B7
B2	Have you ever smoked?	
		<input type="checkbox"/> <input type="text"/> <input type="text"/> years <input type="checkbox"/> Unsure <input type="checkbox"/> Declined/no response
B3	What age did you start smoking regularly?	
		<input type="checkbox"/> <input type="text"/> <input type="text"/> <input type="text"/> cigarettes <input type="checkbox"/> Unsure <input type="checkbox"/> Declined/no response
B4	How many smokes do you have a day?	
		<input type="checkbox"/> <input type="text"/> <input type="text"/> years <input type="checkbox"/> Unsure <input type="checkbox"/> Declined/no response
B5	If you quit smoking, what age did you quit?	
		<input type="checkbox"/> Yes → <input type="text"/> <input type="text"/> years <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Declined/no response
B6	Have there been any whole years when you did not smoke (e.g. during pregnancy)?	
	If yes, for how many whole years did you not smoke?	
B7	Are you being treated by doctors for any serious illness?	
<i>a</i>	Heart disease	<input type="checkbox"/>
<i>b</i>	Circulation problems	<input type="checkbox"/>
<i>c</i>	Stroke	<input type="checkbox"/>
<i>d</i>	Hypertension	<input type="checkbox"/>
<i>f</i>	Skin problems <i>e.g. Rheumatoid arthritis, lupus, scleroderma</i>	<input type="checkbox"/>

<i>g</i>	Stomach ulcers	<input type="checkbox"/>
<i>h</i>	Liver disease	<input type="checkbox"/> If yes, ▼
	<i>Have you been told you have:</i>	<input type="checkbox"/> Portal Hypertension (<i>high blood pressure in the liver</i>) <input type="checkbox"/> Cirrhosis (<i>scarring of the liver</i>) <input type="checkbox"/> Chronic Hepatitis
<i>i</i>	Diabetes	<input type="checkbox"/>
<i>k</i>	Kidney problems	<input type="checkbox"/>
	<i>Have you needed:</i>	<input type="checkbox"/> A Transplant <input type="checkbox"/> Dialysis
<i>l</i>	Other Cancer	<input type="checkbox"/> If yes, ▼
	<i>Was the cancer diagnosed in the last 5 years</i>	<input type="checkbox"/>
<i>m</i>	Has the cancer gotten bigger or spread?	<input type="checkbox"/>

PART C: Social Situation

C1	Do you have anyone at home who you care for /depend on you to look after them?	<input type="checkbox"/> Yes, please specify below ▼ <input type="checkbox"/> No <input type="checkbox"/> Declined, no response
C2	If yes, please specify all options that apply	
<i>a</i>	Child or children	<input type="checkbox"/>
<i>b</i>	Spouse	<input type="checkbox"/>
<i>c</i>	Parent	<input type="checkbox"/>
<i>d</i>	Friend	<input type="checkbox"/>
<i>e</i>	Other	<input type="checkbox"/>
<i>e.i</i>	If Other, please specify	

C3	Do you have a job?	<input type="checkbox"/> Employed/ Self-employed - full time <input type="checkbox"/> Employed/ Self-employed - part time (<35 hrs./week) <input type="checkbox"/> Employed/Self-employed - casual <input type="checkbox"/> Full time home duties <input type="checkbox"/> Unemployed or looking for work <input type="checkbox"/> Student <input type="checkbox"/> Retired <input type="checkbox"/> Permanently ill/unable to work <input type="checkbox"/> Unpaid work in a family business or farm <input type="checkbox"/> Unpaid voluntary work <input type="checkbox"/> Declined/no response
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What sort of work do you do?

- Manager or senior official
 - Professional (e.g. lawyer, teacher, engineer)
 - Administrative or secretarial
 - Skilled trades
 - Sales or customer service
 - Plant or machine operator
 - Manual Labour
 - Unemployed
 - Other
 - Declined/no response
-

PART E: Lung Cancer Awareness

E1 What do you know about lung cancer?

E2 What do you think might cause lung cancer?

E3 I will read off some symptoms a person that might cause a person to visit the doctor. Could you tell me if you think any of them are a warning sign of lung cancer? *(Select all that are answered yes)*

- Weight loss for no reason
 - Cough that won't go away
 - Existing cough changes, gets worse or painful
 - Coughing up blood
 - Ache or pain in chest when breathing
 - Shortness of breath
 - Shoulder pain for no reason
 - lump in the neck
-

E4 How long would you wait to go to the health worker, clinic/doctor if you had any of these things wrong with you?

When participant has answered question, the interviewer says:
"Any of the symptoms mentioned could be a warning sign of lung cancer. These signs can also be caused by other sickness such as an infection"

- Go to health worker, clinic/doctor as soon as I could
 - one to two weeks
 - Longer than 2 weeks
 - Wouldn't go at all *(Could you please explain why)*
 - Unsure
-

E5 Now you know these symptoms might be warning signs of lung cancer, how long would you wait before you went to the health worker, clinic/doctor if you had any of them?

- Go to health worker, clinic/doctor as soon as I could
 - one to two weeks
 - Longer than 2 weeks
 - Wouldn't go at all *(Could you please explain why)*
 - Unsure
-

PART F: Support Services

F1 Do you have a regular general practitioner (GP)?

- Yes GO TO F2
 - No GO TO F4
 - Unsure GO TO F4
-

F2 What is the name of your regular GP?

F3	What is the name of the practice where they work?	
F4	Do you have access to an Indigenous Health worker?	<input type="checkbox"/> Yes GO TO F5 <input type="checkbox"/> No GO TO F6 <input type="checkbox"/> Unsure GO TO F6
F5	Do you use the Indigenous health worker service?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure
F6	Have you heard of the following services and organisations? (Select all that apply)	<input type="checkbox"/> HACC e.g. Blue Care <input type="checkbox"/> ATODS (Alcohol, Tobacco and Drugs Service) <input type="checkbox"/> Lung Foundation Australia <input type="checkbox"/> Cancer Council Queensland <input type="checkbox"/> Have not heard of any of these <input type="checkbox"/> Unsure
F7	Do you know if you can access the following health professionals in your community?	<input type="checkbox"/> Nutrition and Dietetics <input type="checkbox"/> Physiotherapy <input type="checkbox"/> Occupational Therapy <input type="checkbox"/> Social Work <input type="checkbox"/> Psychology <input type="checkbox"/> Psychiatry <input type="checkbox"/> Indigenous Health Worker <input type="checkbox"/> Indigenous Hospital Liaison Officer <input type="checkbox"/> Unsure
F8	Do you use modern medicine when you have an illness? Interviewer prompt: western treatments-white man's medicine	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Declined, no response
F9	Do you use traditional bush medicine or other alternative treatments when you have an illness?	<input type="checkbox"/> Yes if yes go to F10 <input type="checkbox"/> No if no go to F12 <input type="checkbox"/> Declined, no response
F10	What alternative treatments do you or have you used? Interviewer prompt: are these general alternative treatments or traditional bush medicine?	<input type="checkbox"/> Traditional /bush medicine <input type="checkbox"/> Acupuncture <input type="checkbox"/> Chiropractic <input type="checkbox"/> Naturopathic medicine <input type="checkbox"/> Other _____ <input type="checkbox"/> Declined/no response
Can you tell me more about your experience alternative treatments?		
F11	Interviewer: substitute alternative with participants response in F10 e.g. Can you tell me more about your experience with traditional bush medicine?	
F12	Have you known anyone who has sought traditional medicine instead of modern treatments? Could you tell me anything about their experience?	
PART G: Financial and social impact of treatment		
G1	Do you hold a current driver's license?	<input type="checkbox"/> Yes <input type="checkbox"/> No
G2	Do you own or have access to a car?	<input type="checkbox"/> Yes <input type="checkbox"/> No

		<input type="checkbox"/> Private car <input type="checkbox"/> Public transport (e.g. bus, train) <input type="checkbox"/> Transport service (e.g. hospital patient bus) <input type="checkbox"/> Taxi <input type="checkbox"/> Coach (e.g. Greyhound bus service) <input type="checkbox"/> Walk <input type="checkbox"/> Plane or helicopter <input type="checkbox"/> Have never travelled for medical treatment Go to Part H <input type="checkbox"/> Other, please specify <input type="checkbox"/> Unsure
G3	How do you mostly travel if you have to leave your community for medical treatment?	
G4	Who mostly organises travel if you have to leave your community for medical treatment	<input type="checkbox"/> I mostly organise my travel <input type="checkbox"/> The Hospital Travel Department organises my travel <input type="checkbox"/> Other, please specify <input type="checkbox"/> Unsure
G5	Do you mostly take a family member or carer to medical appointments? <i>Interviewer prompt: does someone go with you to the hospital appointments?</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Sometimes <input type="checkbox"/> Declined/no response
G6	When you have travelled a long distance for medical treatment what type of accommodation did you mostly use if it was available?	<input type="checkbox"/> Friend or relatives house <input type="checkbox"/> Hotel or motel (other than hospital accommodation) <input type="checkbox"/> Hospital accommodation <input type="checkbox"/> Boarding house <input type="checkbox"/> Accommodation provided by charity, research foundation or church association <input type="checkbox"/> Other, please specify <input type="checkbox"/> Unsure
G7	What do you think cost you the most money for your medical treatment?	
a	Appointment costs (GP, specialist or other health professional)	<input type="checkbox"/>
b	Diagnostic tests (blood tests, x-rays, scans etc.)	<input type="checkbox"/>
c	Travel to doctor appointments and or test appointments (petrol, fares etc.)	<input type="checkbox"/>
d	Accommodation (meals etc.)	<input type="checkbox"/> <input type="checkbox"/> Other, please specify <input type="checkbox"/> Unsure
G8	Did a family member need to take time off <u>paid</u> work for you to attend medical appointments? This includes time off work that is paid e.g. sick leave	<input type="checkbox"/> Yes, myself <input type="checkbox"/> Yes, a family member <input type="checkbox"/> Yes, both myself and a family member <input type="checkbox"/> No, neither myself or a family member <input type="checkbox"/> Unsure <input type="checkbox"/> Declined, no response
G9	Did you or a family member have to take time off <u>unpaid</u> work for you to attend medical appointments? This includes volunteer work and caring for children or grandchildren	<input type="checkbox"/> Yes, myself <input type="checkbox"/> Yes, a family member <input type="checkbox"/> Yes, both myself and a family member <input type="checkbox"/> No, neither myself or a family member <input type="checkbox"/> Unsure <input type="checkbox"/> Declined/no response

PART H: Information Resources

H1	Have you ever been given any information resources to understand an illness for example, a booklet or a pamphlet?	<input type="checkbox"/> Yes <input type="checkbox"/> No Go to H5 <input type="checkbox"/> Unsure
H2	What type of media was used? Interviewer prompt: how did the doctor or nurse tell you and your family about your illness?	<input type="checkbox"/> Poster <input type="checkbox"/> Pamphlet <input type="checkbox"/> Booklet or flip chart <input type="checkbox"/> DVD <input type="checkbox"/> Doctor's drawing <input type="checkbox"/> Other: describe _____
H3	Was the information designed for Aboriginal and Torres Strait Islander peoples?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure
H4	If the information was not designed for Aboriginal and Torres Strait Islander peoples did you find it useful anyway?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat useful <input type="checkbox"/> Useful <input type="checkbox"/> Extremely useful <input type="checkbox"/> Declined/no response
H5	Would you more likely use information if it is designed for Aboriginal and Torres Strait Islander peoples?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not important Reason: <input type="checkbox"/> Unsure
H6	a. What media do you find most useful? (select all that apply) b. Can you tell me why you like that particular media? Narrative:	<input type="checkbox"/> Poster <input type="checkbox"/> Pamphlet <input type="checkbox"/> Booklet or flip chart <input type="checkbox"/> DVD: information only <input type="checkbox"/> DVD that tells a story <input type="checkbox"/> Other: describe _____
H7	Do you know about the internet?	<input type="checkbox"/> Yes Go to H8 <input type="checkbox"/> No Go to Part I <input type="checkbox"/> Unsure
H8	Do you know how to use the internet?	<input type="checkbox"/> Not at all <input type="checkbox"/> Some knowledge <input type="checkbox"/> Confident in using <input type="checkbox"/> Unsure
H9	Are you able to access the internet?	<input type="checkbox"/> No Go to Part I <input type="checkbox"/> Yes Go to H10 <input type="checkbox"/> Unsure Go to Part I
H10	Do you own any of the listed devices to use the internet?	<input type="checkbox"/> Tablet <input type="checkbox"/> Smart Phone <input type="checkbox"/> Mobile Phone <input type="checkbox"/> Personal computer <input type="checkbox"/> Other please describe

H11	Do you use the internet to learn about your health?	<input type="checkbox"/> Not at all <input type="checkbox"/> Rarely <input type="checkbox"/> Sometimes <input type="checkbox"/> Frequently <input type="checkbox"/> Unsure
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PART I: Reflection

I1	What illness do you worry most about yourself or someone close to you getting?
I2	Thinking about your experience on any previous medical treatment you have received what could have been done better by the health service? <i>We are interested in your views and ideas. Were you given enough support and information?</i>

Questions specific to Indigenous Health Workers

PART D: Access to medical treatment and cultural influences	
D1	Have you known any person in your community that has been referred to a respiratory specialist because the doctor was worried they had lung cancer? <input type="checkbox"/> Yes Go to D2 <input type="checkbox"/> No Go to D3 <input type="checkbox"/> Unsure <input type="checkbox"/> Declined/no response
D2	In your opinion, what were the barriers if any, to the medical treatment patients faced? (What if anything, made it difficult for the patient to have treatment)
D3	Do you know what the lung cancer diagnostic pathway means?
D4	What tests do you think a patient would need if the doctor thought they had lung cancer?
D5	In your experience how do patients mostly travel if they have to leave the community for medical treatment? <input type="checkbox"/> Private car <input type="checkbox"/> Public transport (e.g. bus, train) <input type="checkbox"/> Transport service (e.g. hospital patient bus) <input type="checkbox"/> Taxi <input type="checkbox"/> Coach (e.g. Greyhound bus service) <input type="checkbox"/> Walk <input type="checkbox"/> Plane or helicopter <input type="checkbox"/> Other, please specify <input type="checkbox"/> Unsure
D6	Who mostly organises travel for patients to attend medical treatment <input type="checkbox"/> Patient mostly organises own travel <input type="checkbox"/> Hospital Travel Department mostly organises patient travel <input type="checkbox"/> Other, please specify <input type="checkbox"/> Unsure
D7	Do most patients take a family member or carer to medical appointments? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure

D8	If a patient does have to travel a long distance for medical treatment please specify the type of accommodation you would expect them to mostly use if it were available	<input type="checkbox"/> Friend or relatives house <input type="checkbox"/> Hotel or motel (other than hospital accommodation) <input type="checkbox"/> Hospital accommodation <input type="checkbox"/> Boarding house <input type="checkbox"/> Accommodation provided by charity, research foundation or church association <input type="checkbox"/> Other, please specify <input type="checkbox"/> Unsure
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D9	What do you think would cost the patient most for their medical treatment?	
a	Appointment costs (GP, specialist or other health professional)	<input type="checkbox"/>
b	Diagnostic tests (blood tests, x-rays, scans etc.)	<input type="checkbox"/>
c	Travel to doctor appointments and or test appointments (petrol, fares etc.)	<input type="checkbox"/>
d	Accommodation (meals etc.)	<input type="checkbox"/> <input type="checkbox"/> Other, please specify <input type="checkbox"/> Unsure

PART E: Information resources

E11	Do you think a lung cancer training resource for Indigenous health workers would be useful?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure
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E12	In your opinion what style of training resource would be beneficial to you?	<input type="checkbox"/> Learning package with easy to read information, drawings and quizzes <input type="checkbox"/> Learning by using a game. <input type="checkbox"/> Information only package <input type="checkbox"/> Tutorials by respiratory health professionals <input type="checkbox"/> Training module, which would include in-depth reading and assignments. <input type="checkbox"/> Other please describe
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E13	Have you ever been given any information resources to patients for their illness?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure
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E14	What type of media was used?	<input type="checkbox"/> Poster <input type="checkbox"/> Pamphlet <input type="checkbox"/> Booklet or flip chart <input type="checkbox"/> DVD <input type="checkbox"/> Doctor's drawing <input type="checkbox"/> Other please describe
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E15	Was the information designed for Aboriginal and Torres Strait Islander peoples?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure
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E16	If the information was not designed for Aboriginal and Torres Strait Islander peoples did you find it useful anyway?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat useful <input type="checkbox"/> Useful <input type="checkbox"/> Extremely useful <input type="checkbox"/> Unsure
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E17	If the information was not designed for Aboriginal and Torres Strait Islander peoples did you believe the patient found it useful anyway?	<input type="checkbox"/> Not at all <input type="checkbox"/> Somewhat useful <input type="checkbox"/> Useful <input type="checkbox"/> Extremely useful <input type="checkbox"/> Unsure
E18	Would you more likely use information to inform patients if it is designed for Aboriginal and Torres Strait Islander peoples?	<input type="checkbox"/> Not more likely to use than other general resources <input type="checkbox"/> Somewhat more likely to use <input type="checkbox"/> Definitely would use <input type="checkbox"/> Unsure
E17	a. What media do you find most useful to inform patients (select all that apply) b. Can you tell me why you prefer that particular media to inform patients?	<input type="checkbox"/> Poster <input type="checkbox"/> Pamphlet <input type="checkbox"/> Booklet or flip chart <input type="checkbox"/> DVD: information only <input type="checkbox"/> DVD that tells a story <input type="checkbox"/> Other please describe

Questions specific to patient

Part D: Family support

D1	How many immediate family members do you have? Interviewer prompt: For example children, wife, sisters, brothers, aunts, uncles. Family that are related to you.	1 <input type="checkbox"/> None 2 <input type="checkbox"/> 1-2 3 <input type="checkbox"/> 3-5 4 <input type="checkbox"/> 6-9 5 <input type="checkbox"/> 10 or more 99 <input type="checkbox"/> Declined/no response
D2	How many of these family members do you have contact with at least once a month?	1 <input type="checkbox"/> None 2 <input type="checkbox"/> 1-2 3 <input type="checkbox"/> 3-5 4 <input type="checkbox"/> 6-9 5 <input type="checkbox"/> 10 or more 99 <input type="checkbox"/> Declined /no response
D3	How many close friends do you have?	<input type="checkbox"/> None <input type="checkbox"/> 1-2 <input type="checkbox"/> 3-5 <input type="checkbox"/> 6-9 <input type="checkbox"/> 10 or more <input type="checkbox"/> Declined/no response
D4	How many of these friends do you have contact with at least once a month?	<input type="checkbox"/> None <input type="checkbox"/> 1-2 <input type="checkbox"/> 3-5 <input type="checkbox"/> 6-9 <input type="checkbox"/> 10 or more <input type="checkbox"/> Declined/no response

D5	How many hours each week, if any, do you normally attend a community group? Interviewer prompt: such as a sport group, church-connected group, self-help group, charity, public service or community group?	<input type="checkbox"/> None <input type="checkbox"/> 1 to 2 hours <input type="checkbox"/> 3 to 5 hours <input type="checkbox"/> 6 to 10 hours <input type="checkbox"/> 11 to 15 hours <input type="checkbox"/> 16 or more hours <input type="checkbox"/> Declined/no response
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PART F: Access to medical treatment and support services

F1	Who referred you to the respiratory specialist for your lung symptoms?	<input type="checkbox"/> General Practitioner <input type="checkbox"/> Local Hospital <input type="checkbox"/> Specialist <input type="checkbox"/> Other, <i>please specify</i> <input type="checkbox"/> Unsure
<i>F1.i</i>		

F7	What is your understanding of the reason you were referred to the lung specialist? (Narrative)
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F8	What was the <u>main</u> purpose of your visit to the doctor on the day that the referral to the respiratory specialist was made? <i>Interviewer selects the answer that most closely matches</i>	<input type="checkbox"/> New or worsening symptoms <input type="checkbox"/> General check-up <input type="checkbox"/> Prescription renewal <input type="checkbox"/> Management of existing condition or diagnosis <input type="checkbox"/> Follow up of test results <input type="checkbox"/> For referral to another specialist or allied health professional e.g. physiotherapist <input type="checkbox"/> Other, <i>please specify</i> <input type="checkbox"/> Unsure
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F9	What symptom/s, if any, have you had? <i>Select ALL answers that apply</i>	
a	None	<input type="checkbox"/> ► GO TO F14
b	Cough	<input type="checkbox"/>
c	Weight loss	<input type="checkbox"/>
d	Short of breath	<input type="checkbox"/>
e	Coughing blood	<input type="checkbox"/>
f	Chest pain	<input type="checkbox"/>
g	Pain (other than chest)	<input type="checkbox"/>
h	Lethargy	<input type="checkbox"/>
i	Fever	<input type="checkbox"/>
j	Other	<input type="checkbox"/>
j.i	<i>If other, please specify</i>	

What was the first symptom you noticed?
 F10 Interviewer prompt: what was the first thing you noticed was wrong with you?

The following questions refer to this symptom:

a. How long did you have this symptom?

Months Days

b. How many visits to a doctor have you made since first noticing this symptom?
This does not include the visit to the lung specialist

- 1
- 2
- 3
- 4
- More than 4
- Unsure

F11 Did you wait for a length of time before seeing a doctor?

- Yes (more than 1 week) go to F12
- No Go to F13a
- Unsure

F12 Why did you wait before seeing the doctor?

- Scared of what was wrong
- Not enough time
- Family or work responsibilities
- Distance to access medical treatments
- Hoping symptoms would go away
- Other _____
- Unsure

F13a Could you tell me the type of doctors you have seen since you first had signs or symptoms?

- GP
- Respiratory Specialist
- Thoracic Surgeon
- Cardiologist
- Radiation Oncologist
- Medical Oncologist
- Traditional Healer
- Other _____
- Unsure

Where were the doctors located? *Tick all that apply*

b

- Local Hospital
- Community Health Centre
- Regional Hospital
- Brisbane Hospital
- Other _____
- Unsure

F14 What tests did you have before seeing the respiratory specialist?
Select all that apply:

- a None
- b Chest XRAY
- c CT Scan
- d Sputum test
- e Blood test

f	Other	<input type="checkbox"/> please specify
g	Unsure	<input type="checkbox"/>
F15	How long did it take before you were told by the doctor what was wrong with you?	<input type="checkbox"/> Less than 1 week <input type="checkbox"/> 1 to 2 weeks <input type="checkbox"/> 2 to 4 weeks <input type="checkbox"/> 1 to 2 months <input type="checkbox"/> 2 to 4 months <input type="checkbox"/> more than 4 months <input type="checkbox"/> Unsure
F16	When you were getting medical treatment for your lung illness did you get help from any of the following services? Select all that apply.	<input type="checkbox"/> None <input type="checkbox"/> HACC e.g. Blue Care <input type="checkbox"/> ATODS (Alcohol, Tobacco and Drugs Service) <input type="checkbox"/> Lung Foundation Australia <input type="checkbox"/> Cancer Council Queensland <input type="checkbox"/> Other _____ <input type="checkbox"/> Unsure
F17	Were you aware you could get help from these services?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure
F18	When you were getting medical treatment for your lung illness did you get help from the following health services?	<input type="checkbox"/> None <input type="checkbox"/> Nutrition and Dietetics <input type="checkbox"/> Physiotherapy <input type="checkbox"/> Occupational Therapy <input type="checkbox"/> Social Work <input type="checkbox"/> Psychology <input type="checkbox"/> Psychiatry <input type="checkbox"/> Indigenous Health Worker <input type="checkbox"/> Hospital Liaison Officer <input type="checkbox"/> Other _____ <input type="checkbox"/> Unsure
F19	Were you aware you could get help from these services?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure

Have you an hour spare to help your community?

Are you aware of the effects that lung cancer has on your community or family?

The Queensland Health Indigenous Respiratory Outreach Care (IROC) Program and The University of Queensland are undertaking a research study in (insert community) to improve lung cancer services.

If you belong in any of the groups below, Barbara Page would like to have a yarn with you.

- Have had lung cancer or have lung cancer now
- Have gone to a hospital outside of (insert community) for tests because your doctor was worried you might have lung cancer
- Aboriginal and/or Torres Strait Islander person aged 18 years and older and able to give consent

Barbara will be visiting (insert community) during (insert week and month) and will be at the (insert location)

You can ring her on



Appendix 3: Participant information sheet

HREC No:	
Project Title:	Lung Cancer in rural and remote Aboriginal and Torres Strait Islander communities in Queensland
Name of Researchers:	Barbara Page, A/Prof Ian Yang, A/Prof Rayleen Bowman, Prof Kwun Fong
Sponsor Details:	Queensland Health Indigenous Respiratory Outreach Care Program Cancer Australia 'Supporting people with cancer Grant Initiative 2012'

The Queensland Health Indigenous Respiratory Outreach Care Program (IROC) is doing research to improve lung cancer services for Aboriginal and Torres Strait Islander peoples from rural and remote communities in Queensland. The study is partly funded by Cancer Australia.

Why have I been asked to take part?

We are asking people who have been sent for tests by their doctor to see if they have lung cancer, people with lung cancer or who have had lung cancer before. We are also asking Indigenous health workers and other people who live in the community who may have an interest in lung cancer to take part.

Do I have to take part?

You don't have to take part. If you do, you have to sign a consent form. If you change your mind you can pull out of the research without giving a reason at any time.

What do I have to do?

A researcher from the IROC Program, who is also a student of The University of Queensland, will ask you some questions. This could take about an hour. You can ask for an interpreter or have a family member or friend with you. There will be an Indigenous project officer in the room to help the researcher. After asking questions, the researcher will check your answers with you to make sure you agree with what has been written down. The researcher may also use a digital voice recorder to help make sure what you say has been written down right. You can refuse to have your voice recorded. Any voice recording will be deleted after the project has finished. Apart from using some of your time to help with the research, you could feel uneasy answering questions. You can say no to answering questions you feel uncomfortable with.

Is my information private?

Your name and where you live will only be known by the researcher. Your answers to questions are kept private. Your name will be taken off any paperwork and computer databases once the project has ended and the information is stored. Any voice recordings will be deleted.

What happens to the information that is collected?

The information from interviews will be kept by the research team in a locked cupboard in an office and also in a safe password protected computer database at The Prince Charles Hospital Chermside, Queensland. No names or private details will be stored or shown in any report. Any reports from the research will be given to the community for checking before sending for publication. No person’s private information will be given out to anyone.

Contacts:

Name	Position	Contact
Barbara Page	Principal Investigator	
Insert name of community contact		

Independent contact:

If you have questions and would like to talk to someone who has nothing to do with the research study you can contact the (insert contact name of HREC) who will forward your concerns to the Chair, Human Research Ethics Committee.

Thank you for taking time to read this information sheet.

Barbara Page

Principal Investigator

Appendix 4: Participant Consent Form

HREC No:	
Project Title:	Lung Cancer in rural and remote Aboriginal and Torres Strait Islander communities in Queensland
Name of Researchers:	Barbara Page, A/Prof Ian Yang, A/Prof Rayleen Bowman, Prof Kwun Fong
Sponsor Details:	Queensland Health Indigenous Respiratory Outreach Care Program Cancer Australia 'Supporting people with cancer Grant Initiative 2012'
Community	

I agree to join the 'Lung cancer in rural and remote Aboriginal and Torres Strait Islander communities in Queensland' research study and

	YES	NO
have been given the project information sheet		
understand that I do not have to join the study and can withdraw at any time with no reason		
have been able to ask questions about the research		
can have an interpreter present		
understand research involves an interview with questions that may cause some anxiety		
understand a digital voice recorder will be used to record my answers for clarification purposes		
understand personal details such as name and where I live will not be available to anyone except the research team.		
understand that I can check my answers to the questions after the interview with the researcher		
has been given the contact details of the researcher and the study's organisers		

Participant's name:

Signature: Date: __ / __ / __

Name of Investigator:

Signature: Date: __ / __ / __

Revocation of Consent Form – Participant

HREC No:	
Project Title:	Lung Cancer in rural and remote Aboriginal and Torres Strait Islander communities in Queensland
Name of Researchers:	Barbara Page, A/Prof Ian Yang, A/Prof Rayleen Bowman, Prof Kwun Fong
Sponsor Details:	Queensland Health Indigenous Outreach Care Program Cancer Australia
Community	

- **I am withdrawing my** consent to join the research project described above and understand this will not risk any relationships with (Insert Health Service), or Queensland Health Indigenous Respiratory Outreach Care Program.

Participant’s name (please print):

(Signature)..... Date: __ / __ / __

This Revocation of Consent should be forwarded to:

Barbara Page
 Senior Project Officer / Principle Investigator
 IROC Lung Cancer Project
 Dept. of Thoracic Medicine
 The Prince Charles Hospital
 Rode Road, Chermside QLD 4032

Third Party Authorisation

HREC No:	
Project Title:	Lung Cancer in rural and remote Aboriginal and Torres Strait Islander communities in Queensland
Name of Researchers:	Barbara Page, A/Prof Ian Yang, A/Prof Rayleen Bowman, Prof Kwun Fong
Sponsor Details:	Queensland Health Indigenous Respiratory Outreach Care Program Cancer Australia 'Supporting people with cancer Grant Initiative 2012'
Community	

I.....
 (Name)

of.....
 (Address)

wish to allow another person to be able to speak on my behalf regarding the 'Lung cancer in rural and remote Aboriginal and Torres Strait Islander communities in Queensland' research study and authorise

.....my..... (Name)
 (Nature of relationship e.g. spouse, carer, partner)

	YES	NO
I have been given the project information sheet to read		
Understand that I do not have to be a part of the study and can withdraw my consent for another person to speak on my behalf at any time with no reason		
Have been able to ask questions about the research		
Understand personal details such as name and where I live will not be available to anyone except the research team.		
Understand that the person speaking on my behalf will be able to check the responses with the researcher after the interview		
Have been given the contact details of the researcher and the study's organisers		

Name:

Signature: Date: __/__/____

Name of Investigator:

Signature: Date: __/__/____

Witnessed thisday of, 2013

Signature of Witness..... Name of Witness.....

Revocation of Third Party Authorisation – Participant

HREC No:	
Project Title:	Lung Cancer in rural and remote Aboriginal and Torres Strait Islander communities in Queensland
Name of Researchers:	Barbara Page, A/Prof Ian Yang, A/Prof Rayleen Bowman, Prof Kwun Fong
Sponsor Details:	Queensland Health Indigenous Outreach Care Program Cancer Australia
Community	

- **I am withdrawing my** third party authorisation for the research project described above and understand this will not risk any treatment or my relationship with (Insert Health Service), or Queensland Health Indigenous Respiratory Outreach Care Program.

Participant's name (please print).....

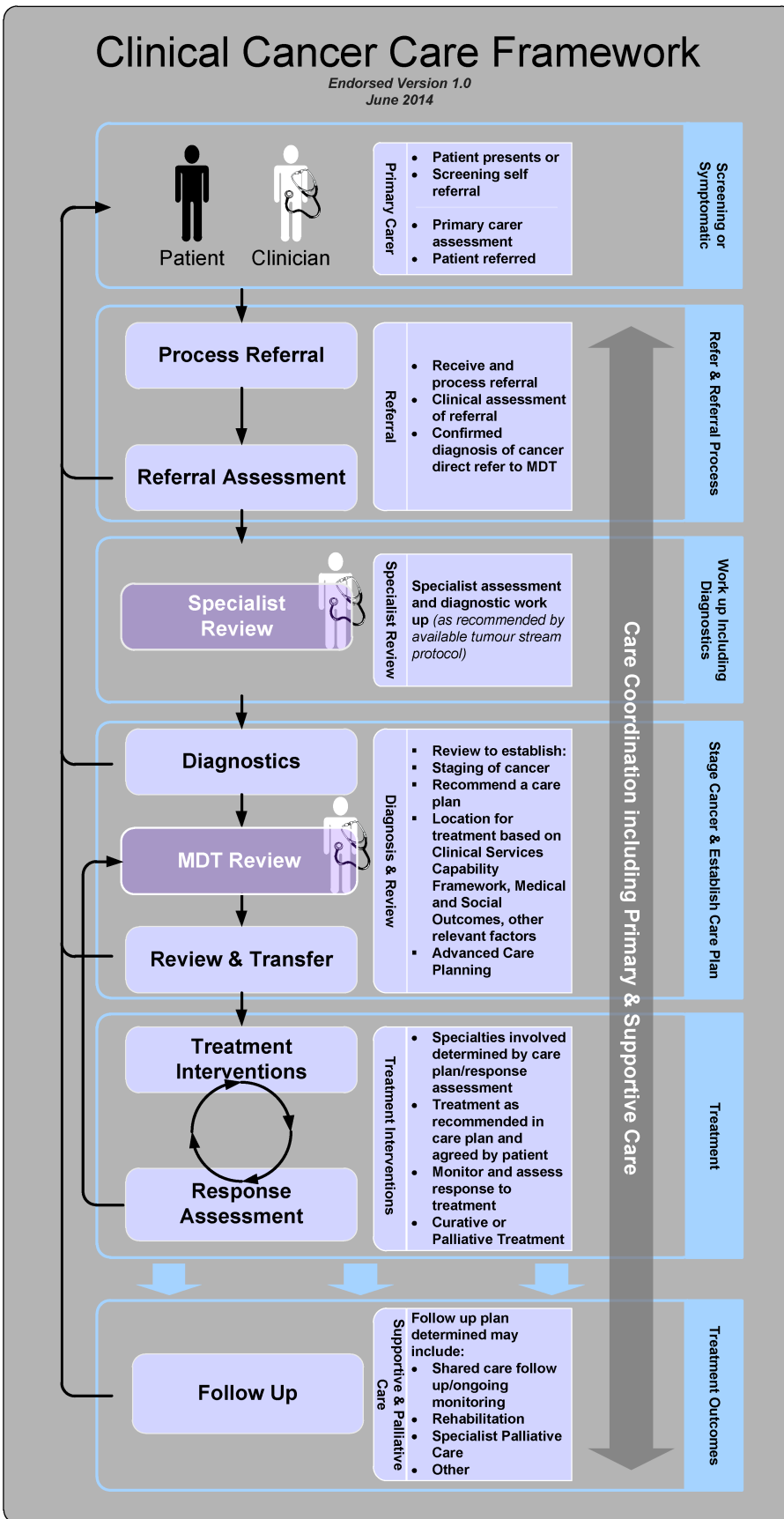
(Signature).....

Date: __ / __ / __

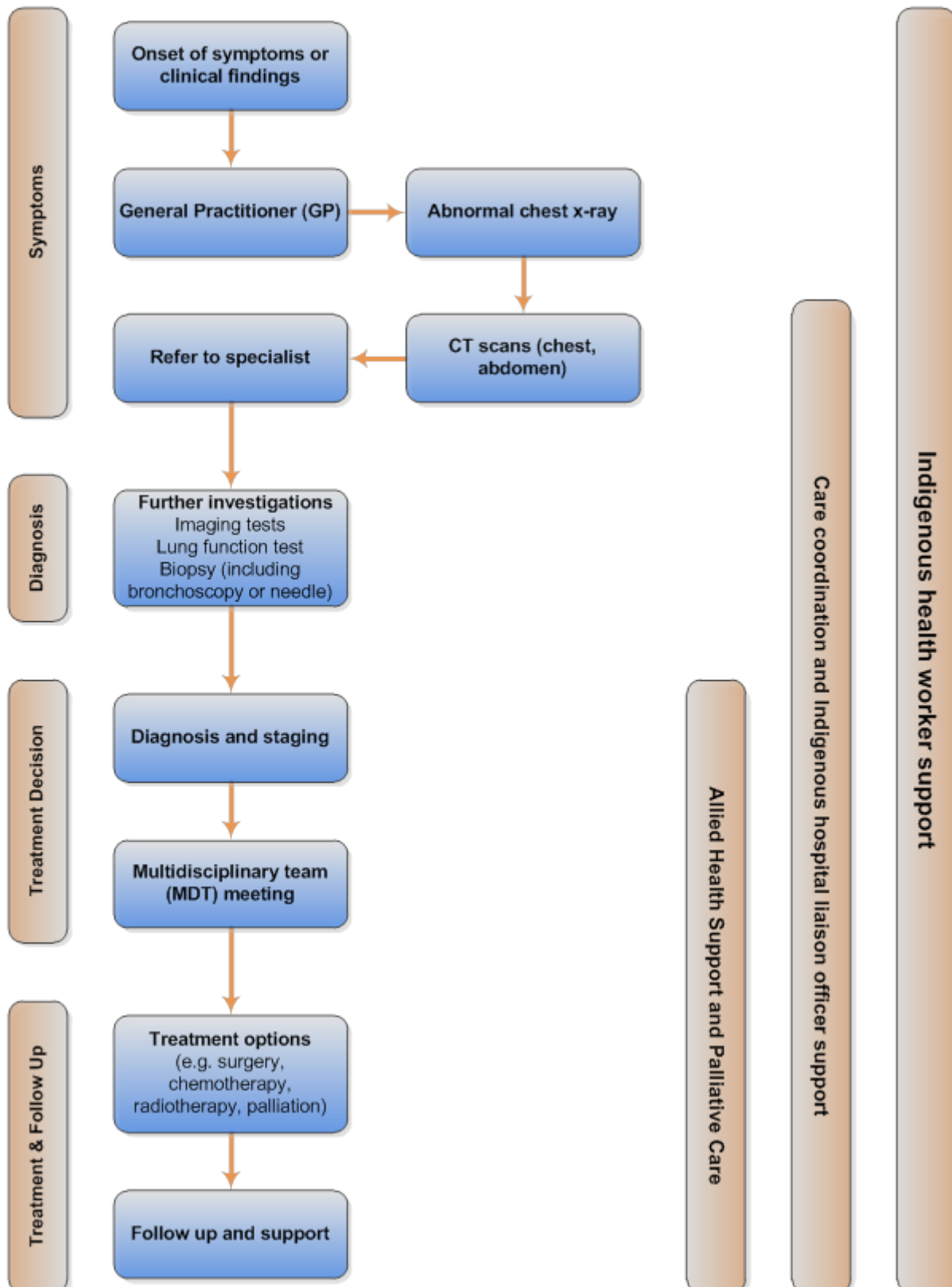
This Revocation of Third Party Authorisation should be forwarded to:

Barbara Page
Senior Project Officer / Principle Investigator
IROC Lung Cancer Project
Dept. of Thoracic Medicine
The Prince Charles Hospital
Rode Road, Chermside QLD 4032

Appendix 5: Clinical Cancer Care Framework



Appendix 6: Lung Cancer Clinical Care Framework



Appendix 7: Examination Lung Cancer Pathway of Care

Lung Cancer Conventional Pathway	Gaps in the pathway	How to achieve improvements
Symptomatic presentation	Individuals with no regular GP use the hospital when needing to see a doctor. GPs may not be in attendance every day and people may have difficulty making appointments due to transport issues. People could view the Indigenous health worker service as a risk to privacy. These factors may influence the patient's time to present for medical care.	Provide more opportunity for Indigenous health workers to be visible in the community in order to provide basic health checks, health promotion and prevention activities.
Diagnostic tests	Chest X-ray and pathology are available in communities but more specialised investigations (e.g. CT Scans) are only available in larger centres. The patient may need to travel long distances. Time to diagnosis might be delayed due to several reasons ranging from family issues, costs, and transport difficulties.	Ensure patient receives information at this point and support from Indigenous health worker and Indigenous hospital liaison officer at larger centre.
Referral to specialist	Lung specialists around the state provide an outreach service to rural and remote Indigenous communities, however this is not frequent and patients will generally need to travel to larger health services. A delay in seeing the specialist may occur at this point.	Effective communication processes such as detailed referral letters, phone calls to the specialist and investigations such as chest x-ray or CTs can be performed prior to appointment. Ensure travel department is aware of issues such as remoteness of residence so appropriate travel arrangements can be made. A video link between the specialist and nurse, Indigenous health worker or Indigenous hospital liaison officer at the local health service should be established at the first appointment to help strengthen coordinated care and communication between health facilities.
Specialised diagnostic tests	The respiratory physician may order further specialised lung cancer diagnostic tests. As these tests are mostly available at tertiary centres i.e. endobronchial ultrasound, MRI or PET, care coordination at this point is highly desirable.	Ensure relevant person at tertiary or regional centre is aware of patient's investigation and initiate care coordination

Lung Cancer Conventional Pathway	Gaps in the pathway	How to achieve improvements
Confirmation of diagnosis	The patient may returned home after having specialised investigations before receiving a confirmed diagnosis. Effective communication processes and care coordination are required at this point. If not available, there is a risk of delay between initial presentation, confirmation of diagnosis and commencement of treatment which could result in poorer outcomes.	Ensure communication processes exist so between specialist, referring doctor and Indigenous hospital liaison officer and Indigenous health workers are kept informed.
Multidisciplinary team (MDT) presentation	Patients may not be aware of their case being presented to the MDT and therefore not be informed of the recommended treatment plan. The local health service may also not be informed.	Communication process to ensure all people involved in the care of the patient are kept informed so decisions about treatment can be made by the patient and their doctor. This should be driven by the MDT including the cancer care coordinator. Patients should be aware of the MDT presentation and the subsequent recommendations. Patients also need time to discuss the recommended treatment plan with their family if they so desire. The cancer care coordinator, hospital indigenous liaison officer or clinician should contact the local health community nurse to ensure all supports will be put in place including travel and escort arrangements for future treatments.
Treatment Interventions	At this stage patients may be overwhelmed with appointments and miscommunication can occur. Patients not well information may be at risk of not commencing or completing treatments	Effective communication processes between health professionals from both facilities is essential. Care coordination in tandem with support from Indigenous health workers and Indigenous hospital liaison officers is also essential
Support services	Support services that a patient may seek are mostly available in communities. However, they are usually a visiting service.	The treating team should ensure the patient has referral at the appropriate time to supportive care services. If local support services do not have the required expertise in cancer care then a process should exist between the allied health, palliative care and other specialised services at the larger hospital. It is also necessary that Indigenous health workers are aware of what support services a person with lung cancer may need to access or has been referred to.

Lung Cancer Conventional Pathway	Gaps in the pathway	How to achieve improvements
Response assessment and follow-up	There is a risk that patients do not get appropriate follow-up after treatment due to travel issues, lack of support in the community or lack of understanding of the importance of follow-up.	Communication, care coordination between treating teams and support from Indigenous health workers are essential interventions at this point. Other models of care could be explored such as shared care arrangements
Information throughout the patient journey.	Patients from rural and remote communities may not get information relevant to their personal needs.	Indigenous health workers can be of benefit at this point. Patients need information that is clear and given at the right time. They need time to absorb information and speak to their families before making decisions. The MDT, GP, local hospital service and Indigenous health worker all play an important role in the provision of information and support for the patient and their family throughout the lung cancer journey.