

The legacy of the exclusion of Aboriginal people in Australia

Leone Malamoo

**A thesis submitted for the degree of Master of Philosophy
Applied Epidemiology**

Australian National University

January 2017



**Australian
National
University**



Field Supervisor and Academic Supervisor: Dr Raymond Lovett

Academic Supervisors:

Dr Kerri Viney, Dr Stephanie Davis, Dr Phyllis Dance

Originality statement

I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at ANU or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by others, with whom I have worked at NSW Health or elsewhere, is explicitly acknowledged in the thesis. I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation or linguistic expression is acknowledged.

Signed.....

Date.....

Acknowledgements

I dedicate this Bound Volume to my much-loved brother Floyd Charles Malamoo (1962-2015) a giving, joyous, honourable and humble man who experienced, learnt and shared much in his short life.

Respect and recognition must also be given to my mother's baby sister, Shirvanne Devow (nee Henaway) a beautiful, strong, no nonsense straight shooter who was determined to be interviewed to tell her story about living with cancer.

I would like to acknowledge and thank the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS); and the National Centre for Epidemiology and Population Health (NCEPH) at the Australian National University (ANU).

Special recognition and many thanks to my supervisor's Dr Ray Lovett, Dr Steph Davis, Dr Kerri Viney and Dr Phyll Dance. Dr Lovett's teaching, insight, generosity of spirit and intellectual honesty was welcomed - his drive and vision for making positive changes in the health and wellbeing of Aboriginal peoples made learning a beautiful thing.

There are many people and family to thank for their support and encouragement - my daughter Litza Malamoo-Jib; my family Shireen & Malcolm Malamoo, Toni & Quent, Vicki, Floyd and Annemarie; Dr Chris Lawrence; Janice Nixon; Peter McCaffery; Sonya Parter; Stacy & Wes Dinsmore; the Burdekin family & community; and the ancestors who sit at my shoulders. I am grateful to them all - for without their strength, sustenance and inspiration this thesis would not have been possible.



“Aboriginal People are the skeleton in the cupboard of Australia’s national life...outcasts in our own land”

Pastor Sir Doug Nicholls, National Day of Mourning Speech, 1938

Thesis Abstract

My placement as a Master of Philosophy in Applied Epidemiology (MAE) scholar was with the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS); later based at the National Centre for Epidemiology and Population Health (NCEPH).

In meeting my Masters requirements I conducted an epidemiology project using mixed methods entitled 'A community perspective of Burdekin rot' - based on the anecdotal reports of 'Burdekin rot' and the perceived higher incidence of cancer (and death) in the Burdekin community. Analysis of cancer incidence and geographic level analysis of Queensland Cancer Registry data was conducted for the period 2003-2012 to ascertain whether cancer rates and mortality rates vary between the Aboriginal and Torres Strait peoples and the general population within each Statistical Division (SD) of Queensland. Qualitative interviews were conducted to understand the experiences of Aboriginal and Torres Strait Islander peoples living in the Burdekin region in terms of cancer diagnosis, treatment and treatment outcomes.

I conducted a cross sectional study and analysis of the 2010 Australian Capital Territory (ACT) Inmate Health Survey to determine if contact (phone and visits) was associated with lower levels of psychological distress. Comparisons of proportions between a range of exposure variables and the outcome variable of psychological distress were conducted to further examine any association between mild to severe psychological distress.

Further, as a team member within NCEPH in collaboration with Qld Health I assisted in an outbreak investigation primarily with undertaking hypothesis generating questionnaires for an outbreak of *Salmonella* Saintpaul cases in Qld. Case information was provided by Qld Health including case pathology reports. My role in the outbreak included case interviews, data analysis comparing current data to Qld *S. Saintpaul* data 2006-2014 and preparing a brief for OzFoodNet in terms of a possible multi-jurisdictional outbreak of *S. Saintpaul*.

My final project to meet study requirements was the evaluation of the Queensland Cancer Registry specifically concerning the completeness of Aboriginal and Torres Strait Islander status data.

Other MAE program core competency components were fulfilled via a group teaching session on measurement bias to the 2015 MAE cohort; a presentation of the preliminary findings of the Burdekin study at the National Indigenous Research and Knowledge Network (NIRAKN) conference 29-30 September 2015 in Adelaide South Australia (p.166-176); and developing and conducting a Lesson from the Field (LFF) on cultural awareness and appropriate community engagement and partnership when conducting research with Aboriginal and Torres Strait Islander peoples.

Contents

Acknowledgements	3
Chapter 1: Queensland Outbreak of Salmonella Saintpaul, 2015	12
Abbreviations	13
1.1.1 Prologue	14
My Role	14
1.1.2 Lessons Learnt	15
1.1.3 Public Health Implications	15
1.1.4 Master of Applied Epidemiology requirement	16
1.2. Abstract	17
Background	17
Methods	17
Results	17
Conclusion	18
1.3 Introduction	18
1.3.1 Mode of transmission	18
1.3.2 Outbreaks	20
1.3.3. Salmonella Saintpaul	20
1.3.4. Increased S. Saintpaul cases in Queensland in early 2015	21
1.3.5. Multiple-Locus Variable number tandem repeat Analysis (MLVA)	21
1.4 Aim	22
1.5 Objectives	22
1.6. Methods	22
1.6.1 Case definition	22
1.6.2 Analysis of notifications	22
1.6.3 Hypothesis generating interviews	24
1.6.4. Ethics	25
1.6.5. Laboratory	25
1.7 Results	25
1.7.1 Descriptive analysis	25
1.7.2. Comparison with previous years	27
1.7.3 Rate	30
1.7.4 Hypothesis generating interviews	31
1.7.5. MLVA	32
1.8. Discussion	34
1.9. Limitations	37
1.10. Public health implications and recommendations	38
1.11. Conclusion	39
1.12. Recommendations	40
1.13. Acknowledgements	40
1.14. References	41
Chapter 1 Appendices	43
Appendix 1. Queensland Health Salmonella Saintpaul Case Questionnaire	43
Chapter 2: ACT Inmate Health Survey: Prisoner contact and psychological distress	52
2.1. Prologue	53
2.1.1 My Role	53
2.1.2 Lessons Learnt	54
2.1.3 Public Health Impact	54
2.2 Abstract	56
Background	56
Aim	56
Methods	56
Results	56
2.3 Introduction	57
2.4 Literature review	57
2.4.1. The global prison population and mental wellbeing	57
2.4.2. Prison health surveys in Australia	58
2.4.3. National prisoner health data	60
2.4.5. Mental Health of Australian prisoners	63
2.4.6. Impact of external contact on prisoners' wellbeing	64
2.5. Rationale for this study	66
2.6. Aim	66

2.7. Objectives	67
2.8. Hypothesis	67
2.9. Methods	67
2.9.1. Study design	67
2.9.2. Participants	67
2.9.3. Analysis	67
2.9.4. Outcome variable: psychological distress	67
2.9.5. Exposure variables	68
2.9.6. Ethics	69
2.10. Results	70
IHS participants	70
Associations between external contact, inmate characteristics and mild/severe psychological distress	72
2.11. Discussion	73
2.12. Limitations	75
2.13 Conclusions and public health implications	76
2.14. References	77
Chapter 2 Appendices	81
Appendix 1: Australian prison characteristics by jurisdiction.	81
Chapter 3: An evaluation of the completeness of Indigenous status in the Queensland Cancer Registry (QCR)	85
3.1 Prologue	86
3.1.1 My Role	86
3.1.2 Key Lessons Learnt	87
3.13 Importance of Public Health surveillance	87
3. Abstract	88
Background	88
Objectives	88
Methods	88
Results	89
3.3 Introduction	89
3.3.1 Australian Cancer Registries	91
3.3.2 The Australian Cancer Database	91
3.3.3 National Aboriginal and Torres Strait Islander Cancer data	94
3.3.4 Description of the Queensland Cancer Registry	95
3.4 Objectives of the Queensland Cancer Registry	98
3.5 Aims of the Evaluation	98
3.6 Methods	98
3.6.1 Ethics	99
3.6.2 Analysis of QCR data	99
3.6.3 QCR Staff Questionnaire	100
3.7 Stakeholders	100
3.8 Description of the QCR system	100
3.8.1 Information collected	102
3.8.2 Data storage	103
3.8.3 Data Analysis/Data quality	103
3.8.4 Dissemination of results	104
3.8.5 QCR Classification and Coding	104
3.9 Performance of QCR in relation to Indigenous notifications	104
3.9.1 Simplicity	104
3.9.2 Flexibility	105
3.9.3. Data quality and Acceptability	105
3.9.4. Acceptability	107
3.9.5 Sensitivity	107
3.9.6 Representativeness	108
3.9.7 Timeliness	110
3.9.8 Sources of Indigenous status recording in the QCR	110
3.10 Discussion and recommendations	112
3.11 Acknowledgements	114
3.12 References	115
Chapter 3 Appendix 1	116
Chapter 4: A community perspective of 'Burdekin rot'	118
4.1.1. Role	120

4.1.2.	Lessons Learnt	120
4.1.3.	Public Health Implications	121
4.1.4.	Ethics	121
4.1.5.	Acknowledgements	122
	Master of Philosophy (Applied Epidemiology) requirement	122
4.2.	Abstract	123
4.3	Introduction	125
4.3.1.	Brief overview of Australian Indigenous health status	125
4.3.2.	National	126
4.3.3.	Queensland	126
4.3.4.	Burdekin Region of north Queensland	126
4.3.5.	Pesticide use in the Burdekin region	128
4.3.6.	Burdekin 'rot'	129
4.4.	Aims	130
4.5.	Methods	130
4.5.1.	Quantitative Analysis	130
4.5.2.	Qualitative Analysis	130
4.6.	Results	131
	Part 1: Queensland Indigenous cancer notifications, deaths rates and survival	131
	Cancer notifications QLD by Indigenous status	131
4.6.1.	Cancer notifications by broad cancer ICD code	134
4.6.2.	Cancer mortality	141
4.6.3	Cancer survival	146
	Part 2: Experiences of the Indigenous people with cancer or their experience with a family's members cancer diagnosis and treatment in the Burdekin region of QLD	148
4.7.1	Experience of cancer diagnosis	148
4.7.2.	Experiences of cancer treatment	149
4.7.3.	Diagnosis journey	151
4.7.4.	Contributing factors to cancer diagnosis	152
4.7 Discussion		154
	Notifications	156
	Mortality	157
	Survival	157
	Experiences of cancer diagnosis and treatment	158
	Strength and limitations	159
4.8 Implications for public health		160
4.9 Conclusion		160
4.10 Recommendations		160
4.11 References		162
	Chapter 4 Appendices	166
	Appendix 1. NIRAKN Conference presentation, Adelaide SA 2015	166
	Appendix 2: AIATSIS ethics application	177
	Appendix 3: QLD Health Public Health Act – Application and Information for Researchers for access to QCR data	185
	Appendix 4: AIATSIS ethics approval	195
	Appendix 5: Participant information sheet and informed consent form	197
	Appendix 6: Letter of support for Ayr community	202
	Appendix 7: Participant recruitment flyer	203
	Appendix 8: Participant interview guide	204
	Appendix 9 – Draft peer review paper: Cancer Mortality in Queensland	207
	Teaching Report: Bias in interpreting Aboriginal and Torres Strait Islander Health Data	218
	Lessons From the Field (LFF): community consultation for research with Indigenous peoples and communities	232

List of Figures

Figure 1: Queensland health zones	23
Figure 2: Queensland hospital and health services districts (Queensland Health, 2016a)	24
Figure 3: Queensland lab notifications of Salmonella Saintpaul from 1 January – 26 February 2015	26
Figure 4: Age and sex of notified cases of S. Saintpaul in Queensland, January – February 2015	27
Figure 5: Geographical distribution of S. Saintpaul notifications January - February 2015 by Zone	27
Figure 6: Geographical distribution of Salmonella Saintpaul cases by Zone, Jan-Feb 2010 – 2014, all of 2010-2014 compared to Jan-Feb 2015	29
Figure 7: Geographical distribution of Salmonella Saintpaul cases by HHS, Jan-Feb 2010 – 2014 compared to Jan-Feb 2015	30
Figure 8: Overall cases and rates of S. Saintpaul by HHS - Qld 2006-2014	31
Figure 9: Overall rate of all salmonella in Queensland compared to the rate of S. Saintpaul in Queensland 2006-2014 by Hospital and Health Service (HHS) region	31
Figure 10: MLVA type by date of onset of case symptoms, 14 January 2015 – 11 February 2015	33
Figure 11: South West HHS Queensland	37
Figure 12. Logistic regression mild/severe psychological distress and IHS participant characteristics (Odds ratio)	72
Figure 13: Relationship flowchart of cancer data between State and Territory jurisdictions, cancer programs and the Australian Cancer Database (ACD), National Statistics Clearing House (NCSCH), Australasian Association of Cancer Registries (AACR) and the cancer data custodians the Australian Institute of Health and Welfare (AIHW)	94
Figure 14: QCR information flow chart	101
Figure 15: Proportion of Indigenous and unknown Indigenous status in QCR notifications 2003-2012	106
Figure 16: Proportion of cancers (by cancer type) notified to QCR with unknown Indigenous status 2003-2012, Queensland	109
Figure 17: Map of mainland Australia outlining the Burdekin region	127
Figure 18: Burdekin Dam	128
Figure 19: Red Stripe Pseudomonas rubrilineans	129
Figure 20: Queensland cancer notifications 2003-2012 by Indigenous status.	132
Figure 21: Cancer cases with missing/unknown Indigenous status in QCR data 2003 – 2012	133
Figure 22: Cancer notifications (%) by Indigenous status and age group Queensland, 2003-2012	137
Figure 23: Indigenous cancer notifications (%) by age group and year (QLD) 2003-2012	139
Figure 24: Non-Indigenous cancer notifications (%) by age group and year QLD 2003-2012.	140
Figure 25: Cancer deaths (%) by broad ICD 10 code by Indigenous status Queensland 2003 - 2012	142

Figure 26: Cancer deaths by Indigenous status and Statistical Division (SD) Queensland 2003	143
Figure 27: Mean age at death Indigenous compared to non-Indigenous by Queensland Statistical Division (SD).....	145
Figure 28: Cancer mortality by Indigenous status and age group	146
Figure 29: Kaplan-Meier cancer survival estimates QLD 2003-2012, by Indigenous status	147
Figure 30: Mean age at death Indigenous compared to non-Indigenous by Queensland Statistical Division (SD).....	214
List of Tables	

Table 1. Number of notifications for Salmonella Saintpaul in Queensland: Comparison January - February 2015 to same time period 2010-2014.....	28
Table 2. Notifications Salmonella Saintpaul in Queensland - Comparison between 2015 and 2010 – 2014	28
Table 3. Reported food exposures for interviewed cases of S.Saintpaul Qld January - February 2015	32
Table 4. Self-assessed health of prisoners 2014/2015.....	62
Table 5. Kessler 10 score levels and the level of psychological distress (Australian Bureau of Statistics, 2012a).....	68
Table 6. Demographic and social characteristics of participants of the Australian Capital Territory Inmate Health Survey, 2010	71
Table 7: Availability of cancer data by Indigenous status and jurisdiction	95
Table 8: Cancer notifications (%) by broad ICD 10 code and Indigenous status 2003-2012, Queensland	134
Table 9: Cancer notifications by broad ICD 10 code and Non-Indigenous status 2003-2012, Queensland	135
Table 10: Cancer notifications (n & %) by broad ICD code by unknown Indigenous status 2003-2012, Queensland	136
Table 11: Cancer notifications (%) by Indigenous status, sex, marital status and statistical division (SD) 2003-2012 Queensland.	138
Table 12: Rate of all cancer deaths by Indigenous status and Statistical Division (SD) Queensland, 2003-2012.....	141
Table 13: Qld cancer 2003-2012 mortality rates by Indigenous status and age group	144
Table 14: Availability of cancer data by Indigenous status and jurisdiction	154
Table 15: Qld cancer 2003-2012 mortality rates by Indigenous status and age group	213

Chapter 1: Queensland Outbreak of Salmonella Saintpaul, 2015

Abbreviations

ACT	Australian Capital Territory
CI	Confidence Interval
DNA	Deoxyribonucleic Acid
EpiInfo	Epidemiology Software
ERP	Estimated Residential Population
GP	General Practitioners
HHS	Hospital and health services
Qld	Queensland
MAE	Master of Applied Epidemiology
MLVA	Multi-locus variable-number tandem repeat analysis
n	Number
NCEPH	National Centre for Epidemiology and Population Health
NNDSS	National Notifiable Diseases Surveillance System
NSSS	National Salmonella Surveillance Scheme
<i>p</i>	Probability Value (p-value)
Qld	Queensland
<i>S.</i>	<i>Salmonella</i>

1.1.1 Prologue

My Role

In response to an increase in notifications of *Salmonella* Saintpaul in Queensland from the beginning of January 2015 to the end of February 2015, a team discussion via teleconference took place at National Centre for Epidemiology and Population Health (NCEPH) between the Convenor of the Master of Applied Epidemiology (MAE) Program, the Coordinating Epidemiologist at OzFoodNet Australian Capital Territory (ACT), two Queensland Health Communicable Diseases Branch epidemiologists, an NCEPH supervisor, and two MAE scholars. The aim of this teleconference was to discuss how MAE scholars may be able to assist in investigating factors associated with the *Salmonella* Saintpaul increase.

I was a member of the team assembled by Associate Professor Martyn Kirk at NCEPH in collaboration with Queensland Health to assist with hypothesis generating questionnaires for *Salmonella* Saintpaul cases in Queensland.

I contributed to this investigation by:

- signing off on documents which would allow me to conduct interviews on behalf of Queensland Health
- acknowledging roles and responsibilities of supervisory team members
- compiling an outbreak investigation plan
- conducting hypothesis generating interviews with cases
- providing a brief to OzFoodNet in relation to a possible multi-jurisdictional outbreak of *Salmonella* Saintpaul
- providing a descriptive analyses of *S. Saintpaul* cases in Queensland comparing current data to previous years (2010-2014) reporting outputs to Queensland Health

Prior to commencing the interviews my MAE colleague and I drew up an outbreak investigation hypothesis generating plan (Appendix 1).

We reviewed the OzFoodNet national hypothesis generating case questionnaire, the OzFoodNet 7-day trawling questionnaire and the Queensland *Salmonella* Saintpaul Case Questionnaire which we modified (Appendix 2) to include:

- Aboriginal and Torres Strait Islander status;
- Fruits and vegetables not included on the list;
- Other possible water sources (such as tank and bore water);

- Takeaway outlets and grocery store access;
- A brief introductory script was developed used as epidemiology registrars based at the Australian National University acting on behalf of Queensland Health; and
- A brief introductory script was developed and used for case treating doctors and parents of child cases.

1.1.2 Lessons Learnt

I learned the importance of epidemiological investigations to:

- rapidly quantify outbreaks;
- update questionnaires to include relevant data for example, extra foods and regional food outlets;
- collect data on Aboriginal and Torres Strait Island case status on health department and pathology forms (recognising the impact of identification of Aboriginal and Torres Strait Islander status on Aboriginal and Torres Strait Islander health, communities and health promotion initiatives)
- rapid response by GPs and labs in outbreak investigations greatly assists case recall when conducting hypothesis generating interviews - increasing the possibility of identifying an outbreak and an outbreak source
- Limitations due to lack of knowledge into various strains of *S. Saintpaul* and geographic spread

1.1.3 Public Health Implications

- Through following up individual cases we reassured members of the public that Queensland health were actively seeking a source for their infection.
- Through making sure that Aboriginal and Torres Strait Islander identification was included on the health department outbreak questionnaires this provides improved data on Aboriginal and Torres Strait Islander health. This is important because Aboriginal and Torres Strait Islander peoples have higher rates of *Salmonella* than the general population. It is important to have good data on this to target public health awareness and implications for Aboriginal and Torres Strait Islander populations and communities in relation to possible transmission

routes of *salmonella* such as foodborne transmission (especially awareness in terms of refrigerating foodstuffs for example, chicken and cold meats on hot days). This issue generally highlights the need for better Aboriginal and Torres Strait Islander identification via other means such as pathology forms, GP, and hospital records and documentation (as per the national guidelines) (Australian Institute of Health and Welfare, 2010).

1.1.4 Master of Applied Epidemiology requirement

This chapter is included in my thesis to fulfil the requirements of the Master of Philosophy in Applied Epidemiology outbreak investigation component.

1.2. Abstract

Background

In early February 2015 Queensland Health reported fifty-nine (59) *Salmonella* Saintpaul (S.Saintpaul) notifications for January 2015, compared to the median of between 20-30 cases per month in previous years. This information provided the impetus for further investigation of a possible outbreak of S.Saintpaul and Master of Applied Epidemiology scholars were asked to assist with this investigation,

Methods

The study was a case series. Hypothesis generating interviews were conducted in early February with case records received from Queensland Health. The case information was provided via email in Microsoft ®Excel format and PDF copies of case pathology forms.

Initial contact via phone was made with case General Practitioners (GPs) as a common courtesy to inform them of our intention to contact their patients. Cases were interviewed using a modified outbreak investigation questionnaire. Multiple-Locus Variable number tandem repeat Analysis (MLVA) tests were conducted during the hypothesis generating interviews. A data analysis was also conducted to compare cases of S. Saintpaul in Queensland from early January 2015 to end of February 2015 by person, place and time with cases from the previous five years.

Results

Twenty-three cases were interviewed over a ten day period in early February 2015. The hypothesis generating interviews highlighted that two thirds (65%) of cases reported exposure to fresh chicken and carrots. MLVA tests of cases revealed eight (8) separate strains of MLVA. During the months of January and February 2015 compared to January and February 2010-2014 - there was a 54% increase in S. Saintpaul cases (n=111) compared to (n=60); the percentage of male cases increased to 60% in 2015 from 50% in 2010-2014. The median age increased from 13 years in 2010-2014 to 20 years in 2015; and the Central zone of Queensland had the highest percentage of cases (44%) for the Jan-Feb 2015 period compared to (36%) 2010-2014.

Conclusion

It was not possible to identify a specific source for this outbreak of *Salmonella*. Saintpaul. MLVA tests revealed there was no common source in this outbreak however there is further need for research on the variability of MLVA among *S. Saintpaul* in outbreaks.

1.3 Introduction

Salmonellosis is a bacterial disease usually manifested by acute inflammation of the small intestine and colon with sudden onset of headache, abdominal pain, diarrhoea, nausea and sometimes vomiting. Dehydration among elderly and infants may ensue and can lead to acute illness. There are approximately 2500 known serotypes of *Salmonella*, a small number of which account for the majority of human infection (Heymann, 2008).

Salmonella bacteria are found in humans, wild animals, farm and pet animals and birds, particularly chicken (State Government of Victoria, 2015).

Salmonella infection of chickens is common, the bacteria can often be found in raw chicken meat and on eggs. The incubation period of salmonellosis is usually between six to 72 hours, meaning that exposure to the pathogen usually occurs during this time. Illness usually lasts for a few days but *Salmonella* bacteria may be present in the faeces for a number of weeks or longer (Heymann, 2008).

1.3.1 Mode of transmission

Person-to-person transmission or animal-to-person spread of salmonellosis is via the faecal-oral route. Ingestion of *Salmonella* via contaminated or improperly cooked foods can also occur. The main foods that have been implicated as vehicles of *Salmonella* transmission are:

- Raw or inadequately cooked eggs and egg products
- Raw milk or raw milk products
- Poultry and poultry products
- Raw red meats and uncooked meat products
- Unwashed salads, grains, seeds and nuts

- raw fruits and vegetables contaminated during growing, harvesting or preparation process and;
- Some shellfish and filter feeders i.e. oysters (Queensland Health, 2016b; State Government of Victoria, 2015)

When raw meat or eggs are not cooked properly the bacteria may survive and infect those who eat it. The process of thoroughly cooking meats and poultry including eggs will kill *Salmonella* bacteria (State Government of Victoria, 2015).

The bacteria may also be spread by cross contamination i.e. from something that is contaminated with bacteria to something that is not. For example, cooked food may be contaminated by raw or undercooked foods or meat that are colonised with *Salmonella*. Therefore standard public health advice is that raw foods should be handled and stored separately from cooked or ready-to-eat foods, and kitchen tools such as chopping boards, blenders, and mixers used to prepare raw foods must be meticulously washed before being reused. (State Government of Victoria, 2015).

Salmonella bacteria is also widely distributed in domestic and wild animals, prevalent in food animals such as poultry, pigs, cattle; and in pets, including cats and dogs, birds and reptiles such as turtles (World Health Organization, 2016)

Salmonellosis can also spread via the person to person. For example, If people do not wash their hands properly after going to the toilet or changing nappies of infected infants, they can spread the bacteria to surfaces which may be touched by other people or infect food which may be eaten by other people (State Government of Victoria, 2015).

The period of communicability through the course of infection is unpredictable, usually several days to several weeks. A temporary carrier state sometimes continues for months, especially in infants and 1% of infected adults and 5% of children under 5 excrete the organism for >1year. Antibiotics can extend the period of shedding hence communicability (Queensland Health, 2016b).

1.3.2 Outbreaks

Salmonella outbreaks are typically due to foodborne sources, however waterborne outbreaks have been reported due to a wide range of contamination by animal sources such as bird droppings, lizards - including geckos and other reptiles, amphibians - frogs and toads, reptiles, bovine, ovine, porcine, equine, canine, avian and marsupial species (Taylor, Sloan, Cooper, Morton, & Hunter, 2000). According to Australian Department of Health, foodborne salmonellosis was estimated to have increased from 28,000 annual infections in 2000 to 39,600 annual infections in 2010; a rate increase of 24% from 1,500 cases per million to 1,850 cases per million annually (Glass, Ford, Brown, & Hall, 2014).

The most commonly reported *Salmonella* serotype, that accounted for 48% of all *Salmonella* notifications, was *Salmonella* Typhimurium (OzFoodNet Working Group, 2011b).

OzFoodNet sites reported 1,719 outbreaks of gastrointestinal illness affecting 29,839 people causing 872 people to be hospitalised, with 103 associated deaths. The majority 1,352 (79%) of outbreaks were attributed to person-to-person transmission, while 151 (9%) were suspected or confirmed foodborne. *Salmonella* was the most common aetiological agent identified in foodborne outbreaks, with restaurants the most commonly reported food preparation setting (OzFoodNet Working Group, 2011b). In Australia, *Salmonella* outbreaks are most frequent in summer and spring (September to February) (Kirk et al., 2011).

1.3.3. *Salmonella* Saintpaul

S. Saintpaul is a serovar of *Salmonella*. *S. Saintpaul* infections are more widespread in the northern parts of Australia, such as Queensland (Qld) and the Northern Territory (NT) and comparatively rare in other states (Taylor et al., 2000).

Northern Territory and Queensland were the only two states to report *S. Saintpaul* in 2008 and 2009. In 2008 Northern Territory had 38 cases; Queensland 154 cases - in 2009 Northern Territory had 58 cases; Queensland 207 cases (OzFoodNet Working Group, 2011a)

Of all *Salmonella* isolates from the central Queensland area, *S. Saintpaul* normally accounts for around 12% of all typed human salmonella isolates.

According to National *Salmonella* Surveillance Scheme (NSSS) reports, *S. Saintpaul* falls consistently among the top 10 serovars in Australia; with Queensland accounting for around two thirds of Australia's overall reported cases (Taylor et al., 2000).

1.3.4. Increased *S. Saintpaul* cases in Queensland in early 2015

In January 2015 Queensland Health reported an increase in *S. Saintpaul* notifications. This information led to the identification of a potential outbreak of *S. Saintpaul* and provided the momentum for further investigation.

At the time there were also increased cases notified in Western Australia (Western Australia, New South Wales, Victoria and South Australia) and no point source had been determined. In order to identify a source all jurisdictions agreed to undertake hypothesis generating interviews.

1.3.5. Multiple-Locus Variable number tandem repeat Analysis (MLVA)

In addition to the hypothesis generating interviews, all jurisdictions agreed to further laboratory testing of isolates using Multiple Locus variable-number tandem repeat analysis (MLVA).

MLVA is extensively used to assess the molecular fingerprint of micro-organisms such as bacteria. It is a method used to perform molecular typing of certain microorganisms, and it uses the naturally occurring difference in the number of tandem repeated DNA sequences found in a number of different loci in the genome of a range of organisms (National Institute for Public Health and the Environment, 2016).

The method comes from forensic science where it is used for DNA fingerprinting in samples from human origin. The molecular typing profiles are used to:

- study transmission routes;
- assess sources of infection; and
- assess the impact of human intervention, such as vaccination and use of antibiotics on the composition of bacterial populations (National Institute for Public Health and the Environment, 2016).

Performing MLVA early in an outbreak has the advantage of determining whether samples have a common source of exposure. (May, 2015).

1.4 Aim

- To investigate the increase in *S. Saintpaul* notifications in Queensland in January and February 2015 and recommend appropriate public health actions

1.5 Objectives

- To analyse notifications of *S. Saintpaul* from early January 2015 to end of February 2015 by person, place and time and compare these characteristics with the previous five years
- To compare rates of *S. Saintpaul* in Qld by location, to rates of overall *Salmonella* in Qld
- To conduct descriptive analysis of data from cases notified to Queensland Health from beginning of January to end of February 2015
- To identify potential sources of infection through hypothesis generating interviews

1.6. Methods

1.6.1 Case definition

A case was considered anyone with laboratory confirmed *Salmonella* Saintpaul infection in Queensland with onset after January 1st 2015.

1.6.2 Analysis of notifications

The age and sex distribution of cases from beginning of January to end of February 2015 were compiled. These were compared to notifications of *S. Saintpaul* for the same time distribution (i.e. January to February) for the previous 5 years, and then to notifications for the whole of the previous 5 years.

Geographical distribution of cases was also examined, and then compared to previous years by examining the zones and Hospital Health Service (HHS) districts (Figure 2) where cases were notified from. Zones are a Qld health geographic classification that groups Hospital and Health Service (HHS) districts (Figure 1).

There are three zones in Queensland:

- North, comprising of: Cairns and Hinterland HHS; Mackay HHS; Townsville HHS; Torres and Cape HHS; North West HHS
- Central, comprising of: Central Qld HHS; Central West HHS; Metro North HHS; Sunshine Coast HHS; Wide Bay HHS
- South, comprising of: Darling Downs HHS; Gold Coast HHS; Metro South HHS; South West HHS; West Moreton HHS

To further investigate the geographical distribution I calculated rates for *S. Saintpaul* and for all *Salmonella* by HHS from 2006 - 2014, using Estimated Residential Population (ERP) data obtained from Queensland Health. Data were analysed and figures created using Microsoft®Excel. It was practical and appropriate to use Microsoft®Excel as data was received from Qld Health in this format.

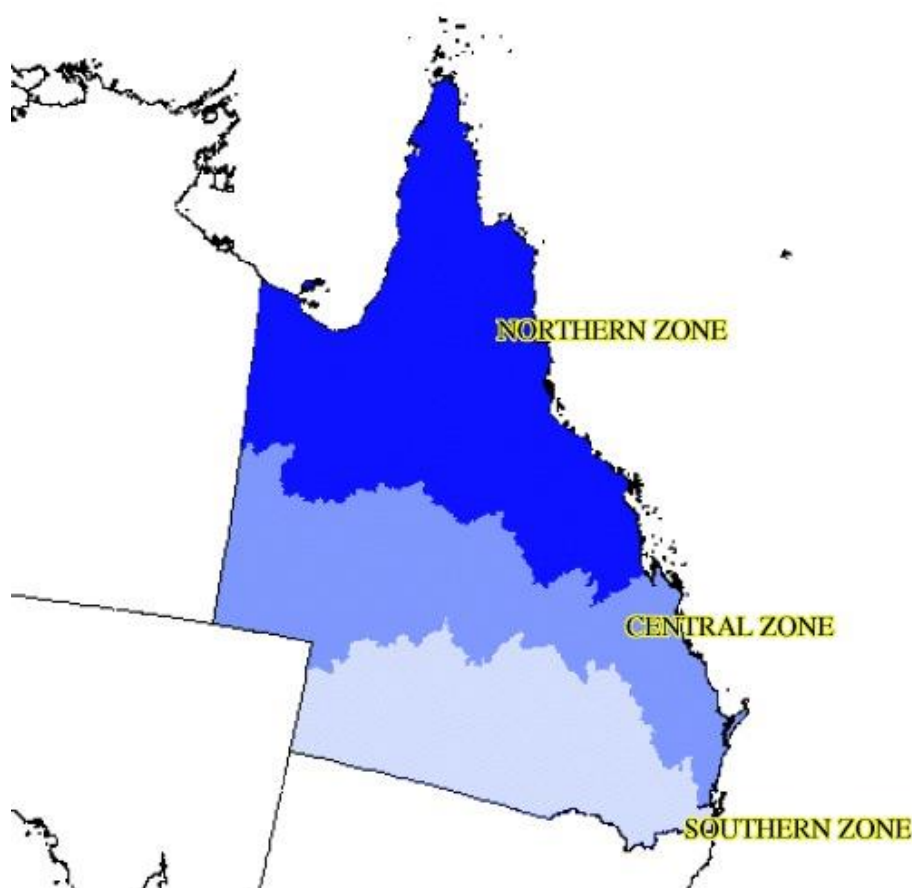


Figure 1: Queensland health zones

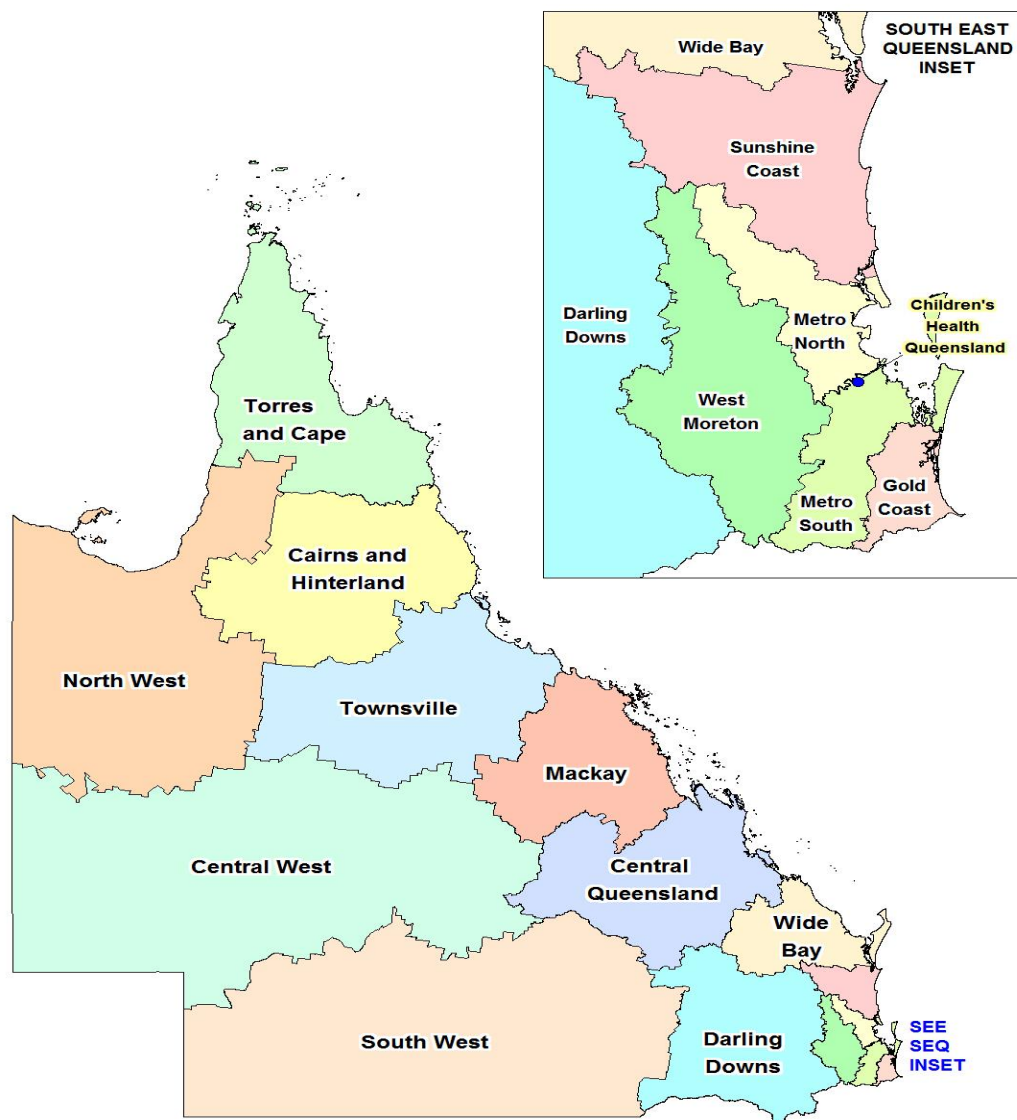


Figure 2: Queensland hospital and health services districts (Queensland Health, 2016a)

1.6.3 Hypothesis generating interviews

Introductory telephone scripts were developed for GPs and cases. A draft questionnaire for this outbreak (supplied by Queensland health) was compared with the existing OzFoodNet hypothesis generation questionnaire for *Salmonella*, and the draft questionnaire modified for inclusion of data fields such as Aboriginal and Torres Strait Islander status and additional foods. To ensure quality and clarity the introductory scripts and upgraded hypothesis generating questionnaires were shared with a supervisor for comment and approval.

The questionnaire contained information on:

- Demographic information

- Medical and diagnostic information
- Clinical details i.e. symptoms, date of onset, etc.
- Exposure information
 - Travel history
 - Attendance at social events/functions
 - Food outlets
 - Meat, poultry and egg consumption
 - Animal and environmental exposure
 - Water consumption and contact

The questionnaire asked about exposures on day of illness and 3 days prior.

Case notification data were provided by Queensland Health in Microsoft®Excel format, and laboratory results with case contact details were supplied.

Interviews commenced on 29 January 2015. My initial contact with GPs was via a courtesy phone call using the introductory script to inform them that as a representative of Queensland Health I would be contacting the patient for interview.

Cases were interviewed using the questionnaire (Appendix 1). Cases were interviewed via telephone beginning with those cases with the most recent notifications date.

1.6.4. Ethics

Information collected for the hypothesis generating interviews was done so under the provisions of *Health Services Act 1991 (Qld) Deed Poll of Confidentiality and Privacy*, and therefore this study did not require ethics approval (Queensland Health, 2013).

1.6.5. Laboratory

MLVA typing was undertaken by Qld Health reference laboratory for all isolates from cases with dates of onset from 14 January 2015 -11 February 2015.

1.7 Results

1.7.1 Descriptive analysis

There were 111 cases of *S. Saintpaul* notified to Queensland Health from January 1st to end February 2015. At this point cases were decreasing and

Queensland health did not require further assistance. The epi curve is shown in Figure 3.

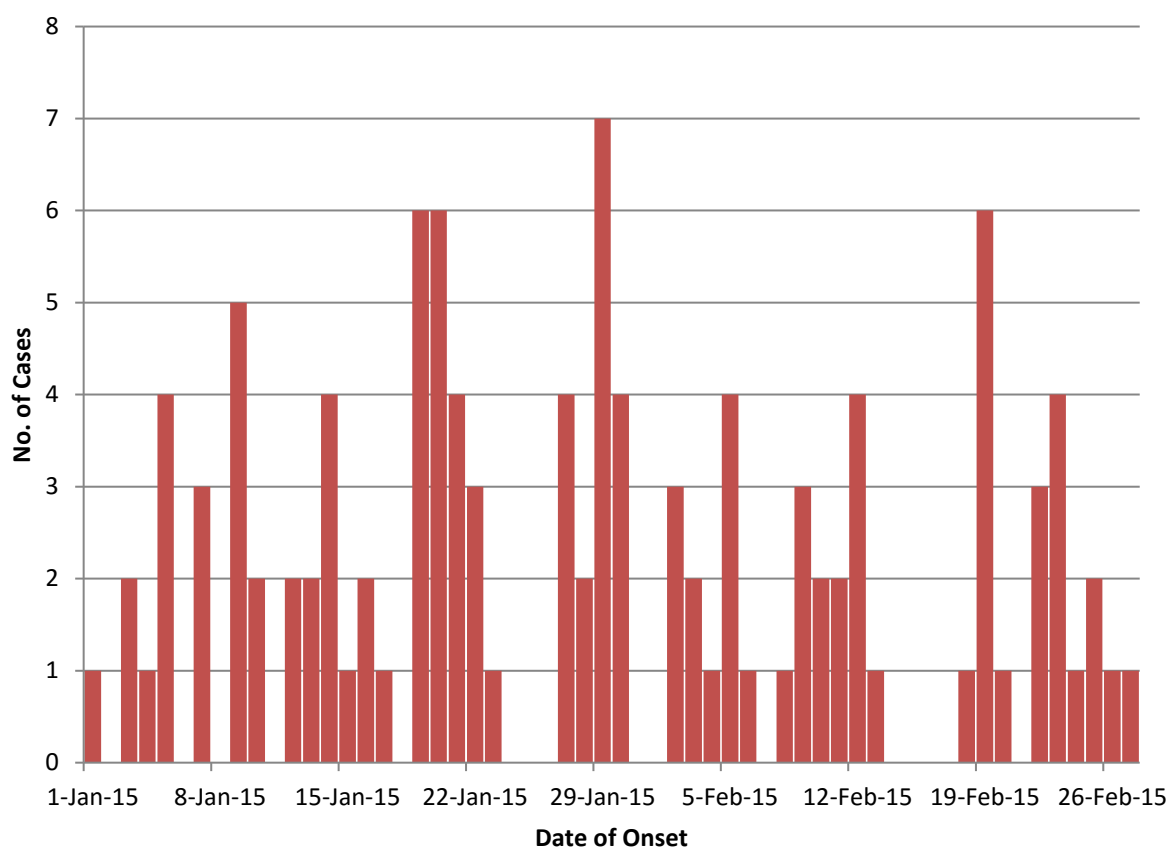


Figure 3: Queensland lab notifications of Salmonella Saintpaul from 1 January – 26 February 2015

Age and sex distribution of all notified cases (n=111) for January and February 2015 is shown in Figure 4. This indicates that the bulk of cases (n=26) were males aged 0-4 years. Geographical distribution of cases is shown in Figure 5; this shows the majority of cases (n=48, 44%) were from the central zone (which covers Central Qld HHS; Central West HHS; Metro North HHS; Sunshine Coast HHS; and Wide Bay HHS).

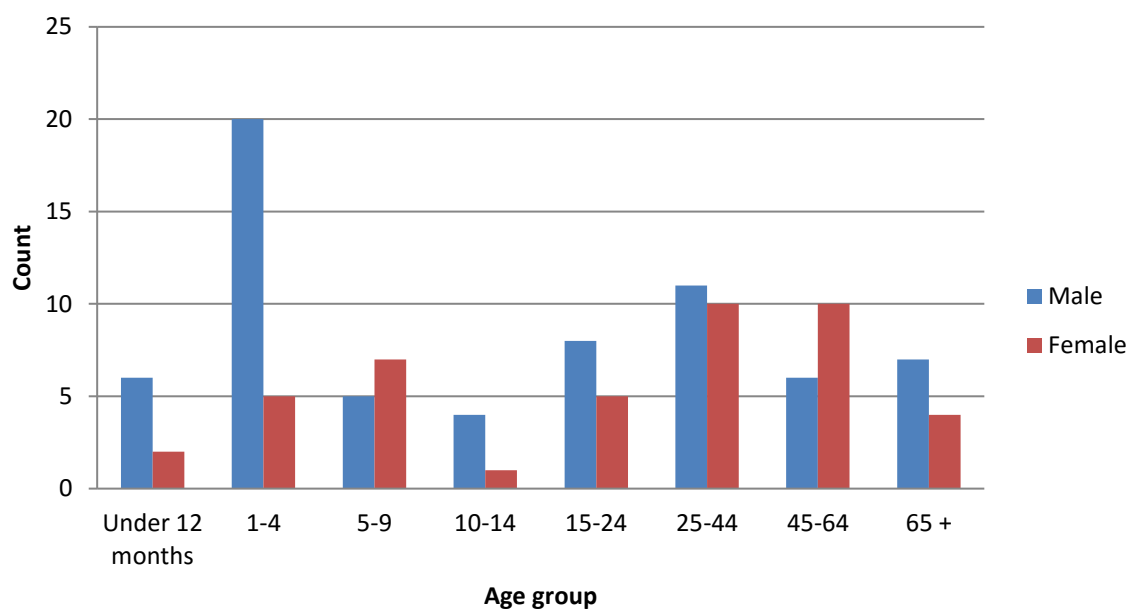


Figure 4: Age and sex of notified cases of *S. Saintpaul* in Queensland, January – February 2015

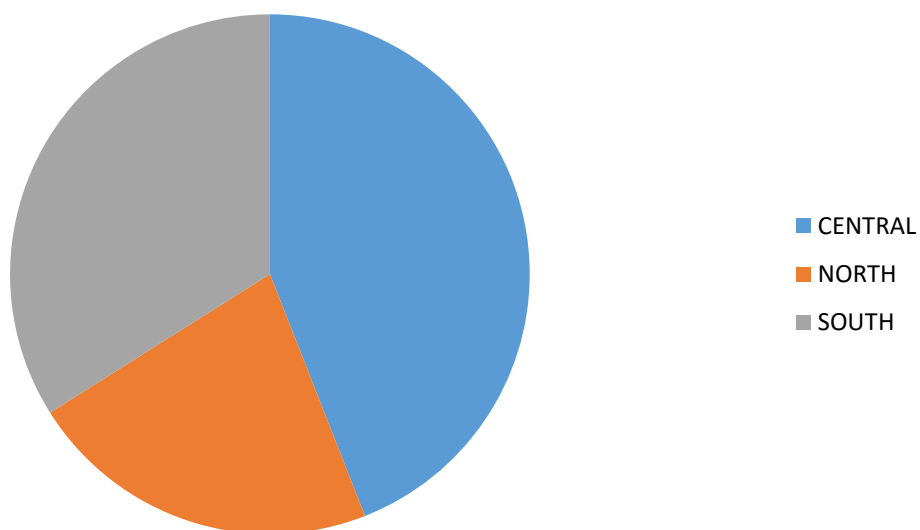


Figure 5: Geographical distribution of *S. Saintpaul* notifications January - February 2015 by Zone

1.7.2. Comparison with previous years

The total notifications (n=111) for January and February 2015 was higher than the median number of 60 for this time period during the previous five years (2010-2014); an increase in notifications of 54% (Table 1).

Table 1. Number of notifications for *Salmonella* Saintpaul in Queensland: Comparison January - February 2015 to same time period 2010-2014

Variable	2015 (n=111)	2010-2014 (n=1046) (median)
Notifications: January	67	23
Notifications: February	44	34
TOTAL Jan/Feb	111	60

The median age in 2015 compared to previous years notifications age increased from 13 years to 20 years, with a considerable increase in male cases from 50% to 60%. Age distributions were similar between 2015 and the comparison periods (Table 2).

*Table 2. Notifications *Salmonella* Saintpaul in Queensland - Comparison between 2015 and 2010 – 2014*

Variable	Jan Feb 2015 (n=111)	Jan-Feb 2010-2014	2010-2014 (n=1046)
Median Age (years)	20	14	13
Under 12 months (%)	7	13	13
1-4 years	23	24	24
5-9 years	11	7	9
10-14 years	5	5	6
15-24 years	12	10	9
25-44 years	19	20	18
45-64 years	14	12	13
65+ years	10	9	9
Sex: male (%)	60	53	50

When considered by geographic location, the Central zone had the highest proportion of cases for each year however, the relative proportion was higher in

2015 (44%) than in previous years of cases from 2010-2014 (36%) in total and for the first two months of each year. The proportion of cases from the Northern zone was lower (Figure 6).

In terms of HHS district, the majority of cases January – February 2015 were from the Metro North and Wide Bay HHS districts (n=15, 14% from each) followed by Metro South and Townsville (n=12, 11% from each). This was a comparison to the previous 5 years where the majority of cases were from Townsville (15%) followed by Metro South (11 %) (Figure 7).

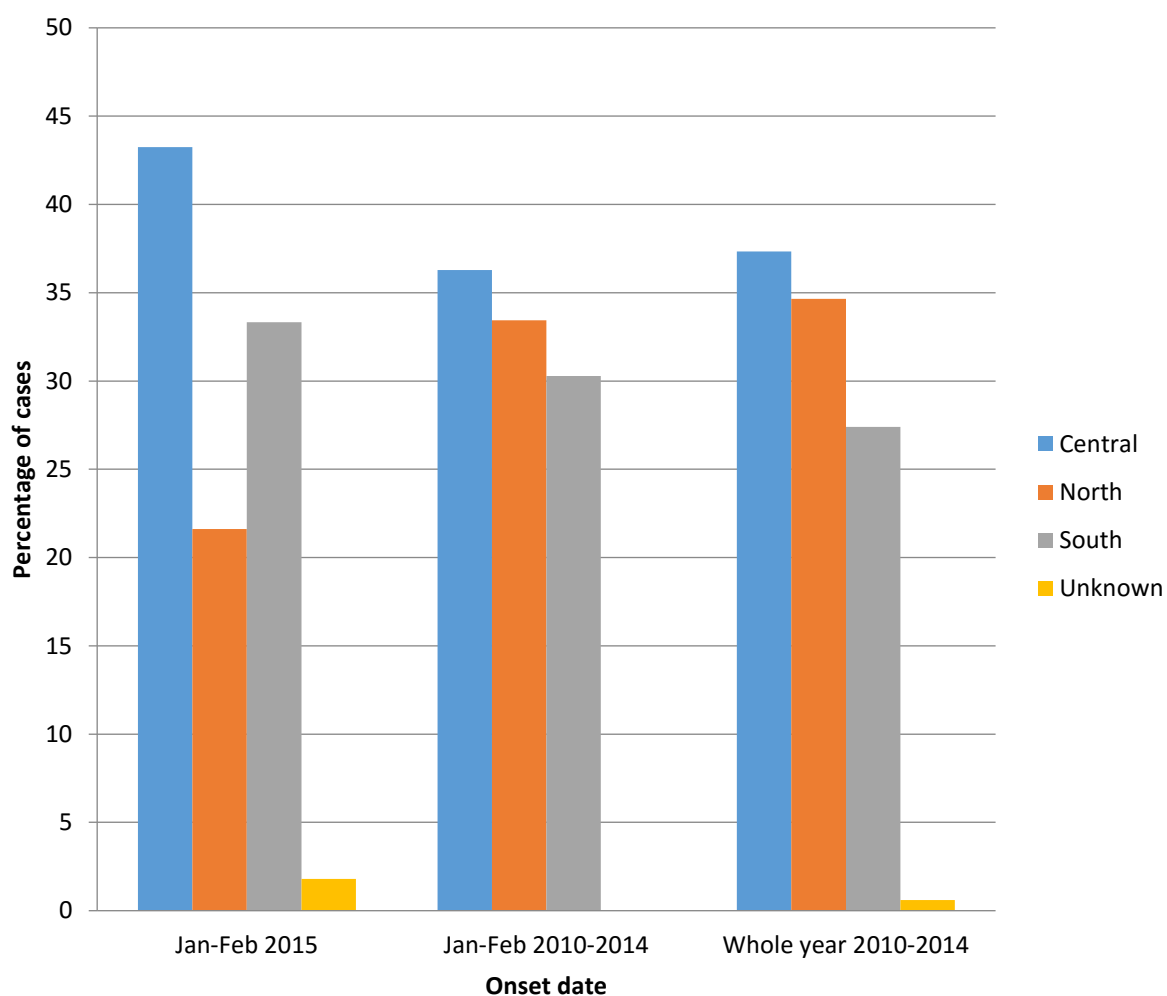


Figure 6: Geographical distribution of *Salmonella* Saintpaul cases by Zone, Jan-Feb 2010 – 2014, all of 2010-2014 compared to Jan-Feb 2015

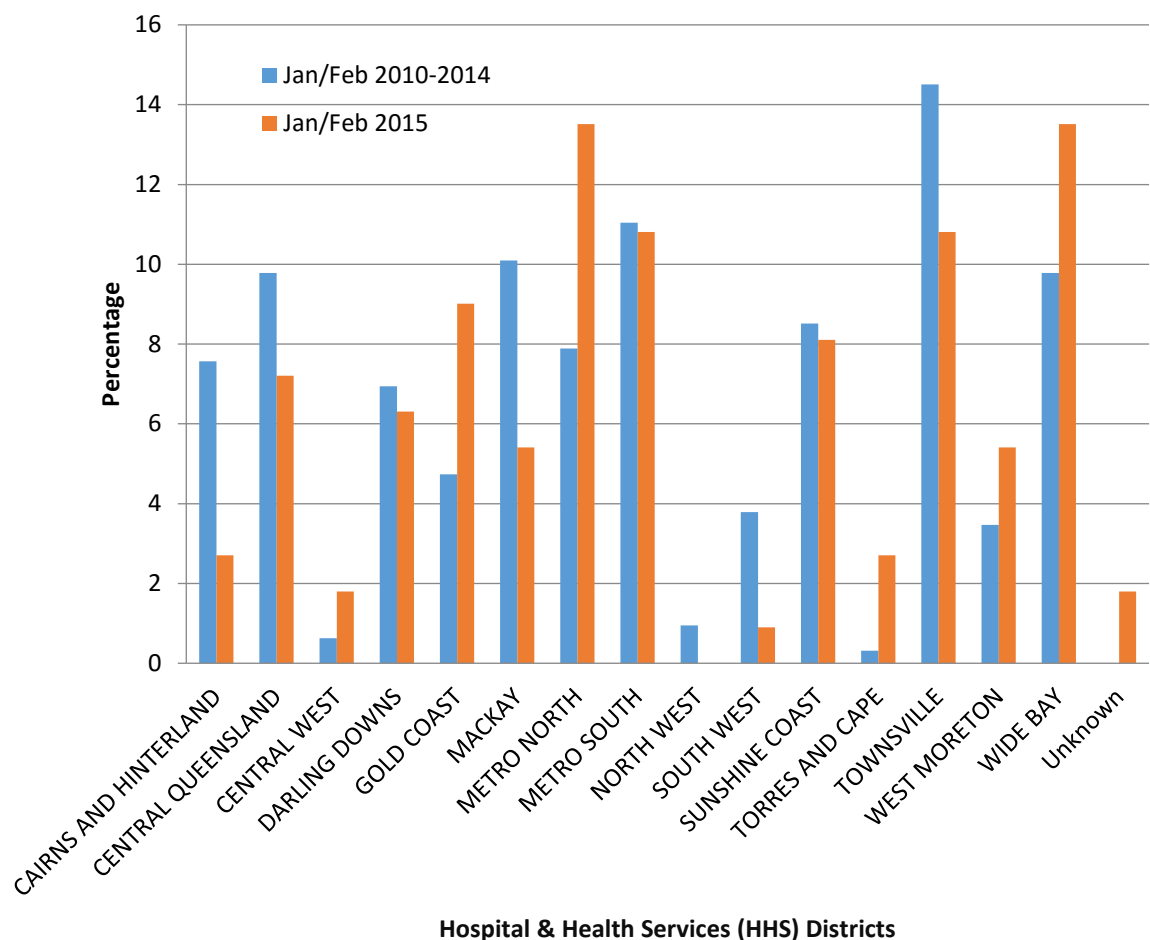


Figure 7: Geographical distribution of *Salmonella* Saintpaul cases by HHS, Jan-Feb 2010 – 2014 compared to Jan-Feb 2015

1.7.3 Rate

Although Townsville HHS had the highest number of cases (318) for years 2006-2014, the highest overall rate is in the South West HHS region of Queensland with an overall rate of 300 per 100,000 per year (Figure 8).

By HHS, the rate of *S. Saintpaul* closely tracks the pattern of the rate for all types of *Salmonella* notifications in Queensland. The overall rate of all types of *Salmonella* in Queensland are highest in the North West HHS and Central West HHS while the highest overall rate of *S. Saintpaul* is in the South West HHS followed by Townsville HHS (Figure 9).

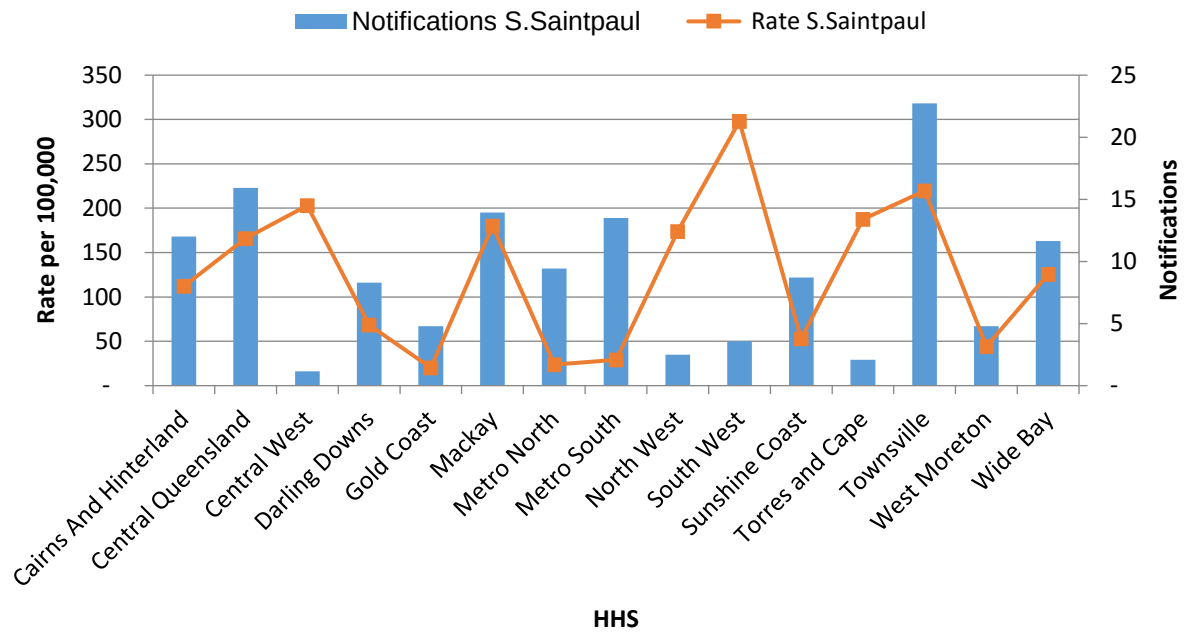


Figure 8: Overall cases and rates of *S. Saintpaul* by HHS - Qld 2006-2014

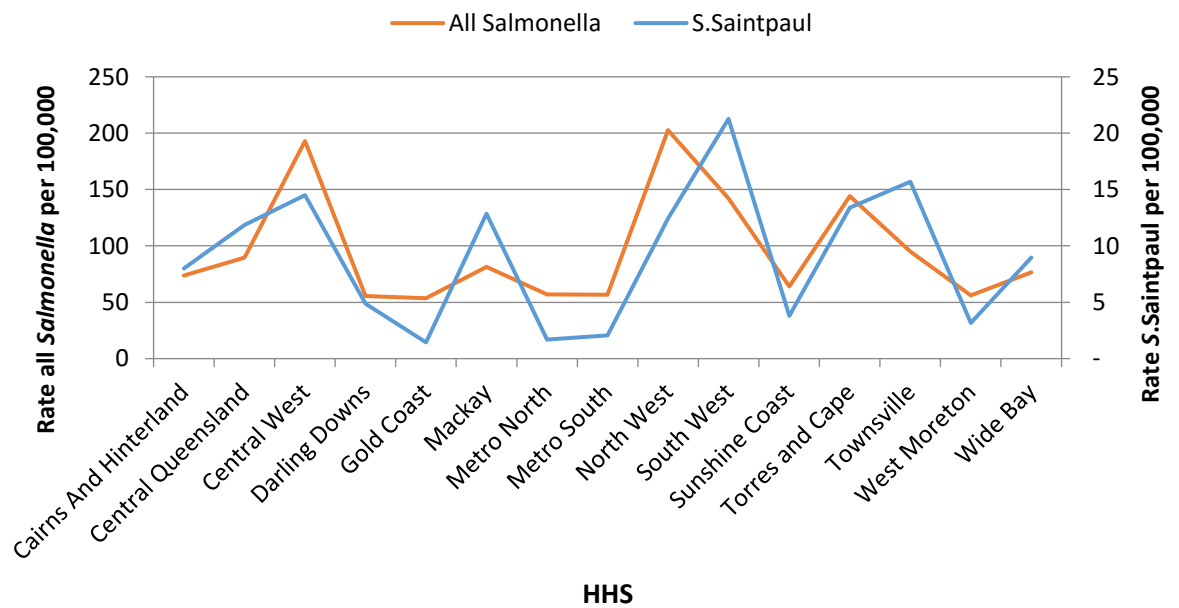


Figure 9: Overall rate of all salmonella in Queensland compared to the rate of *S. Saintpaul* in Queensland 2006-2014 by Hospital and Health Service (HHS) region

1.7.4 Hypothesis generating interviews

There were 23 hypothesis generating interviews conducted, with nine (9) undertaken by me. I initially contacted GPs and then cases; all GPs responded within 48 hours. Cases were all interviewed within 24 hours of their GP being contacted. All nine cases were contacted and consented to be interviewed.

Food exposures from the hypothesis generating interviews indicated the most commonly consumed foods were chicken and carrots (65%) (Table 3).

Table 3. Reported food exposures for interviewed cases of S.Saintpaul Qld January - February 2015

Food	Proportion	(n) (24)
Chicken (fresh)	65%	15
Carrot	65%	15
Banana	61%	14
Iceberg Lettuce	57%	13
Raw tomato	57%	13
Packaged ham	52%	12
Cucumber	52%	12
Egg	48%	11
Mince (fresh)	48%	11
Beef sausage	48%	11
Packaged bacon	48%	11
BBQ chicken	44%	10
Grapes	44%	10
Tank water	39%	9

1.7.5. MLVA

There were 8 different strains of MLVA identified among cases interviewed during the hypothesis generating interviews. The results of the MLVA tests are displayed in Figure 10 (note that the 'other category' contains 6 separate strains).

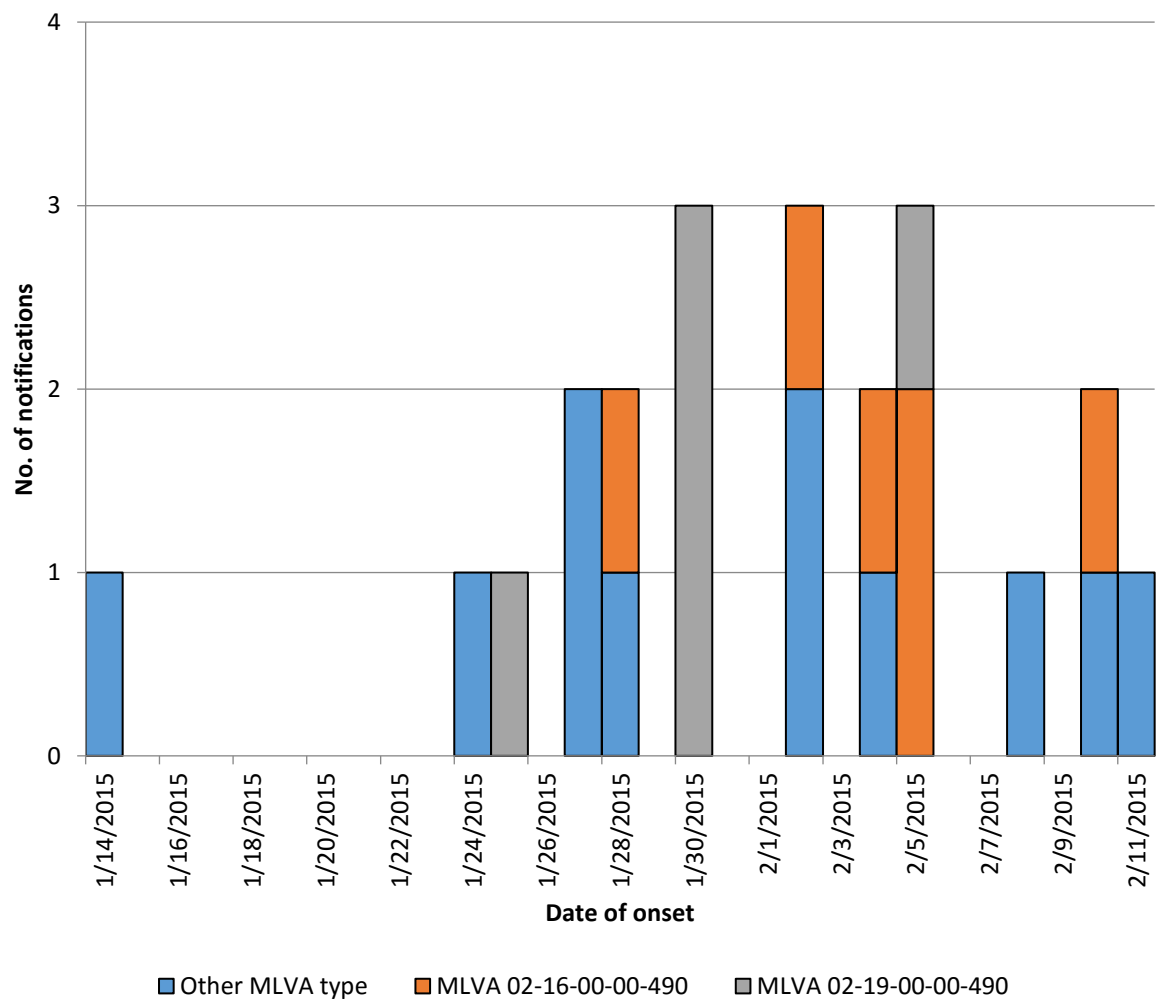


Figure 10: MLVA type by date of onset of case symptoms, 14 January 2015 – 11 February 2015

1.8. Discussion

This report describes the initial investigations into an increase in *S. Saintpaul* in January and February in Queensland, as part of a larger increase in *S. Saintpaul* notifications in other jurisdictions, in 2015 for which no common source was found.

As with any increase in notifications, it is necessary to ask from the outset whether this was likely to be a real increase of disease or an artefactual increase in notifications. In this case the increase was more likely to be real disease as there was no known change in the laboratory technique used to test for *Salmonella*, nor was there any reason to think that more tests were being conducted as the cases had a wide demographic and geographic distribution.

Our hypothesis generating interviews however, did not identify an associated exposure of *S. Saintpaul* infection. While the highest frequency exposures reported by cases (chicken and carrots) could be considered as plausible vehicles of *S. Saintpaul*, it is impossible to tell if these are associated with illness without knowing the exposure in the general population (Taylor et al., 2000).

While *Salmonella* outbreaks overall are most frequently associated with eggs, outbreaks of *S. Saintpaul* in Australia have been associated with a variety of food sources including the consumption of boiled eggs, rockmelon, untreated drinking water and bean sprouts. (Munnoch, Ward, Sheridan, Fitzsimmons, Shadbolt, Piispanen, Wang, Ward, Worgan, Oxenford, et al., 2009). On an international level, *S. Saintpaul* outbreaks have been attributed to the consumption of paprika and paprika-flavoured potato chips, bean sprouts, hospital prepared formula and mangoes (Beatty, LaPorte, Phan, Van Duyne, & Braden, 2004).

The differing MLVA strains appear to provide further evidence that there was no common source for this outbreak. However, this cannot be conclusively stated as the potential level of variation between MLVA in strains of *S. Saintpaul* has not been well established. While other outbreaks of *S. Saintpaul* have been traced to a single MLVA type (Munnoch, Ward, Sheridan, Fitzsimmons, Shadbolt, Piispanen, Wang, Ward, Worgan, & Oxenford, 2009), some point source outbreaks of *S. Typhimurium* have shown that these may contain different but related MLVA types (Franklin et al., 2009). Due to the level of

variation between MLVA strains in this outbreak and the fact that the MLVA variability of *S. Saintpaul* is not well studied, the MLVA types in this outbreak could not be determined to be related. More research is required on MLVA types of *S. Saintpaul* to determine whether point source outbreaks can contain different but related MLVA types.

A hypothesis I initially considered was that the increased notifications of *S. Saintpaul* were due to environmental contamination; specifically due to climate variability and its effects on recreational and potable water sources. The reasons I considered this were: 1) The lack of an obvious identified point source or other vehicle of infection through the hypothesis generating interviews 2) ecological characteristics of *S. Saintpaul* and 3) the climate in Queensland during 2014 and early 2015.

In terms of ecological characteristics of *S. Saintpaul*; while waterborne disease outbreaks are seldom reported in association with drinking water (Dale et al., 2010) previous outbreaks of *S. Saintpaul* have shown that water can act as a vehicle of transmission for this serotype. For example Taylor et al. (2000) reported an outbreak of *S. Saintpaul* in workers at a remote construction site in Central Queensland which involved 28 cases overall. The researchers found through microbiological sampling, reinforced by epidemiological results, compelling evidence that the outbreak of *S. Saintpaul* was most likely caused by a contaminated water supply (tanks) in which live green tree frogs lived (Taylor et al., 2000). The Qld town of Roma, situated in the South West HHS, has also had a previous waterborne *S. Saintpaul* outbreak attributed to the access of abattoir effluent to an unchlorinated drinking water bore casing. (Water Quality Research Australia, 2012) . In addition, a study conducted in north-east Spain investigated the incidence of serotypes of *Salmonella* in three types of environmental water (sea, river and fresh reservoirs). The study performed at specific sampling locations during the summer for a period of five years (1992–1996), it was observed that *S. Saintpaul* existed in all types of environmental water (Polo et al., 1998).

It is also interesting that the highest rates of *S. Saintpaul* occur in the South-West HHS (compared with *Salmonella* overall, for which rates are highest in North West Queensland). The South West HHS, which sits in the central zone, is a rural district which covers a vast area of South West Queensland. The

district services an area of 319,870 square km with an estimated population of 27,000 people (see Figure 11). (Queensland Government, 2016).

In 2009, 2010, 2013 and 2014, South West HHS had the highest rates for *S. Saintpaul*, and in 2011 and 2012 South West HHS had the second highest rates for *S. Saintpaul* – highlighting the fact that the South West HHS is consistently and constantly affected by *S. Saintpaul* in the five year 2009-2014 timeframe. In this area a higher proportion of the population either use tank water alone, or a combination of town water and tank water as potable water (*pers obs*). This is particularly the case for people living in Aboriginal and Torres Strait Islander communities in this HHS, as well as other areas of the central zone (*pers obs*). Interestingly two cases, a man and his son-in-law who lived in close proximity to each other in the Kingaroy/Wondai area, who had identical MLVAs stated that they both drank untreated tank water from the same source during their incubation periods, although they also shared a meal of shepherd's pie during this period. Although this is not direct evidence of waterborne *S. Saintpaul*, it does provide one plausible source.

In terms of climatic variability, Queensland experienced a dry year in 2014 with rainfall 10% below average overall. This was followed by several high rainfall events during the period of the outbreak (January and February) (Bureau of Meteorology, 2016).

Given this I hypothesised that there may have been an increase in waterborne transmission of *S. Saintpaul* via tank water, due to roof-harvested water and other collection points contaminated by faeces from birds or other animals. Other outbreaks of *Salmonella* have resulted via these means (Ashbolt & Kirk, 2006; Franklin et al., 2009; Heyworth, Glonek, Maynard, Baghurst, & Finlay-Jones, 2006; Koplan, Deen, Swanston, & Tota, 1978; Taylor et al., 2000), and it has been previously reported that the quality of tank water decreases after severe and extended drought conditions followed by a major rain event (Yaziz, 1989). Whilst this climatic variability hypothesis is appealing there is no direct evidence for this. It is also not supported by the percentage distribution of cases during the outbreak period, in which the highest percentage of cases were from metro North, an area in which people are less likely to use tank water rather than mains water for potable water. Regardless, as a general health measure it

seems that there is a need for health promotion in terms of the potential health risks of personal water storage tanks used for potable water purposes.

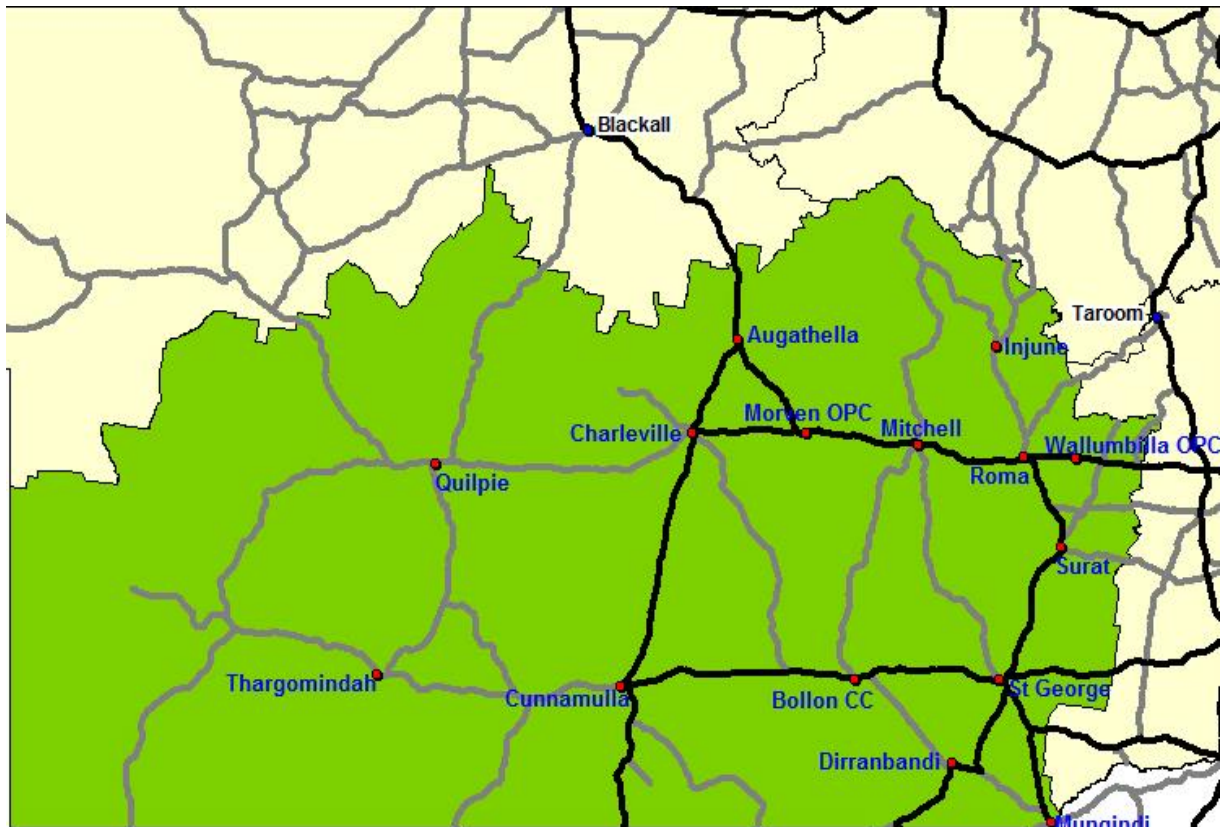


Figure 11: South West HHS Queensland

1.9. Limitations

A major limitation of the hypothesis generating interviews was the time interval between laboratory tests, case notification and interview. This was due to the lack of human resources at Qld Health to conduct the hypothesis generating interviews early. Many of the early cases were contacted on average 2-3 weeks after diagnosis increasing recall bias for items on the hypothesis generating interview questionnaire.

Another limitation was that we did not systematically collect data on other potential exposures such as tank water, bore water, private and public swimming pools. Intriguingly, the majority of cases I interviewed (7/9) reported swimming daily and/or had exposure to tank water. However, as mentioned above a major limitation of this investigation was the lack of a comparison group inherent to hypothesis generating interviews. Therefore we were unable to compare exposures between cases and non-cases, including to water activities and potable water. Had a study been considered, the most appropriate design

would have been a case control study due to the wide geographical spread of cases and lack of a defined cohort.

In this situation, as there were no implicated foods a traceback investigation was not necessary. If it had been, a traceback investigation would include examining the distribution pathway for implicated food items associated with the cases, or investigations to determine whether food handlers were ill before cases onset of illness to identify practices in food preparation, handling and storage also, food samples along the distribution chain for example packing facilities and farms to determine a possible source of contamination (Behravesh et al., 2011).

No environmental sampling was conducted as part of this investigation. While there was no implicated water source in this outbreak, if there were unlimited resources it would be of interest to conduct bacteriological analysis of water sources such as water tanks, bores and private and public swimming pools used by cases in the Central zones of Qld.

A final limitation of this investigation was the use of a very specific, laboratory confirmed case definition for *S. Saintpaul*. This is likely to have led to selection bias whereby the majority of cases in the community would not have been included in the investigation as they would have either not presented for health care, or would not have been tested. This type of bias is common in outbreak investigations, and can be overcome by active case finding.

1.10. Public health implications and recommendations

This investigation did not find a source for the outbreak and so no direct control methods occurred as a result.

In spite of this an extremely important public health implication from our input was including Aboriginal and Torres Strait Islander status on the questionnaire used for investigating this outbreak. From the data I have seen it is unclear to me whether Aboriginal and Torres Strait Islander status is routinely collected for *Salmonella* cases in Queensland. The inconsistency of collecting Aboriginal and Torres Strait Islander status and under-identification of Aboriginal and Torres Strait Islander peoples in Qld health data sets creates complications for measuring the gap in health outcomes between Indigenous and non-Indigenous

Australians and for monitoring progress in closing the gap (Australian Institute of Health and Welfare, 2010). Our inclusion of this field on the questionnaire in this investigation ensured better data for this investigation, and this field should routinely be collected in all health datasets.

As discussed above the delay between notifications being received and interviews being done with cases was a major limitation of this investigation. This lack of timeliness was due to a lack of timeliness with notifications in general, but also due to limited human resources at Queensland health. A solution to this may be an emergency roster of trained interviewers (not necessarily with a public health background) who can be on-call for surge capacity when this need arises.

My data analysis showed that rural areas in Qld, in particular the Central zone, have consistently higher rates of *Salmonella* than the rest of the state. Although I did not analyse these data by Aboriginal status, generally Aboriginal and Torres Strait Islander peoples have higher rates of *Salmonella* than the rest of the Australian population (Phillips, 2009). This highlights the need for health promotion initiatives around communicable disease awareness in rural and remote areas.

1.11. Conclusion

There was no common source identified for the increase in notifications. Multiple MLVA strains found in this outbreak also supported there not being a common source, however there is a need for further research on the variability of *S. Saintpaul* MLVA in outbreaks. A hypothesis I considered plausible was climate variability however there is no direct evidence for this. The effects of climate variability on water sources is also plausible however this transmission path was not explored. An important public health implication of this investigation was the inclusion of Aboriginal and Torres Strait Islander status on the hypothesis generation questionnaire. As a general health measure it seems that there is a need for health promotion in terms of the potential health risks of personal water storage tanks used for potable water purposes, and alternative exposure water sources in terms of swimming pools (private and public), lakes, and creeks and bore water.

1.12. Recommendations

1. That Indigenous status notification be routinely collected for all outbreaks of *Salmonella*, and more broadly. Ideally this should be completed at all stages of data collection (GPs, laboratory, hospital and public health unit documentation); including data linkage with Medicare as per recommendations made in the National best practice guidelines for collecting Indigenous status in health data sets (Australian Institute of Health and Welfare, 2010).
2. Consideration should be given to developing teams within health departments that can be deployed at short notice to conduct hypothesis generating interviews within 2 days of *Salmonellosis* notifications
3. More investigation is needed into the MLVA strains for *S. Saintpaul* so that we can determine the relatedness of different MLVA strains in outbreaks of *S. Saintpaul*
4. There should be ongoing health promotion (e.g. annual campaigns) about *Salmonella* and transmission pathways to high risk groups.

1.13. Acknowledgements

I would like to thank Queensland Health, OzFoodNet and NCEPH for the opportunity of participating in the outbreak investigation including:

- Associate Professor Martyn Kirk
- MAE Supervisors: Dr Stephanie Davis, Dr Ray Lovett and Dr Kerri Viney
- Dr Ben Polkinghorne
- Dr Russell Stafford and
- MAE colleague Dr Jason Agostino

1.14. References

- Ashbolt, R., & Kirk, M. (2006). Salmonella Mississippi infections in Tasmania: the role of native Australian animals and untreated drinking water,. *Epidemiology Infections*, 134(6), 1257-1265.
- Australian Institute of Health and Welfare. (2010). National best practice guidelines for collecting Indigenous status in health data sets,. In Australian Institute of Health and Welfare (Ed.). Canberra.
- Beatty, M. E., LaPorte, T. N., Phan, Q., Van Duyne, S. V., & Braden, C. (2004). A Multistate Outbreak of Salmonella enterica Serotype Saintpaul Infections Linked to Mango Consumption: A Recurrent Theme. *Clinical Infectious Diseases*, 38(9), 1337-1338. doi:10.1086/383156
- Behraves, C. B., Mody, R. K., Jungk, J., Gaul, L., Redd, J. T., Chen, S., . . . Williams, I. T. (2011). 2008 Outbreak of Salmonella Saintpaul Infections Associated with Raw Produce,. *The New England Journal of Medicine*, 364(10), 918-927.
- Bureau of Meteorology. (2016). Climate summaries archive,. Retrieved from (<http://www.bom.gov.au/climate/current/annual/qld/archive/2014.summary.shtml>)
- Franklin, L. J., Fielding, J. E., Gregory, J., Gullan, L., Lightfoot, D., Posnanski, S. Y., & Vally, H. (2009). An outbreak of *Salmonella* Typhimurium 9 at a school camp linked to contamination of rainwater tanks,. *Epidemiology and Infection*, 137, 434-440. doi:10.1017/S095026880800109X
- Glass, K., Ford, L., Brown, K., & Hall, G. (2014). *Foodborne illness in Australia: Annual incidence circa 2010*,. Canberra ACT: National Centre for Epidemiology and Population Health, Australian National University,.
- Heymann, D. L. (2008). *Control of Communicable Diseases Manual* (19th ed.). Washington, DC: American Public Health Association.
- Heyworth, J., Glonek, G., Maynard, E., Baghurst, P., & Finlay-Jones, J. (2006). Consumption of untreated tank rainwater and gastroenteritis among young children in South Australia. *International Journal of Epidemiology*, 35(4), 1051-1058. doi:10.1093/ije/dyl105
- Kirk, M. D., 1,2 , Lator, K., Raupach, J., Combs, B., Stafford, R., Hall, G. V., & Becker, N. (2011). Food and Waterborne Disease Outbreaks in Australian Long-Term Care Facilities, 2001–2008,. *Foodborne Pathogens and Disease*, 8(1). doi:10.1089=fpd.2010.0648
- Koplan, J., Deen, R. D., Swanston, W. H., & Tota, B. (1978). Contaminated roof-collected rainwater as a possible cause of an outbreak of salmonellosis,. *Journal of Hygiene*, 81, pp 303-309. doi:10.1017/S0022172400025146
- May, F. (2015). [MLVA].
- Munnoch, S., Ward, K., Sheridan, S., Fitzsimmons, G., Shadbolt, C. T., Piispanen, J., . . . Oxenford, C. (2009). A multi-state outbreak of Salmonella Saintpaul in Australia associated with cantaloupe consumption. *Epidemiology and Infection*, 137(03), 367-374.
- Munnoch, S., Ward, K., Sheridan, S., Fitzsimmons, G. J., Shadbolt, C., Piispanen, J., . . . Durrheim, D. (2009). A multi-state outbreak of Salmonella Saintpaul in Australia associated with cantaloupe consumption,. *Epidemiology and Infection*, 137, 367-374. doi:10.1017/S0950268808000861
- National Institute for Public Health and the Environment. (2016). Welcome to the Multiple-Locus Variable number tandem repeat Analysis home page,. Retrieved from <http://www.mlva.net/default.asp>
- OzFoodNet Working Group. (2011a). *Monitoring the incidence and cause of diseases potentially transmitted by food in Australian Annual report of the OzFoodnet Network, 2011*, . Retrieved from Canberra ACT:
- OzFoodNet Working Group. (2011b). *Monitoring the incidence and causes of diseases potentially transmitted by food in Australia: Annual Report of the OzFoodNet Network, 2011*, . Retrieved from Canberra, ACT:

- Phillips, A. (2009). Health status differentials across rural and remote Australia,. *Australian Journal of Rural Health*,, 17(1), 1440-1584. doi:10.1111/j.1440-1584.2008.01029.x
- Polo, F., Figueras, M. J., Inza, I., Sala, J., Fleisher, J. M., & Guarro, J. (1998). Relationship between presence of *Salmonella* and indicators of faecal pollution in aquatic habitats. *FEMS Microbiology Letters*, 160(2), 253-256. doi:10.1111/j.1574-6968.1998.tb12919.x
- Queensland Government. (2016). Queensland Health, South West Hospital and Health Service,. Retrieved from <https://www.health.qld.gov.au/southwest/>
- Queensland Health. (2013). Student Deed Poll. from Queensland Government publications, <https://www.health.qld.gov.au/publications/portal/student-deeds/student-deed-poll.pdf>
- Queensland Health. (2016a). Queensland Hospital and Health Services maps,. Retrieved from <https://www.health.qld.gov.au/maps/>
- Queensland Health. (2016b). *Salmonella* Infection, Queensland Health Guidelines for Public Health Units,. Retrieved from <https://www.health.qld.gov.au/cdcg/index/salmonella.asp#res>
- State Government of Victoria. (2015). *Infectious diseases epidemiology and surveillance*,. Melbourne: Victorian Government Retrieved from <http://ideas.health.vic.gov.au/diseases/salmonellosis.asp>.
- Taylor, R., Sloan, D., Cooper, T., Morton, B., & Hunter, I. (2000). A waterborne outbreak of *Salmonella* Saintpaul,. *Communicable Disease Intelligence*,, 24(11), 336-340.
- Water Quality Research Australia. (2012). Health Stream, Information and analysis for water and health professionals, . from WQRA
- World Health Organization. (2016). *Salmonella* (non-typhoidal),. Retrieved from <http://www.who.int/mediacentre/factsheets/fs139/en/>
- Yaziz, M. I. (1989). Variations in rainwater quality from roof catchments. *Water research (Oxford)*, 23(6), 761-765. doi:10.1016/0043-1354(89)90211-X

Confidential – for public health use only



Salmonella Saintpaul Case Questionnaire

Attempt	Date	Time	Outcome
1	___ / ___ / ____	_____ am / pm	_____
2	___ / ___ / ____	_____ am / pm	_____
3	___ / ___ / ____	_____ am / pm	_____
4	___ / ___ / ____	_____ am / pm	_____

Interviewer: _____

Call Outcomes
 OC1 – No Answer
 OC2 – Subject not home, call back
 OC3 – Appointment to call back
 OC4 – Refusal
 OC5 – Interviewed

"Hello, my name is _____ and I'm calling from Queensland Dept. of Health.

May I please speak with _____ (name of case or parent)?"

Queensland Dept. of Health is conducting an investigation into a recent increase in cases of Salmonella infection in the community. I understand **(case name)** recently had a gastroenteritis caused by a Salmonella infection? Salmonella infections are notifiable to the Queensland Dept. of Health by doctors and laboratories. We would like your assistance in answering some questions regarding your **(or case's name)** illness, travel history and foods that were eaten prior to becoming ill. It should only take 15 – 20 minutes to complete. The information collected is kept confidential and no identifying information is released without your consent. Can I proceed with the interview?"

Note: The following preliminary information can be recorded prior to interview if known

Personal details

First Name: _____ Address: _____
 Last Name: _____
 Telephone: _____ (Home) _____
 _____ (Work) Post Code: _____
 Date of Birth: ___ / ___ / ____ Age: _____ Gender: Male / Female

Do you identify as being of Aboriginal or Torres Strait Islander Origin?

No / Unknown / Aboriginal / Torres Strait Islander / Both Aboriginal Torres Strait Islander

Medical & diagnostic information

Treating GP: _____ Telephone: _____
 Medical Practice: _____
 Salmonella: _____ Phage Type (if known): _____
 Specimen type: _____ Collection Date: ___ / ___ / ____ Day: _____

Clinical details

'We would like to obtain some detail on your *Salmonella* infection and the symptoms you experienced.'

1. During your illness, did you experience any of the following symptoms?

	Yes	No	DK/NS
Vomiting.....	☐	☐	☐
Diarrhoea.....	☐	☐	☐
Stomach Cramps.....	☐	☐	☐
Blood in stools.....	☐	☐	☐
Nausea.....	☐	☐	☐
Fever.....	☐	☐	☐
Other symptoms.....	☐	☐	☐
Specify: _____			

2. What date and time did (your / your child's) gastrointestinal symptoms begin?
(Vomiting, diarrhoea or stomach cramps only)

____/____/____ AM / PM

3. For how long did (your / your child's) diarrhoea or vomiting symptoms last? _____
(Specify in days)

4. (Were you / Was your child) admitted to hospital overnight for this illness?

Yes..... ☐₁ Hospital Name: _____
 No..... ☐₂
 Don't Know / Not Sure..... ☐₃

Exposure Information

5. In the five days prior to (your / your child's) illness did (you / your child) have contact with anyone with a similar illness such as friends, family members, work colleagues, etc...?

Yes..... ☐₁ Specify _____
 No..... ☐₂ _____
 Don't Know / Not Sure..... ☐₃ _____

6. **CASES 15 YEARS+**

When your symptoms began, were you employed as a health care worker, child-care worker or food preparer / food handler?

Yes..... ☐₁ Specify _____
 No..... ☐₂
 Don't Know / Not Sure..... ☐₃

7. CHILDREN <14 YEARS

Did your child attend childcare, day-care or school in the week prior to illness?

Yes..... ☐ 1 Name of facility _____
 No..... ☐ 2
 Don't Know / Not Sure..... ☐ 3

Travel

8. In the five days prior to (your / your child's) illness, did (you / your child) travel overseas, to another state or territory or anywhere within the state?

Yes..... ☐ 1 Location _____
 No..... ☐ 2
 Don't Know / Not Sure..... ☐ 3

IF OVERSEAS TRAVEL – END INTERVIEW

Social Events / Functions

In the five days prior to (your / your child's) illness...

	Yes	No	DK/NS	Details
9. Did (you / your child) attend any large gatherings where food was consumed? Eg. weddings, social events, clubs, church, parties, festivals, fairs or BBQ's?	☐	☐	☐	_____ _____ _____
	↓	↳	↳	Go to 10
Gathering / Outing	Date	Location		
1. _____	___/___/___	_____		
2. _____	___/___/___	_____		

Food Outlet Exposures

10. In the five days prior to (your / your child's) illness, did (you / your child) eat food from any of the following places?

	Yes	No	DK/NS	Food Item	Food Outlet Details & Location
Restaurant (sit down).....	☐	☐	☐	_____	_____
Takeaway / Fast food outlets.....	☐	☐	☐	_____	_____
Bakery.....	☐	☐	☐	_____	_____
Temporary food stall (eg. markets, fetes, festivals).....	☐	☐	☐	_____	_____
Salad / sandwich bar.....	☐	☐	☐	_____	_____
Other (specify) _____	☐	☐	☐	_____	_____

Fruit & Vegetables

11. In the five days prior to (your / your child's) illness, did (you / your child) consume any of the following?

	Yes	No	DK/NS	Food Item Additional Info	Place of Purchase / Consumption /Locality
Fruits					
Mangos.....	☐	☐	☐		
Pawpaw.....	☐	☐	☐		
Apples.....	☐	☐	☐		
Apricots.....	☐	☐	☐		
Avocados.....	☐	☐	☐		
Bananas.....	☐	☐	☐		
Berries.....	☐	☐	☐		
Cherries.....	☐	☐	☐		
Coconut.....	☐	☐	☐		
Oranges.....	☐	☐	☐		
Mandarins.....	☐	☐	☐		
Grapefruits.....	☐	☐	☐		
Kiwi fruit.....	☐	☐	☐		
Grapes.....	☐	☐	☐		
Peaches.....	☐	☐	☐		
Pears.....	☐	☐	☐		
Pineapples.....	☐	☐	☐		
Plums.....	☐	☐	☐		
Watermelon.....	☐	☐	☐		
Rockmelon/cantaloupe.....	☐	☐	☐		
Other fruit.....	☐	☐	☐		
Vegetables					
Lettuce.....	☐	☐	☐		
Bagged lettuce.....	☐	☐	☐		
Other lettuce.....	☐	☐	☐		
Uncooked tomatoes.....	☐	☐	☐		
Semi/sun-dried tomatoes...	☐	☐	☐		
Raw celery.....	☐	☐	☐		
Uncooked broccoli.....	☐	☐	☐		
Uncooked shallots.....	☐	☐	☐		
Asparagus.....	☐	☐	☐		
Beans.....	☐	☐	☐		
Beets.....	☐	☐	☐		
Cabbage.....	☐	☐	☐		
Carrots.....	☐	☐	☐		
Corn / baby corn.....	☐	☐	☐		
Cucumber.....	☐	☐	☐		
Eggplant.....	☐	☐	☐		
Alfalfa / bean sprouts.....	☐	☐	☐		
Other uncooked vegetables	☐	☐	☐		

	Yes	No	DK/NS	Food Item Additional Info	Place of Purchase / Consumption /Locality
Pre-prepared coleslaw.....	☐	☐	☐	_____	_____
Pre-prepared salad mix.....	☐	☐	☐	_____	_____
Pre-prepared potato salad..	☐	☐	☐	_____	_____
Pre-prepared bean salad....	☐	☐	☐	_____	_____

Meat, poultry & egg consumption

12. In the five days prior to illness, did you / your child consume any ...

	Yes	No	DK/NS	Food Item	Place of Purchase / Consumption / Locality
Eggs (fried, poached, scrambled)	☐	☐	☐	_____	_____
Egg dishes (e.g. quiche).....	☐	☐	☐	_____	_____
Foods with raw eggs (e.g. egg nog, hollandaise sauce, mayonnaise).....	☐	☐	☐	_____	_____
Seafood (e.g. fish, shellfish)	☐	☐	☐	_____	_____
Game meat or offal.....	☐	☐	☐	_____	_____

13. Where did (you / your child) obtain the eggs that were eaten in the five days prior to illness?

Home chickens.....	☐	
Direct from farm.....	☐	Specify: _____
Supermarket	☐	Specify: _____
Supplied by friend / relative.....	☐	Specify: _____
Other.....	☐	Specify: _____
Don't Know / Not Sure.....	☐	

14. What types of eggs were consumed in the five days prior to illness?

Free range.....	☐	
Organic.....	☐	
Caged	☐	
Barn laid.....	☐	
Other	☐	Specify: _____
Don't Know / Not Sure.....	☐	

15. In the five days prior to (your / your child's) illness did (you / your child) consume any ...?

	Yes	No	DK/NS		Home cooked	Cooked elsewhere	Place of Purchase / Consumption (if other than home)
Chicken.....	☐	☐	☐		☐	☐	
Duck	☐	☐	☐		☐	☐	
Turkey	☐	☐	☐		☐	☐	
Frozen poultry.....	☐	☐	☐		☐	☐	
BBQ chicken.....	☐	☐	☐		☐	☐	
Chicken kebabs.....	☐	☐	☐		☐	☐	
Other chicken dishes	☐	☐	☐		☐	☐	
Specify: (e.g. wraps, salads etc...)							

16. If chicken consumed at home, what type of chicken was purchased?

	Yes	No	DK/NS	Purchased Frozen	Purchased Fresh
Whole chicken.....	☐	☐	☐	☐	☐
Chicken breast.....	☐	☐	☐	☐	☐
Chicken pieces (thigh, wing, leg)	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐

17. Where do you usually purchase chicken from?

Store	Store Location
Woolworths.....	
Coles.....	
IGA.....	
Aldi	
Fruit store / grocery.....	
Food Markets.....	
Other.....	
Don't buy chicken.....	
Don't Know / Not Sure.....	

Animal & environmental exposure

18. In the five days prior to (your / your child's) illness, did (you / your child) come in close contact or touch any of the following:

	Yes	No	DK/NS	Details	Locality
Animal Contact					
Farm animals.....	☐	☐	☐		
Animals, birds or reptiles from a petting zoo or animal sanctuary	☐	☐	☐		
Household pets (dogs, cats, guinea pigs, reptiles, birds etc).	☐	☐	☐		
Native animals (kangaroos, possums, wallabies, etc.)	☐	☐	☐		

Water consumption & contact

	Yes	No	DK/NS	Details	Locality
19. Did (you / your child) drink or have contact with water from any of the following sources in the five days prior to illness?					
Drink tank / rain water.....	☐	☐	☐		
Drink river / stream water	☐	☐	☐		
Drink bore water.....	☐	☐	☐		
Swimming (ocean, pool, lake, river etc.)	☐	☐	☐		

On the day the illness began, what was eaten for breakfast, lunch and dinner?

Mon / Tue / Wed / Thurs / Fri / Sat / Sun Date: ____ / ____ / ____

Day of Onset of Illness	
Breakfast (Include condiments and sauces)	Place of Consumption / Purchase <i>(Circle home if meal was prepared at home otherwise specify)</i>
	Home
	Home
Snacks eaten:	
Lunch (Include condiments and sauces)	Place of Consumption / Purchase <i>(Circle home if meal was prepared at home otherwise specify)</i>
	Home
	Home
Snacks eaten:	
Dinner (Include condiments and sauces)	Place of Consumption / Purchase <i>(Circle home if meal was prepared at home otherwise specify)</i>
	Home
	Home

On the day before the illness began, what was eaten for breakfast, lunch and dinner?

Mon / Tue / Wed / Thurs / Fri / Sat / Sun Date: ____ / ____ / ____

1 Day Prior to Onset of Illness	
Breakfast (Include condiments and sauces)	Place of Consumption / Purchase <i>(Circle home if meal was prepared at home otherwise specify)</i>
	Home
	Home
Snacks eaten:	
Lunch (Include condiments and sauces)	Place of Consumption / Purchase <i>(Circle home if meal was prepared at home otherwise specify)</i>
	Home
	Home
Snacks eaten:	
Dinner (Include condiments and sauces)	Place of Consumption / Purchase <i>(Circle home if meal was prepared at home otherwise specify)</i>
	Home
	Home

On the two (2) days before the illness began, what was eaten for breakfast, lunch & dinner? Mon /
Tue / Wed / Thurs / Fri / Sat / Sun Date: ____ / ____ / ____

2 Days Prior to Onset of Illness	
BREAKFAST (Include condiments and sauces)	Place of Consumption / Purchase (Circle home if meal was prepared at home otherwise specify)
	Home
	Home
Snacks eaten:	
LUNCH (Include condiments and sauces)	Place of Consumption / Purchase (Circle home if meal was prepared at home otherwise specify)
	Home
	Home
Snacks eaten:	
DINNER (Include condiments and sauces)	Place of Consumption / Purchase (Circle home if meal was prepared at home otherwise specify)
	Home
	Home

On the three (3) days before the illness began, what was eaten for breakfast, lunch and dinner?
Mon / Tue / Wed / Thurs / Fri / Sat / Sun Date: ____ / ____ / ____

3 Days Prior to Onset of Illness	
Breakfast (Include condiments and sauces)	Place of Consumption / Purchase (Circle home if meal was prepared at home otherwise specify)
	Home
	Home
Snacks eaten:	
Lunch (Include condiments and sauces)	Place of Consumption / Purchase (Circle home if meal was prepared at home otherwise specify)
	Home
	Home
Snacks eaten:	
Dinner (Include condiments and sauces)	Place of Consumption / Purchase (Circle home if meal was prepared at home otherwise specify)
	Home
	Home

Chapter 2: ACT Inmate Health Survey:

Prisoner contact and psychological distress

In Western Australia, minerals are being dug up from Aboriginal land and shipped to China for a profit of a billion dollars a week. In this, the richest, 'booming' state, the prisons bulge with stricken Aboriginal people, including juveniles whose mothers stand at the prison gates, pleading for their release. The incarceration of black Australians here is eight times that of black South Africans during the last decade of apartheid.

John Pilger

2.1. Prologue

The Alexander Maconochie Centre (AMC) is a correctional facility in the Australian Capital Territory (ACT). It received its first residents on 30 March 2009 and all ACT prisoners were repatriated from New South Wales (NSW) by end of May 2009.

The first study on inmate health conducted in the AMC was the 2010 ACT Inmate Health Survey (IHS), which was adapted from the NSW Inmate Health Survey. The ACT Corrections Health Program conducted the IHS with assistance from ACT Corrective Services, Justice Health (NSW), the ACT Dental Health Program and Mental Health ACT.

As a Master of Philosophy in Applied Epidemiology (MAE) candidate, I was granted ethics approval by ACT Health to conduct a secondary cross-sectional analysis of data from the 2010 ACT Inmate Health Survey. These data were used to examine the relationship between external contact (visits and phone calls) and psychological distress. Upon receipt of the IHS dataset I discovered that a crucial component was missing for respondents. Sixty-four of 135 responses for Question 9 of the Kessler 10 scale data were missing. My first approach aimed to assess whether multiple imputation could be used to impute the missing data. However, due to the extent of missing data (47%), and based on recommendations from a number of statisticians consulted, the decision was made to abandon this approach (Soley-Bori, 2013).

Data analysis is a core component of the MAE program. Therefore, to meet this requirement, I continued with the secondary analysis on the smaller sample. I conducted a descriptive analysis and logistic regression to examine the association between the outcome variable (mild to severe psychological distress) and a range of exposures; controlling for age and sex.

2.1.1 My Role

Contact was made with the data custodian at ACT Health and two meetings were held with them to discuss the project and the data. I applied for ethics approval from the Australian Capital Territory (ACT) Human Research Ethics Committee, the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Ethics Committee, and the Australian National University (ANU) Human

Research Ethics Committee. The ethics documentation I submitted to each of these institution's Human Research Ethics Committees (HRECs) also included a data analysis plan. Ethics approval was granted by all three HRECs and the data were transferred electronically from ACT Health.

2.1.2 Lessons Learnt

This study provided the opportunity to review and develop Stata14 skills, and improve my analytical skills. The project provided the opportunity of a 'hands on' experience in a statistical analysis of a real health department survey dataset. I learned to carefully inspect and format the variables into a dataset that could provide rapid results and informative information. I discovered very quickly that not all datasets are complete, which was very disappointing and frustrating under the circumstances, as almost half of the study outcome variable (psychological distress) of interest was missing (47%). After much deliberation, I along with my supervisor considered whether imputing values for the missing data and consulted with a few statisticians. This undertaking took quite some time and in the end proved futile. I learnt that the 'missingness' of data dictates the type of analysis you conduct and with 47% of your study outcome variable missing your initial study aim will change and/or may be abandoned. However, another important lesson learnt was that there is still value in the process in terms of how to deal with so many missing data. The discovery that there were missing data was upsetting, as I was confident that not having regular family contact, and/or being removed or institutionalised at an early age, severely impacts psychological distress.

2.1.3 Public Health Impact

Prisoner health is public health, as prisons are part of our communities and prisoners are part of our society. Prisoners receive visitors, are in contact with health care workers and other prison staff, attend outside work placements or health care facilities, and prison personnel constantly rotate between prisons and their communities. The majority of prisoners will ultimately leave prison and reintegrate into society. Their level of health and wellbeing upon release affects public health in the wider community (WHO Regional Office for Europe, 2014). Globally, one third of prisoners leave prison every year. To assist their reintegration into society, a focus on the good health and wellbeing of inmates

should be a priority. For this to occur, appropriate prison health care services need to be provided (WHO Regional Office for Europe, 2014).

The study results may have proved useful to influence policy around prisoner contact and provide input into the ongoing discussion in relation to regular contact and the levels of prisoner psychological distress.

2.2 Abstract

Background

The Alexander Maconochie Centre (AMC) correctional facility in the Australian Capital Territory (ACT) received its first residents on 30 March 2009, and all ACT prisoners were repatriated from New South Wales (NSW) by end of May 2009.

The first health study conducted in the AMC was the 2010 ACT Inmate Health Survey (IHS). It was adapted from the NSW Inmate Health Survey, and conducted by the ACT Corrections Health Program with assistance from ACT Corrective Services, Justice Health (NSW), the ACT Dental Health Program and Mental Health ACT.

Aim

The aim of this study was to examine the impact of external contact, in particular, phone calls and visits on the psychological wellbeing of ACT prisoners.

Methods

Cross-sectional analysis of secondary data from the 2010 ACT Inmate Health Survey. I carried out a descriptive analysis of prisoner characteristics to determine if external contact variables and other inmate characteristics were associated with different levels of psychological distress. Associations between mild to severe psychological distress and a range of exposures were assessed by logistic regression, controlling for age and sex. Stata 14 was used to conduct all analyses.

Results

Of the 205 prisoners at the Alexander Maconochie Centre, 135 volunteered to participate in the survey. There was no significant difference in psychological distress levels when comparing inmates who had visits in the past two weeks compared to those who had no visits (OR 0.72, CI 0.25-2.09). There was no significant difference in the level of psychological distress between participants who received phone calls in the past two weeks and participants who did not (OR 1.03 CI 0.17-6.16).

2.3 Introduction

The 2010 ACT Inmate Health Survey (IHS) was the first health survey conducted in the ACT prison, the Alexander Maconochie Centre (AMC). Results from the survey aimed to provide the best available evidence to form a baseline assessment of the health needs of ACT prisoners. The results were to inform the provision of health services and policy development, ensuring health service delivery in correctional facilities met the needs of the inmate population (Epidemiology Branch, 2011). In this chapter, I present a secondary analysis of data collected from the IHS with a specific focus on psychological wellbeing of prisoners. I begin by presenting a literature review of prison populations and psychological distress.

2.4 Literature review

To better understand prison populations and psychological distress, this section provides an overview of mental health data relating to the global prison population. It then focuses on the Australian context and examines why prisoner health is important. An overview of the prison health survey system and prison health data collection in Australia is provided, including discussion of the health status of Australian prisoners. The final section provides an overview of the literature about the impact of prison contact policies and their contribution to psychological wellbeing.

2.4.1. The global prison population and mental wellbeing

The Institute for Criminal Policy Research (ICPR) currently reports 10.35 million prisoners in the world, not including those in detention or administrative detention camps/prisons in China and North Korea which would likely push this figure in excess of 11 million prisoners (Institute for Criminal Policy Research, 2016).

While prisoners suffer disproportionately from a range of diseases and conditions, mental health is particularly important given its personal and public health impact and burden in prisons.

In 2002 findings from a systematic review conducted on 62 psychiatric surveys from 12 countries comprising nearly 23,000 prisoners found that:

1 in 7 prisoners in western countries have a psychotic illness or major depression (disorders that may be risk factors for suicide);

around 1 in 2 male prisoners have antisocial personality disorders; and

1 in 5 female prisoners have antisocial personality disorders (Fazel & Danesh, 2002b).

The review also highlighted that:

1. The risk of having a severe psychiatric disorder is considerably higher in prisoners than in the general population.
2. More research is required to clarify whether the extent of the excess risk was due to causes and/or consequences of imprisonment, or the effects of substance abuse on the prevalence of psychosis in prisoners (which is unknown).

The burden of treatable serious mental disorder in prisoners is significant and that prison resources may not provide appropriate care as mandated by the European Convention on Human Rights and other international charters.

One-third of the world's prisoners live in western countries, with 99% of available data from prison surveys originating from western populations highlighting the need for psychiatric research in non-western populations (Fazel & Danesh, 2002a).

Why is prisoner health important?

Prisoners are community members who are temporarily incarcerated but return to communities. Therefore, the provision of health care across the community-prison divide is important. It is in society's interest to ensure prisoners receive proper health care for disease or illness while in prison. From a social justice viewpoint, doing 'what is right' means ensuring society is engaged in providing adequate health care to reduce health inequalities among populations, including prison populations. Given the majority of prisoners are from the most vulnerable groups of societies, with disproportionately low levels of education, employment experience and opportunities, protecting prisoner health contributes to public health as a whole (WHO Regional Office for Europe, 2014).

2.4.2. Prison health surveys in Australia

This section provides a brief overview of the Australian prison health survey history.

New South Wales (NSW)

The first inmate health survey of prisoner populations in NSW was conducted by Corrections Health Services (CHS) in 1996 and published in 1997, with a follow

up survey in 2001 (Indig et al., 2010). The 1996 survey of the NSW inmate population was focused on gathering reliable epidemiological data on the health status of the prisoner population and gave one of the most complete descriptions of prisoner health. These descriptions included physical health; self-assessment of health; chronic diseases; medication; health services utilisations; dental health; hearing; asthma and lung function; diabetes and blood sugar; infectious diseases; vaccination history; fitness and sun protection; diet and nutrition; men's health; women's health; mental health; suicide and self-harm; behavioural risks; and sexual health (T Butler & Milner, 2003). The survey delivered precise information allowing CHS to garner increased funding for prison health services and demonstrated the importance of an evidence based approach to health service development. Given the evidence provided by the 1996 survey, it was decided that a follow-up survey was to be conducted every five years to examine changes in health status and identify trends in key health indicators. This approach has allowed new topics to be incorporated to reflect areas of emerging concern such as intellectual disability, head injury and mental health (T Butler & Milner, 2003). CHS changed its name to Justice Health in 2004 (NSW Health, 2016).

Victoria (Vic)

The first general health status survey of the Victorian prisoner population was conducted by Deloitte Consultancy for the Victorian Department of Justice in 2002 and published in 2003. The survey questionnaire was a modification of the NSW Prison Health Survey. Data originated from 500 (15%) of the Victorian prisoner population of approximately 3,500 prisoners. Inmates participated in one or more sections of the survey (physical, mental, dental and pathology); 450 inmates participated in the two main sections of physical and mental health (Deloitte Consulting for the Department of Justice, 2003).

Western Australia (WA)

WA has not conducted a specific inmate health survey, but has surveyed particular groups within the inmate population. These surveys have largely focused on alcohol and illicit drug issues (Duckworth, Foley-Jones, Lowe, & Mallert, 1982; Indermaur, 1986; Johnson & Egan, 1985; Northcott, Jennings, & Indermaur, 1986).

Queensland (QLD)

In Queensland, limited research had been undertaken on prison systems and inmate health. In early 2002, a preliminary study, Opportunities for health promotion in the Qld women's prison system, was undertaken to ascertain the health of the female prisoner population (Young, Waters, Falconer, & O'Rourke, 2005).

Australian Capital Territory (ACT)

The 2010 ACT IHS was the first survey conducted in the AMC by the Epidemiology Branch of the ACT Government Health Directorate. A baseline assessment was developed based on evidence from this survey to implement and provide improved service provision and to develop policy to meet correctional facility inmate health requirements. (Epidemiology Branch, 2011).

Tasmania

In Tasmania, a preliminary survey was conducted titled: 'Alcoholism amongst the Tasmanian prison population'. This survey is reported in the Australian New Zealand Journal of Criminology and includes data on inmate social characteristics (marital, employment and educational history). The information was obtained from a classification form completed by every inmate soon after sentencing. At the time of an inmate's initial medical evaluation, a 'test' for alcohol abuse was given. This 'test' provided information on an inmate's alcohol usage (R. White & Boyer, 1985).

2.4.3. National prisoner health data

The National Prisoner Health Data Collection (NPHDC) is the primary data source for reporting on the National Prisoner Health Indicators (NPHI) in the report series, The health of Australia's prisoners. Since 2009, the data custodian of the NPHDC is the Australian Institute of Health & Welfare (AIHW). The NPHDC contains data provided by the state and territory departments responsible for prisoner health. The data were collected from prisons throughout Australia, and include de-identified confidential unit record data for prison entrants, prison dischargees, and prison clinic visits over a two week period. There are data on medications taken by prisoners, information on the operation of prison clinics and information on prison health services at jurisdictional level (Australian Institute of Health and Welfare, 2009). The data

are collected and sent to the AIHW for collation, analysis and reporting (Australian Institute of Health and Welfare, 2013b).

The NPHDC does not provide complete coverage of the prisoner population. This is because the AIHW has yet to receive full participation from every State and Territory in the NPHDC. Furthermore, the collection is based on convenience sampling with prisoners voluntarily participating (Australian Institute of Health and Welfare, 2013c).

The bulk of the data collected for the entrants and dischargee sections are self-reported data providing an easy and effective method of collecting data. The advantages of self-reported data is that interviewers do not require specialised training, it is often faster than diagnostic interviewing (for health conditions), and the method provides an individual perspective of the participants (Australian Institute of Health and Welfare, 2013c).

The National Prisoner Health Information project is in the process of building a national data collection on the health of Australia's prisoners (Australian Institute of Health and Welfare, 2014). The indicators assist in monitoring the health of prisoners, inform prisoner health service planning and delivery, and gauge service provision. (Australian Institute of Health and Welfare, 2014).

2.4.4 The health of Australian prisoners

Prisoner populations are characterised by extreme disadvantage, backgrounds of abuse and neglect, stigmatisation and social exclusion. (T Butler, 2008), p. 2

According to the ABS, as of 30 June 2015, the number of prisoners in adult corrective services facilities is 36,314 – an increase of 7% from 2014. In 2015, Australia had a national imprisonment rate of 196 prisoners per 100,000 adult population. This represents a 6% increase from 186 prisoners per 100,000 adult population in 2014 (Australian Bureau of Statistics, 2015b).

Studies consistently observe that large numbers of Australian prisoners engage in risk behaviours of alcohol and other drug use, injecting drug use, tobacco smoking and unsafe sexual practices (T. Butler & Papanastasiou, 2008).

Prisoners engaging in risky behaviour are particularly vulnerable to blood borne diseases such as viral hepatitis, HIV, sexually transmitted diseases, mental illness and other chronic health problems (Australian Institute of Health and Welfare, 2010, 2011, 2013a, 2015a; T Butler, 2008; T Butler et al., 2008).

Currently in Australia, 25% of prisoners have had one or more chronic conditions; with asthma the most common (17%) followed by arthritis (9%) (Australian Institute of Health and Welfare, 2015c).

Notable NPHDC health statistics include:

- 3 in 4 prisoners are smokers – 5 times the rate of the general population;
- 2 in 3 prisoners used illicit drugs in the 12 months prior to imprisonment;
- 2 in 5 prisoners drank alcohol at dangerous levels prior to prison – this was more than half for Aboriginal and Torres Strait Islander prisoners;
- 1 in 4 prisoners received medication for mental health related problems while in prison; and
- 1 in 3 prisoners had an ongoing health condition or disability which restricted their daily activities or participation in education or employment (Australian Institute of Health and Welfare, 2015b).

The NPHDC data indicate that the proportion of prison entrants who rated their physical health as good, very good or excellent was 73% and the proportion of prison dischargees rated their physical health as good, very good or excellent was 78% (Australian Institute of Health and Welfare, 2015a).

The 2015 self-assessed health status is for prison entrants and prison dischargees, and forms two parts: self-assessed physical health status and self-assessed mental health status. Self-assessed health status is frequently used in Australia to give a point of comparison between the health of prisoners and the health of the general community (Australian Institute of Health and Welfare, 2015a).

As Table 4 indicates, individuals entering prison had lower levels of excellent and very good health compared with the Australian population overall. Prisoners were more likely to report higher levels of good, fair or poor health. Small improvements in the good, fair and poor categories of self-reported health were observed from discharged prisoners (Australian Bureau of Statistics, 2015a; Australian Institute of Health and Welfare, 2015a).

Table 4. Self-assessed health of prisoners 2014/2015

Self-rated health	Australia ¹	Prison Entrant ^{2 3}	Prison Discharge ^{2 4}
Excellent	20	9	10
Very good	37	26	27
Good	29	38	41
Fair	10	18	13
Poor	4	7	3
Total	100	98	94

1: Australian Health survey 2014

2: Entrance and discharges 2015 NPHDC

3: 23 entrants unknown self-rated health

4: 21 discharges unknown self-rated health

(Australian Bureau of Statistics, 2015a; Australian Institute of Health and Welfare, 2015a)

Other results of the survey indicate:

- 40% male and 24% of female released prisoners rated their health 'very good' or 'excellent'.
- 59% of 18-24 year olds rated their health as 'very good' or 'excellent' compared to 30% of 45 years and older group.
- 20% female and 16% of male released prisoners rated their health 'fair' or 'poor'.
- 20% of released prisoners aged 35 and over rated themselves as 'fair' or 'poor' compared to the 18-24 age group.

A higher proportion of non-Aboriginal released prisoners (19%) rated themselves low health compared to released Aboriginal and Torres Strait Islander prisoners (13%) (Australian Institute of Health and Welfare, 2015a).

2.4.5. Mental Health of Australian prisoners

There have been a limited number of studies comparing mental wellbeing among the Australian prison population to the general population. What we do know is that Australian remand centres regularly hold more severe mentally ill people than general hospital mental health inpatient units (P. White & Whiteford, 2006).

Deinstitutionalisation in Australia has seen the number of public and private psychiatric hospital beds drop from 30,000 in the early 1960s, to 8,000 in recent times. Yet during the same period, the Australian population has doubled (Whiteford & Buckingham, 2005).

A study conducted in 2006 compared the prevalence of psychiatric disorders among prisoners to the results of the community-based National Survey of Mental Health and Wellbeing. They found the prevalence of psychiatric disorders in prisoners were more than double the general population (Tony Butler, Allnutt, Cain, Owens, & Muller, 2005).

According to *The health of Australia's prisoners*, the proportion of prison entrants with high or very high level of psychological distress was 31%, using the Kessler 10 scale (Aboriginal and Torres Strait Islander 20%: non-Aboriginal and Torres Strait Islander 34%). The proportion of prison dischargees with high or very high level of psychological distress was 19%, using the Kessler 10 scale (Aboriginal and Torres Strait Islander 17%: non-Aboriginal and Torres Strait Islander 20%) (Australian Institute of Health and Welfare, 2015a).

2.4.6. Impact of external contact on prisoners' wellbeing

Maintaining family ties during incarceration is vitally important for both inmates and their family members. For instance, family visitations may help in the preservation of the family unit (C. Hairston, 1988). Hairston states that spousal and parental relationships are vulnerable during incarceration as couples are denied the daily interactions, experiences and sharing, that sustain a marital relationship (C. Hairston, 1991). Many criminological concepts suggest that social ties can decrease offending, whether due to encouraging an individual's bonds with society or the resources he or she has either to be successful in life or to ease stressful situations (Perry, 2012).

An Australian prison study conducted by Butler and Milner in 2003 found that 43% of women and 49% of men had not received a family/friend visit in the past four weeks, and approximately 85% of men and 90% of women had received at least one phone call or letter in the past two weeks. The Beck Depression Inventory (BDI) tool used in the study found that inmates who had received no visits in the last four weeks, and no phone calls or letters in the last two weeks, were more likely to be either 'moderately' or 'severely' depressed than those who had received phone calls and/or letters (37% vs. 24%). The study also found that almost half of reception (46%), and over one-third (38%) of sentenced prisoners, had suffered a mental disorder (psychosis, affective disorder, or anxiety disorder) in the previous 12 months (T Butler & Milner, 2003).

2.4.7. Impact of contact on arrest and recidivism

For over 40 years, research studies have constantly found that prisoners who maintain close contact with their family members while in prison have improved post-release outcomes and lower recidivism rates (Friedmann, 2014).

In the 1972 Holt and Miller report *Explorations in Inmate-Family Relationships*, researchers observed that contact for inmates reduced arrest rates by 20 percent over the following 12 months post incarceration. They also found that 'loners' were 6 times more likely to end up back in prison during the first year (12% returned to prison compared to 2% for those who had three or more visitors) (Friedmann, 2014; Holt & Miller, 1972).

A study by Bales and Mears (2008) in Florida prisons over a 12-month period focused on the effects of inmate visits and the potential to reduce recidivism. Their study explored crime theories and the importance of social ties to community re-entry. The study aimed to examine the effects of separate aspects of visitation such as:

- receiving no visits vs. receiving any visits;
- the frequency of visits;
- type of visit and by whom (parent, sibling, offspring, friend, relative, significant other or other);
- recidivism and timing to recidivism; and
- how recent the visit and its effect on recidivism (Bales & Mears, 2008).

Bales and Mears found that any visit, as well as more frequent visits, were both associated with a lower likelihood of recidivism; visits were associated with delaying the onset, or timing of recidivism; and visits of many types, including from family and friends, was associated with reduced and delayed onset of recidivism. Furthermore, visits that occurred closer to release from prison were more strongly associated with reduced recidivism than visits that took place further back in time. Notably, there was no statistically significant association between recidivism and receiving child visits. More frequent child visits were associated with an increased risk for recidivism. The study also found that visitation had a stronger impact among men, non-whites and individuals with longer histories of incarceration (Bales & Mears, 2008).

There are a number of theoretical concepts relevant to social contact for prisoners that seek to explain the relationship between recidivism and social contact.

General strain theory suggests that released inmates with many social ties are more likely to have better coping strategies and support networks to assist them in effectively managing the challenges faced with their reintegration into the wider community (Agnew, 1992; Perry, 2012). Social capital theory maintains that beyond providing social control, social support, and the incentive for identity transformation, family ties also provide a contributing function in the post-release environment.

Both general strain and social capital theories explain the importance of visits for inmates while in custody and after their release (Perry, 2012). Therefore, the evidence suggests that inmates who sustain close links with their families and friends during imprisonment are more likely to reintegrate positively into community life on release, resulting in lower rates of post-release reoffending than inmates who do not maintain these ties (Indig et al., 2010).

2.4.8. Contact policies for prisoners

Visitation timetables at prisons vary depending on the type of prison/detention centre (e.g. low to moderate security prisons and male or female only prisons). The number of prisoners and the capacity of Australian prisons listed is approximate based on current available information provided by State Corrections and/or Justice websites (see Appendix 1 for a national list).

2.5. Rationale for this study

Concerns about potential decreasing of contact for ACT prisoners was the motivation for this study. In addition, there is a gap in the literature concerning the impact of external contact (i.e. phone calls and physical visits) on the levels of psychological distress for the ACT prison population. This study sought to use data from the 2010 ACT inmate health survey to explore this relationship.

2.6. Aim

The aim of this project was to examine the impact of external contact (i.e. phone calls and physical visits) on the psychological wellbeing of ACT prisoners.

2.7. Objectives

1. To describe the ACT prison population's psychological wellbeing as defined by Kessler 10 results in 2010 ACT Inmate Health Survey
2. To examine the association between external contact (i.e. phone calls and physical visits) and psychological distress.

2.8. Hypothesis

That the level of psychological distress is influenced by the levels of external contact that prisoners receive.

2.9. Methods

2.9.1. Study design

Secondary analysis of the 2010 ACT Inmate Health Survey cross sectional data.

2.9.2. Participants

The participants of the 2010 ACT Inmate Health Survey were 135 inmates at the AMC who volunteered and consented to participate in the survey in 2010.

2.9.3. Analysis

I conducted a descriptive analysis of inmate socio-demographic characteristics producing numbers and proportions. In addition, I conducted logistic regression analysis to examine associations between mild-severe psychological distress and exposure variables, adjusting for age and sex. These data are presented in a forest plot. I used Stata version 14 for all analyses. The significance level was set at $p < 0.05$.

2.9.4. Outcome variable: psychological distress

The Kessler Psychological Distress Scale (K10 or Kessler 10) was formulated in 1994 and is used for screening populations for psychological distress. It is used frequently in population health surveys such as the Australian National Survey for Mental Health and Wellbeing 2003 (Saunders & Daly, 2001), and more recently in the alcohol and other drug use among Aboriginal and Torres Strait Islander and non-Indigenous men entering prison in New South Wales study (Doyle et al., 2015). The K10 is administered by a trained interviewer and provides a simple measure of general psychological distress, without identifying

or exploring causal factors. K10 is a screening tool used to identify people who may require further assessment for anxiety and depression. Referral to a trained health care professional should follow if a patient is found to have anxiety and/or depression. Andrews and Slade conducted validity and reliability tests on the K10 in 2001, finding that it is a comparatively reliable instrument for measuring psychological distress (Andrews & Slade, 2001). Table 5 shows the scores indicating distress by the K10.

Table 5. Kessler 10 score levels and the level of psychological distress (Australian Bureau of Statistics, 2012a)

K10 Score Levels	Total Level of psychological distress
10-19	The score indicates that the client or patient may currently <u>not be experiencing significant feelings of distress</u> .
20-24	The client or patient may be experiencing <u>mild levels of distress</u> consistent with a diagnosis of a mild depression and/or anxiety disorder.
25-29	The client or patient may be experiencing <u>moderate levels of distress</u> consistent with a diagnosis of a moderate depression and/or anxiety disorder.
30-50	The client or patient may be experiencing <u>severe levels of distress</u> consistent with a diagnosis of a severe depression and/or anxiety disorder.

2.9.5. Exposure variables

Exposure variables in the study included:

- number of visits received by a prisoner in the last two weeks;
- number of phone calls in the last two weeks;
- inmate gender;
- employment in prison;
- education in prison;
- age group;
- Aboriginal and Torres Strait Islander status;
- relationship status;
- number of biological or foster children;

- education status;
- school exclusion;
- age that the inmate left school;
- current incarceration time;
- incarceration status;
- first time prisoner;
- placed in care before the age of 16;
- employment 6 months prior to prison; and
- accommodation status prior to prison.

2.9.6. Ethics

Ethics approval was granted by:

1. The ACT Human Research Ethics Committee – ETHLR.14.247
2. The ANU Human Research Ethics Committee Protocol – 2015/301
3. The AIATSIS Human Research Ethics Committee – E021/22052014

2.10. Results

2010 ACT Inmate Health Survey participants

Of the 276 prisoners at the AMC during the survey period, six were in a pre-release centre and were excluded from participating as they were unable to access the survey team. A further seven participants had previously taken part in the NSW Inmate Health Survey. Eventually 202 eligible inmates were invited to participate in the ACT IHS, with 135 (67%) prisoners volunteering, consenting and completing the survey. Of the 135 participating inmates, 8% (n=11) were female, 92% (n=124) were male and 17% (n=23) were Aboriginal and Torres Strait Islander peoples (Epidemiology Branch, 2011). Kessler 10 data were only available on 64 of the 135 (47%) IHS participants as these data had been lost in the data collection process.

Demographic characteristics of participants are presented in Table 6. Of the IHS participants:

- Slightly more than half (55%, n=74) were 29 years of age or older;
- 57% (n=77) had biological children;
- 17% (n=23) had foster children;
- 66% (n=42) experienced mild to severe psychological distress in the four weeks prior to the survey;
- 59% (n=79) received one or more visits in the two weeks prior to the survey; and
- 84% (n=108) received one or more phone calls in the two weeks prior to the survey.

Table 6. Demographic and social characteristics of participants of the Australian Capital Territory Inmate Health Survey, 2010

Characteristic	n	%
Aboriginal and/or Torres Strait Islander		
Yes	23	17
No	112	83
Gender		
Male	124	92
Female	11	8
Age group		
18- 28 years	61	45
29 years and above	74	55
Children		
No biological children	57	43
One or more biological children	77	57
No foster children	112	83
One or more foster children	23	17
Visits received (in the past two weeks)		
No visits	56	41
One or more visits	79	59
Phone contact (in the past two weeks)		
No phone calls	20	16
One or more phone calls	108	84
Psychological distress (K10)		
Mild-Severe distress	42	66
No distress	22	34

Associations between external contact, inmate characteristics and mild/severe psychological distress

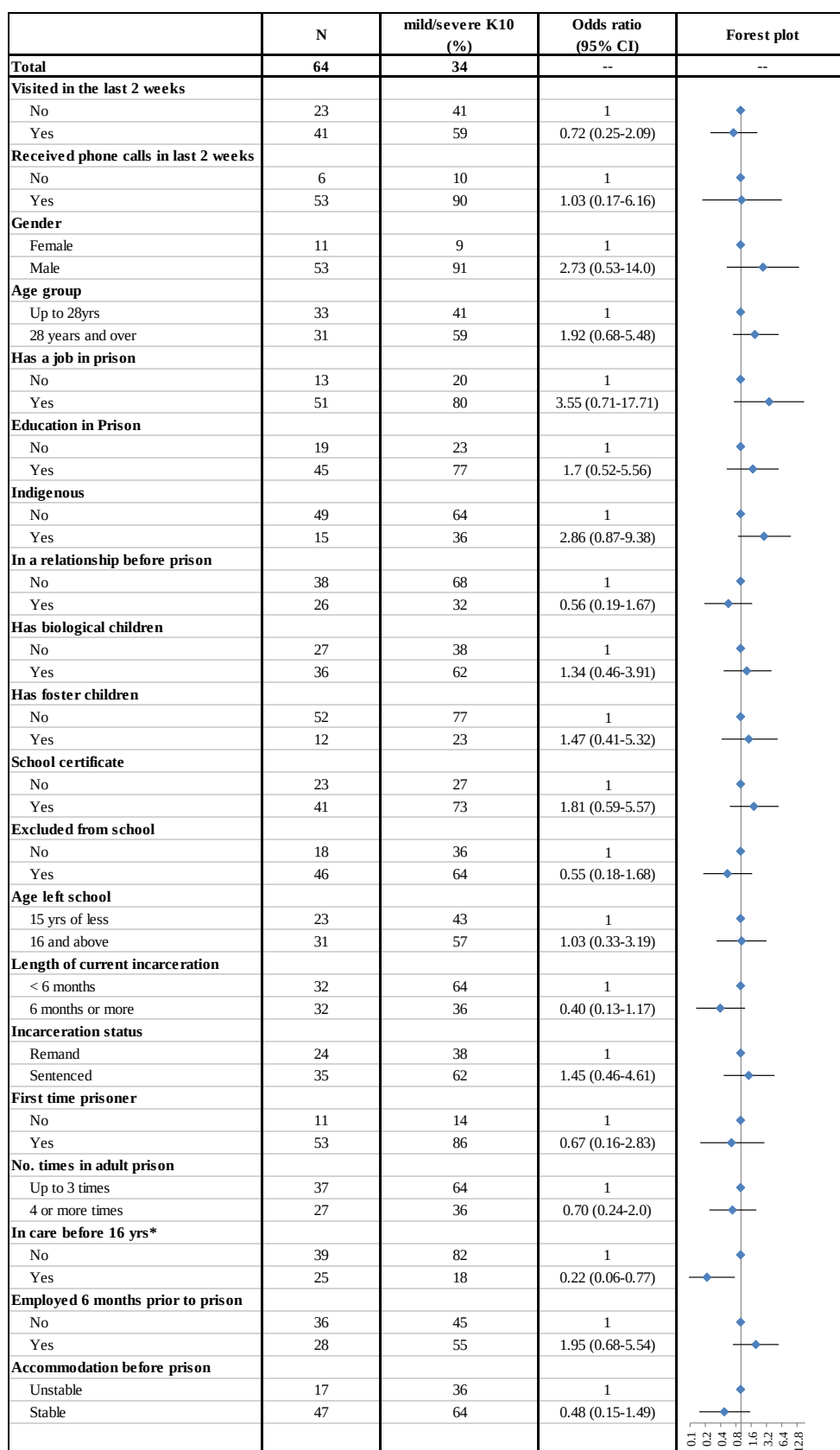


Figure 12. Logistic regression mild/severe psychological distress and IHS participant characteristics (Odds ratio)

The regression analysis results in Figure 12 shows no significant difference in psychological distress levels when comparing inmates who had visits in the past two weeks with those who had no visits in the past two weeks (OR 0.72, CI 0.25-2.09).

There was no significant difference in the level of psychological distress between participants who received phone calls in the past two weeks and participants who did not (OR 1.03 CI 0.17-6.16).

Participants in the 29 years and older age group experienced nearly twice the level of mild to severe psychological distress compared to participants in the 18-28 year age group (OR 1.92 CI 0.68-5.48). Although not significant, the results for Aboriginal and Torres Strait Islander participants indicate that they were 3 times more likely to experience mild to severe psychological distress compared to non-Aboriginal and Torres Strait Islander participants (OR 2.86 CI 0.87-9.38).

Those who had experienced the child protection system before the age of 16 years were much less likely to report mild to severe psychological distress (OR 0.22, CI 0.06-0.77).

Inmates employed in the 6 months prior to prison experienced mild to severe distress at twice the rate of those not employed before prison (OR 1.95 CI 0.68-5.54).

2.11. Discussion

Due to the small sample size affecting the data, I am unable to demonstrate an association with external contact (visits and phone calls) on inmates levels of psychological distress. However other studies report positive mental wellbeing associations with contact (C. Hairston, 1988, 1991; Perry, 2012) and reducing recidivism (Bales & Mears, 2008; Friedmann, 2014; Holt & Miller, 1972).

Contact, including phone contact is important in maintaining regular communications as part of a daily routine, such as receiving updates on daily events for the prisoner and family. Phone contact also provides reassurance for the prisoner and their family that the prisoner and their family members are safe and well (C. F. Hairston, Rollin, & Han-jin, 2004; C. F. Hairston, Rollin, & Jo, 2004; Sharratt, 2014).

Distance plays a major role in visits from friends and family. The Hairston 2004 study, *Family Connections during Imprisonment and Prisoners' Community Re-entry*, found that the distance prisoners were from their homes influenced the degree to which they saw families and friends. Prisoners who lived furthest away from their homes, were in the higher percentage of those who had no visitors in the month prior to the survey. Of those prisoners, whose homes (at the time of their arrest) were within 50 miles of the prison where they were incarcerated, 46% did not have any visitors compared with:

- 56% who lived 50 to 100 miles from the prison;
- 70% who lived 101 to 500 miles; and
- 84% who lived over 500 miles away (C. F. Hairston, Rollin, & Han-jin, 2004).

Prisoners whose homes were located closer to the prison had the most visits. Of those prisoners who lived within 50 miles of the prison, 20% reported having four or more visits. This was compared with:

- 12% who lived 50 to 100 miles away from the prison;
- 5% who lived 101 to 500 miles away; and
- 2% who lived more than 500 miles away (C. F. Hairston, Rollin, & Han-jin, 2004).

The psychological distress of having a family member incarcerated can impact on the family's mental health. Adults in Australia who have a family member in prison in the past 12 months display high levels of psychological distress, parallel to those of prison entrants (Baker, 2014). Visits from family can be beneficial for prisoners and are associated with reduced re-offending up to 5 years later (Duwe & Clark, 2011).

Strong family ties during imprisonment and after release underpin the transition back into the society. An earlier study of imprisonment and wellbeing using Household Income and Labour Dynamics of Australia (HILDA) data found that, while there were negative mental health outcomes among prisoners, there was reported better satisfaction with family relationships (Baker, 2014; Velamuri & Stillman, 2007).

The data indicate that exposure to the care and protection system during the inmate's youth were associated with lower levels of mild to severe psychological distress in this population. This is also reflected in the general population, where

those exposed to early life trauma including abuse and neglect are at higher risk of psychological distress in later life (Briere, Agee, & Dietrich, 2016). It is also known that impacts of exposure to care and protection systems, child abuse and neglect, last well into adulthood and is a risk factor for criminal activity (Nussbaum, Collins, Cutler, Zimmerman, & Jacques, 2002). This result may be a reflection of both constructs, namely, the association between child abuse and/or neglect as a child and criminal activity; and lower levels of psychological distress for those inmates previously exposed to the care and protection system during youth.

Aboriginal and Torres Strait Islander prisoners were 3 times more likely to experience mild to severe levels of psychological distress than non-Aboriginal and Torres Strait Islander prisoners. Mild-severe psychological distress is also 3 times more common among Aboriginal and Torres Strait Islander people than in the general community. This finding is consistent with the Aboriginal and Torres Strait Islander population level data nationally (Australian Bureau of Statistics, 2015a).

Older inmates, 29 years and over, had twice the level of mild-severe psychological distress. Inmates with experience of imprisonment had mild-severe psychological distress (36% vs. 34%) consistent with the trend in the national prison health survey population. These findings are similar to those reported by AIHW for those going to prison for the first time (27% vs. 25%) (Australian Institute of Health and Welfare, 2015a).

As formerly stated, given the majority of prisoners are from the most vulnerable groups of societies, with disproportionate low levels of education and employment experience and opportunities, protecting prisoner health contributes to public health as a whole (WHO Regional Office for Europe, 2014). Prisoner health is public health. Because the majority of prisoners will ultimately leave prison and reintegrate into society, the level of health and wellbeing upon release affects public health in the wider community (WHO Regional Office for Europe, 2014).

2.12. Limitations

An important limitation for this data analysis task was the high level of missing data in the outcome measure of the K10: Question 9, which asks the participant

'In the past 4 weeks, how often did you feel so sad that nothing could cheer you up?' To remedy this, we considered the option of using the K6 scale, which consists of 6 questions about depressive and anxiety symptoms that a person has experienced in the most recent 4-week period. The K6 is a shortened version of the K10 scale in which 4 questions are not used: the 'tired out for no good reason'; 'so nervous that nothing could calm you down'; 'so restless you could not sit still'; and 'how often do you feel depressed?' (Australian Bureau of Statistics, 2012b). The K6 instrument was also not able to be used as Question 9 from the original K10 is one of the questions in the modified K6 scale. This lead to our final analysis being limited to 64/135 responses which severely affected the analyses. In addition, we conducted 20 statistical tests to determine associations. Conducting 20 tests on a small amount of data increases the chance of observing at least one significant result when there is a strong possibility of this not being the case (Goldman, 2008).

2.13 Conclusions and public health implications

In conclusion, prisoner health is public health.

Evidence of past inmate studies indicate that prisoners who have contact with family and friends have better post release outcomes and lower recidivism rates. Policies about or affecting the amount of contact between those incarcerated and their family or important social connections needs to consider the impact on inmate health (and recidivism). International evidence indicates that reducing or limiting external contact impacts health and wellbeing, and recidivism.

Due to problems in the IHS data collection process (lost data), I was unable to determine the association between inmate contact and distress/mental wellbeing within the population of the AMC.

Robust data collection and backup procedures need to be defined and implemented for the AMC inmate health survey to prevent these issues in the future.

2.14. References

- Agnew, R. (1992). Foundation for a General Strain Theory of Crime and Delinquency. *Criminology*, 30, 47-87.
- Andrews, G., & Slade, T. (2001). Interpreting scores on the Kessler population. *Australian and New Zealand Journal of Psychiatry, Psychological Distress Scale (K10)*. *Australian and New Zealand Journal of Public Health*, 25, 94-497.
- Australian Bureau of Statistics. (2012a). 4817.0.55.001 - Information Paper: Use of the Kessler Psychological Distress Scale in ABS Health Surveys, Australia, 2007-08, . from ABS
<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4817.0.55.001Chapter92007-08>
- Australian Bureau of Statistics. (2012b). *Information paper: Use of the Kessler Psychological Distress Scale in ABS Health Surveys, Australia, 2007-2008*. Canberra Retrieved from
<http://www.abs.gov.au/ausstats/abs@.nsf/lookup/1BF12FE00641EA89CA2579D50015D70F?opendocument>.
- Australian Bureau of Statistics. (2015a). 4364.0.55.001 - National Health Survey: First Results, 2014-15, . from ABS
<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4364.0.55.0012014-15?OpenDocument>
- Australian Bureau of Statistics. (2015b). Prisoners in Australia, 2015, . Retrieved 22 January 2016, from ABS
<http://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/8D5807D8074A7A5BCA256A6800811054?opendocument>
- Australian Institute of Health and Welfare. (2009). National Prisoner Health Data Collection, . from AIHW
<http://meteor.aihw.gov.au/content/index.phtml/itemId/635601>
- Australian Institute of Health and Welfare. (2010). *The health of Australia's prisoners 2009*. Canberra: AIHW Retrieved from
<http://www.aihw.gov.au/publication-detail/?id=6442468371>.
- Australian Institute of Health and Welfare. (2011). *The health of Australia's prisoners 2010*. Canberra: Australian Institute of Health and Welfare,.
- Australian Institute of Health and Welfare. (2013a). *The health of Australia's prisoners 2012*. Canberra: Australian Institute of Health and Welfare.
- Australian Institute of Health and Welfare. (2013b). National Prisoner Health Data Collection: Identifying and definitional attributes, . from AIHW
<http://meteor.aihw.gov.au/content/index.phtml/itemId/534531>
- Australian Institute of Health and Welfare. (2013c). Prisoner Health NBEDS, 2015; Quality Statement, . from AIHW
<http://meteor.aihw.gov.au/content/index.phtml/itemId/643458>
- Australian Institute of Health and Welfare. (2014). *Prisoner health services in Australia 2012*. Canberra.
- Australian Institute of Health and Welfare. (2015a). *The health of Australia's prisoners 2015*,. Canberra: AIHW.

- Australian Institute of Health and Welfare. (2015b). Prisoner health. Retrieved from <http://www.aihw.gov.au/prisoner-health/>
- Australian Institute of Health and Welfare. (2015c). Prisoner health. Retrieved 27 November 2015, from Australian Government <http://www.aihw.gov.au/prisoner-health/>
- Baker, D. (2014). *Unlocking Care: continuing mental health care for prisoners and their families*, . Retrieved from Canberra ACT:
- Bales, W. D., & Mears, D. P. (2008). Inmate Social Ties and the Transition to Society: Does Visitation Reduce Recidivism? *Journal of Research in Crime and Delinquency*, 45(3), 287-321. doi:10.1177/0022427808317574
- Briere, J., Agee, E., & Dietrich, A. (2016). Cumulative trauma and current posttraumatic stress disorder status in general population and inmate samples,. *Psychological Trauma: Theory, Research, Practice, and Policy*, 8(4), 439-446. doi:10.1037/tra0000107
- Butler, T. (2008). Centre lines: issuing forth Prisoner health research: why bother? (Vol. 24, pp. p. 2). Sydney: National Drug Research Institute,.
- Butler, T., Allnutt, S., Cain, D., Owens, D., & Muller, C. (2005). Mental disorder in the New South Wales prisoner population. *Australian and New Zealand Journal of Psychiatry*, 39(5), 407-413.
- Butler, T., Belcher, J., Champion, U., Kenny, D., Allerton, M., & Fasher, M. (2008). The physical health status of young Australian offenders. *Aust N Z J Public Health*, 32, 73 - 80.
- Butler, T., & Milner, L. (2003). *The 2001 New South Wales Inmate Health Survey*, . Retrieved from Sydney:
- Butler, T., & Papanastasiou, C. (2008). *National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey Report 2004 & 2007*,.
- Deloitte Consulting for the Department of Justice. (2003). *Victorian Prisoner Health Study*. Retrieved from Melbourne:
- Doyle, M. F., Butler, T. G., Shakeshaft, A., Guthrie, J., Reekie, J., & Schofield, P. W. (2015). Alcohol and other drug use among Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander men entering prison in New South Wales,. *Health & Justice*, 3(15). doi:10.1186/s40352-015-0027-1
- Duckworth, A., Foley-Jones, C., Lowe, P., & Mallert, M. (1982). Imprisonment of Aborigines in North Western Australia,. *Australian & New Zealand Journal of Criminology*, 15.
- Duwe, G., & Clark, V. (2011). Blessed Be the Social Tie That Binds: The Effects of Prison Visitation on Offender Recidivism,. *Criminal Justice Policy Review*, XX(X), 1-26. doi:10.1177/0887403411429724
- Epidemiology Branch, A. G. H. D. (2011). *ACT Inmate Health Survey 2010: Summary results*, . Retrieved from Canberra
- Fazel, S., & Danesh, J. (2002a). Serious mental disorder in 23 000 prisoners: a systematic review of 62 surveys. *The Lancet*, 359(9306), 545-550.
- Fazel, S., & Danesh, J. (2002b). Serious mental disorder in 23 000 prisoners: a systematic review of 62 surveys. *The Lancet*, 359(9306), 545-550. doi:10.1016/s0140-6736(02)07740-1

- Friedmann, A. (2014). Lowering Recidivism through Family Communication, . <https://www.prisonlegalnews.org/news/2014/apr/15/lowering-recidivism-through-family-communication/>
- Goldman, M. (2008). Stat C141/ Bioeng C141 - Statistics for Bioinformatics,. Retrieved from <http://www.stat.berkeley.edu/users/hhuang/141C-2008.html>
- Hairston, C. (1988). Family ties during imprisonment: Do they influence future criminal activity? *Federal Probation*, 52, 48-52.
- Hairston, C. (1991). Family ties during imprisonment: Important to whom and for what? *Journal of Sociology and Social Welfare*, 18(1), 87-104.
- Hairston, C. F., Rollin, J., & Han-jin, J. (2004). Family Connections During Imprisonment and Prisoners' Community Reentry,. In Jane Addams Center for Social Policy and Research (Ed.). Chicago, Illinois: University of Illinois.
- Hairston, C. F., Rollin, J., & Jo, H.-j. (2004). *Family Connections During Imprisonment and Prisoners' Community Reentry*, . Retrieved from Chicago: https://jacsw.uic.edu/research_public_service/files/familyconnections.pdf
- Holt, N., & Miller, D. (1972). *Explorations in Inmate-Family Relationships*, . United States of America,: California State Department of Corrections,.
- Indermaur, D. (1986). Substance Abuse History of Fremantle Prisoners: A Survey Conducted of Prisoners, . Perth WA: Western Australian Department of Corrective Services,.
- Indig, D., Topp, L., Ross, B., Mamoon, H., Border, B., Kumar, S., & McNamara, M. (2010). *2009 NSW Inmate Health Survey: Key Findings Report*. Sydney: Justice Health, NSW Health.
- Institute for Criminal Policy Research. (2016). World Prison Brief, . from Institute for Criminal Policy Research, <http://www.prisonstudies.org/>
- Johnson, C., & Egan, G. (1985). *Current Treatment Programs for Drug and Alcohol Dependents in the West Australian Prison System*, . Retrieved from Perth WA:
- Northcott, D., Jennings, R., & Indermaur, D. (1986). *Program Needs of Substance Abusers in Western Australian Prisons: A Report of the Western Australian Prisons Department Program Support Working Party*, . Retrieved from Perth:
- NSW Health. (2016). The History of Justice & Forensic Mental Health Service, . from NSW Government, <http://www.justicehealth.nsw.gov.au/about-us/jh-fmhn-history>
- Nussbaum, D., Collins, M., Cutler, J., Zimmerman, B., & Jacques, I. (2002). Crime type and specific personality indicia: Cloninger's TCI impulsivity, empathy and attachment subscales in non-violent, violent and sexual offenders. . *American Journal of Forensic Psychology*, 20, 23-56.
- Perry, V. (2012). *Maintaining the Link: A Survey of visitors to New South Wales Correctional Centres*,. Sydney: Corporate Research Evaluation & Statistics,.

- Saunders, D., & Daly, A. (2001). *2000 Collaborative Health and Wellbeing Survey: Psychological distress in Western Australian population*, . Retrieved from Perth:
- Sharratt, K. (2014). Children's experiences of contact with imprisoned parents: A comparison between four European countries. *European Journal of Criminology*, 11(6), 760-775.
doi:10.1177/1477370814525936
- Soley-Bori, M. (2013). *Dealing with missing data: Key assumptions and methods for applied analysis*, . Retrieved from Boston USA:
- Velamuri, M., & Stillman, S. (2007). *Longitudinal Evidence on the Impact of Incarceration on Labour Market Outcomes and General Well-being*, . Retrieved from New Zealand:
- White, P., & Whiteford, H. (2006). Prisons: mental health institutions of the 21st century? *Medical Journal of Australia*, 185(6), 302-303.
- White, R., & Boyer, K. (1985). Alcoholism amongst the Tasmanian prison population: research note,. *Australian New Zealand Journal of Criminology*, 18, 109-114.
- Whiteford, H., & Buckingham, W. (2005). Ten years of mental health reform in Australia: are we getting it right?,. *Medical Journal of Australia*, 182.
- WHO Regional Office for Europe. (2014). *Prisons and Health*. Denmark: WHO.
- Young, M., Waters, B., Falconer, T., & O'Rourke, P. (2005). Opportunities for health promotion in the Queensland women's prison system,. *Australian and New Zealand Journal of Public Health*, 29, 324-327.
doi:10.1111/j.1467-842X.2005.tb00201.x

Chapter 2 Appendices

Appendix 1: Australian prison characteristics by jurisdiction.

Jurisdiction	Prison	Capacity	Gender	Visiting (days)	Security level	Private/Public
WA						
	Acacia	1426	Male	7	Medium	Private
	Albany Regional Prison	500	Male	5	All	
	Bandyup Women's Prison	321	Female	7	All	Public
	Boronia Pre-Release Prison	95	Female & children	2	Minimum	Public
	Broome Regional Prison	117	Male & Female	7	All	Public
	Bunbury Regional Prison	384	Male	7	All	Public
	Casuarina Prison	1032	Male	7	All	Public
	Eastern Goldfields Regional	123	Male & Female	7	All	Public
	Greenough Regional	332	Male & Female	7	All	Public
	Hakea Prison	1205	Male	5	All	Public
	Karnet Prison Farm	328	Male	2	Minimum	Public
	Pardelup Prison Farm	85	Male	2	Minimum	Public
	Roebourne Regional	189	Male & Female	2	All	Public
	Wandoo Reintegration Facility	77	Male	2	Minimum	Public
	West Kimberley Regional	158	Male & Female	n/a	Min/Medium	Public
	Wooroloo Prison Farm	365	Male	2	Minimum	Public
QLD						
	Arthur Gorrie Correctional	890		7	High	Private
	Brisbane Correctional Centre	600		5	High	Public
	Brisbane Womens Correctional	270	Female	7	High	Public
	Capricornia Correctional	500		3	High & Low	Public
	Helana Jones Centre		Female	3	Low	Public
	Lotus Glen	500		2	High & Low	Public
	Maryborough Correctional	500		2	High	Public
	Numinbah Correctional	129	Female	2	Low	Public
	Palen Creek Correctional	170		2	Low	Public

Jurisdiction	Prison	Capacity	Gender	Visiting (days)	Security level	Private/Public
	Southern Qld Correctional	300	Male	3	High/Low	Private
	Townsville Correctional	494	Male & Female	2	High/Low	Public
	Wolston Correctional Centre	600	Female	4	High	Public
	Woodford Correctional Centre	1008	Male	5	High/Max	Public
NSW						
	Amber Laurel	56	Male & Female			
	Bathurst	222	Male	2	Min/Medium	Public
	Brewarrina (Yetta Dhinnakkal)	70	* Young Aboriginal Males	2	Minimum	Public
	Broken Hill		Male & Female	2	Min/Medium	Public
	Cessnock	750	Male	2	Min/Maximum	Public
	Compulsory Drug Treatment (Parklea)		Male	2	Min/Medium	Public
	Cooma Correctional Centre	160		2	Min/Medium	Public
	Dawn de Loas Correctional Centre		Male	3	Minimum	Public
	Silverwater Womens	200	Female		Maximum	Public
	Metro Remand & Reception		Male	3	Maximum	Public
	Emu Plains		Female	2	Minimum	Public
	Glen Innes	95	Male	2	Minimum	Public
	Goulburn		Male	2	Min/Maximum	Public
	- High Risk Management Centre		Male	2	Maximum	Public
	Grafton Intake & Transient Centre	64	Male & Female	4		
	Ivanhoe (Warakirri)	55	Male (80% Aboriginal)	2	Minimum	Public
	John Morony	200	Male	2	Medium	Public
	Dillwynia	200	Female	2	Min/Medium	Public
	Outer Metro Multi- purpose		Male	2	Minimum	Public
	Junea	790	Male	3	Min/Medium	Private
	Kariong			2		
	Kirkconnell Correctional Centre	250	Male	2	Minimum	Public

Jurisdiction	Prison	Capacity	Gender	Visiting (days)	Security level	Private/Public
	Lithgow Correctional		Male	2	Maximum	Public
	Long Bay Correctional	1100		2	Min/Maximum	Public
	- Metro Special Programs		Medical/Psych/Remand	2	Min/Maximum	Public
	- Long Bay Hospital		Medical/Psych/Remand	3	Min/Maximum	Public
	Mannus Correctional Centre	164	Male	2	Minimum	Public
	Mid North Coast Correctional	500	Male & Female	2	Min/Medium	Public
	Oberon Correctional	100	Young Males	2	Minimum	Public
	Parklea Correctional	893		6	Maximum	Private
	South Coast Correctional	549		2	Min/Maximum	Public
	St Heliers Correctional	256	Male	2	Minimum	Public
	Tamworth Correctional	100	Male	2	Medium	Public
	Wellington	650		2		
VIC						
	Acheron Boys Home	10	Male			Public
	Barwon Prison	448	Male	2	Maximum	Public
	Beechworth Correctional	120		2	Minimum	Public
	Dame Phyllis Frost	260	Female	7	All	Public
	Dhurringile Prison	174		2	Minimum	Public
	Fulham Correctional Centre	837	Male	2	Min/Medium	Private
	Hopkins Correctional Centre	532		2	Medium	
	Judy Lazarus Transition Centre	25			Minimum	Public
	Langi Kal Kal Prison	448		2	Minimum	Public
	Loddon Prison	482		3	Medium	Public
	Marngoneet Prison	577		2	Medium	Public
	Melbourne Assessment Prison	263	Male	3	Maximum	Public
	Metropolitan Remand Centre	1006		7	Maximum	Public
	Port Phillip Prison	1087		7	Maximum	Private
	Tarngower Prison	72		2	Minimum	Public
	Ravenhall Prison Project (Opening 2016//2017)	1300	Male		Medium	Private
NT						

Jurisdiction	Prison	Capacity	Gender	Visiting (days)	Security level	Private/Public
	Alice Springs Correctional	470		2	All	Public
	Barkly Work Camp			2	Low	Public
	Berrimah Correction	750	Male & Female	7		Public
	Darwin Correctional Centre			7		Public
	Datjala Work Camp Nhulunbuy	50	Male		Low/Remand	Public
ACT						
	Bimberi Youth Justice Centre	40				
	Periodic Detention Centre	26			Minimum	Public
	Alexander Maconochie Centre	300	Male & Female	5	All	Public
SA						
	Yatala Labour Prison	468		2	All	Public
	Adelaide Remand Centre	267		7		Public
	Mobilong Prison	327		2	Low/Medium	Public
	Port Augusta Prison	392		2	All	Public
	Cadell Training Centre	180		2	Low	Public
	Port Lincoln Prison	90		2	Low/Medium	Public
	Adelaide Womens Prison	148	Female	6	All	Public
	Adelaide Pre-release Centre	104	Male & Female	6	Low	Public
	Mount Gambier Prison	172	Male	3	All	Private
TAS						
	Hobart Reception Prison	50	Male & Female	7	Maximum	Public
	Launceston Reception Prison	33	Male & Female	4	Maximum	Public
	Mary Hutchinson Womens Prison	45	Female	5	All	Public
	Ashley Youth Detention	51	Male & Female			
	Risdon Prison Complex	280	Males	5	Medium to Maximum	Public
	Ron Barwick Minimum Security (within Risdon Prison)			7		

Chapter 3: An evaluation of the completeness of Indigenous status in the Queensland Cancer Registry (QCR)

3.1 Prologue

Assessing cancer morbidity and mortality among the Indigenous population depends on identification of a person's Indigenous status in data collections. The completeness and therefore reliability of data concerning Indigenous peoples in Australia's health data sets has been a priority over the last 20 years due to a lack of reliability in Indigenous status in health data sets.

This evaluation is linked to my major epidemiological study, in that the data being used from the Queensland Cancer Register (QCR) showed increased reporting of the 'unknown' response to the Indigenous status variable.

This evaluation's primary aim is focused on evaluating the QCR with a specific emphasis on how the data collection is affecting reporting of Indigenous cancer for the State and looks at the processes involved to enable improvement. The primary aims of the evaluation are to:

- Describe the cancer notification system for Queensland (emphasis on Indigenous status notification).
- Evaluate the system attributes using the Centers for Communicable Disease Control and Prevention Updated Guidelines for Evaluating Public Health Surveillance Systems.
- Document and report findings.
- Make recommendations for improving the system.

3.1.1 My Role

My role was to design and conduct the evaluation of the QCR public health surveillance system, make recommendations and disseminate the findings to the QCR.

3.1.2 Key Lessons Learnt

I learnt the importance of documenting communications with data custodians, and maintaining contact throughout the process; planning of the evaluation and methods; and utilising CDC evaluation guidelines to gain a more in-depth understanding of system attributes and evaluation procedures. I learnt the importance of data extraction, cleaning, analysing and interpretation of data from government departments such as the QCR. I also learnt about critical appraisal of publications (including articles and graphs, charts and statistics) from jurisdictional data. I learnt about how to critique data and reporting of these data with the view to understanding: is this a true picture of Aboriginal cancer mortality and morbidity?

3.13 Importance of Public Health surveillance

The accuracy of Indigenous status is fundamental to measuring Indigenous health status and the effectiveness of services including, access and support, and health promotion programs, including those for cancer prevention, diagnosis and treatment. Identification of Indigenous people in datasets is a vital and necessary starting point to the improvement of Indigenous people's health and the Closing the Gap initiatives.

It is timely to assess the recording of Indigenous status for cancer notification and deaths in Queensland to determine if there are discrepancies in recording Indigenous status and if so, to make recommendations on how to further improve the recording of Indigenous status in the future. The main aim in executing this task is to more accurately ascertain the burden of morbidity and mortality of cancer among Aboriginal and Torres Strait Islander peoples in Queensland, and to advance and better target prevention, diagnosis and treatment services.

3. Abstract

Background

This evaluation of the QCR was generated from my interest in cancer morbidity and mortality in my family and community in Queensland. The evaluation of the QCR surveillance system was an extension of my epidemiological study that I had undertaken as another core requirement of the Masters of Philosophy in Applied Epidemiology.

Objectives

The purpose of this evaluation was to evaluate QCR system attributes according to the *Centers for Communicable Disease Control and Prevention (CDC) (2001), Updated Guidelines for Evaluating Public Health Surveillance Systems* (Centers for Communicable Disease Control and Prevention, 2001). Specific to Indigenous cancer notifications.

Methods

This evaluation was undertaken using the Centers for Communicable Disease Control and Prevention (CDC) (2001), *Updated Guidelines for Evaluating Public Health Surveillance Systems* (Centers for Communicable Disease Control and Prevention, 2001). My evaluation focus was on assessing simplicity, flexibility, acceptability, data quality, representativeness, timeliness and usefulness of the data. I used a mixed methods approach. The quantitative element concerned examining 10 years of QCR data (2003 – 2012), and a qualitative component consisting of a survey completed by key QCR staff.

Results

The level of 'unknown' Indigenous status in QCR data from 2003-2012 has increased substantially. From 2003 to 2005, the rate of 'unknown' Indigenous status averaged 12%. In 2006 there was a sharp decline from 13% to 10%. However, from 2007 the rate of unknown Indigenous status increased dramatically to almost 16% in 2012. This level of unknown data will likely affect the reliability of data about Indigenous rates of cancer for Queensland. I identified inconsistencies of recording Indigenous status on notification forms and in electronic systems. Issues around acceptability of completing some of these forms might also be a contributing factor to increasing 'unknown' status. The system is timely in that notification frequency is legislated. The system is not as flexible as it could be, due to the complexity of the multiple notification modes. There is some doubt as to its representativeness for Indigenous people due to data completeness. Attempts at understanding the point at which these types of datasets are assessed as 'representative' needs clarifying.

3.3 Introduction

In 2014, it was estimated that 123,920 people were diagnosed with cancer and 45,780 people died from cancer (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2014b). Results from recent global burden of disease studies show that cancer contributed between 16% and 19% of the total disease burden in Australia (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2014b). In 2014 the number of new cancers cases diagnosed will be 2.6 times as high as the number of new cases in 1982; and this increasing trend is attributed to the escalating number of cases of prostate cancer, breast cancer in females, and bowel cancer

(Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2014a).

These increases in cancer have been attributed to better quality diagnoses through population-based screening programs and developments in technology and procedures used for identifying and diagnosing cancer, combined with Australia's ageing population (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2014a).

Assessing Cancer morbidity and mortality among the Indigenous population depends on a person's Indigenous status being recorded in data collections. Australian cancer data do not include information about whether a new case of cancer was identified through screening, or if cancers identified through screening are diagnosed at an earlier stage than for those that present naturally. In addition, there is no national system for reporting Indigenous status on pathology forms. As a result, state and territory cervical cytology (Pap test) registers are not able to report Aboriginal and Torres Strait Islander status. For that reason, the reporting of cervical screening is not available for Aboriginal and Torres Strait Islander women at the national level (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries 2014)

While complete data are lacking, poorer cancer outcomes for Indigenous people are due to more advanced cancer stages at diagnosis, higher levels of co-morbidity and poorer access to inclusive and culturally appropriate care (Cunningham, Rumbold et al. 2008, Garvey, and Cunningham et al. 2011).

Aboriginal and Torres Strait Islander identification has been poor in health records overall, including cancer registries, and require improvement if cancer trends and

outcomes for Aboriginal and Torres Strait Islander people are to be monitored and tackled effectively (Australian Government 2008).

3.3.1 Australian Cancer Registries

All Australian states and territories have legislation requiring reporting of all cancers (except basal and squamous cell carcinomas of the skin). Population based cancer registries in all jurisdictions receive information on cancer diagnoses from a number of sources including pathology laboratories; radiotherapy centres; registries of births, deaths and marriages; and hospitals (Australian Institute of Health and Welfare 2016). All jurisdictions in Australia are required by law to notify a cancer diagnosis to their respective registry.

Members of the Australasian Association of Cancer Registries (AACR) are:

- National Cancer Statistics Clearing House
- Australian Capital Territory Cancer Registry
- New South Wales Cancer Registries System
- Northern Territory Cancer Registry
- Queensland Cancer Registry
- South Australian Cancer Registry
- Tasmanian Cancer Registry
- Western Australia Cancer Registry
- Victorian Cancer Registry
- New Zealand Cancer Registry (Australian Institute of Health and Welfare 2016)

3.3.2 The Australian Cancer Database

The Australian Cancer Database (ACD) is the primary source of national population-based cancer data in Australia. The ACD, previously known as the National Cancer Statistics Clearing House (NCSCCH) database, is assembled and

administered by the Australian Institute of Health and Welfare (AIHW) in collaboration with Australia's cancer registries through the AACR. The ACD is a data source used extensively by governments, clinicians, health services and policymakers, and is fundamental to health performance reporting, service planning and evaluation, and meets various national health reporting obligations (Australian Institute of Health and Welfare 2014).

Additional to the ACD, the AIHW also maintains the three sources of national, population-based cancer screening data for BreastScreen Australia, the National Cervical Screening Program, and the National Bowel Cancer Screening Program.

These data are collected separately by the state and territory BreastScreen and cervical screening programs and the Australian Government Department of Human Services, and are provided to the AIHW for national monitoring and reporting. The relationships and the flow of data between these organisations are presented in Figure 13 (Australian Institute of Health and Welfare 2012).

The ACD was first developed in 1986 to:

- Monitor and report on levels of cancer incidence and trends in Australia;
- Facilitate research and planning with the aim of reducing cancer incidence and mortality; and
- Improve outcomes for people diagnosed with cancer (Australian Institute of Health and Welfare, 2014).

Data items in the ACD data set include personal details such as: personal identification number (assigned by jurisdiction); surname; first, second and third given names; sex; date of birth; date of birth accuracy indicator (the linking of client records to ensure accuracy and integrity of collected data); Aboriginal and Torres Strait Islander status; country of birth; date of death; age at death and cause of death. The ACD also records tumour-level attributes such as:

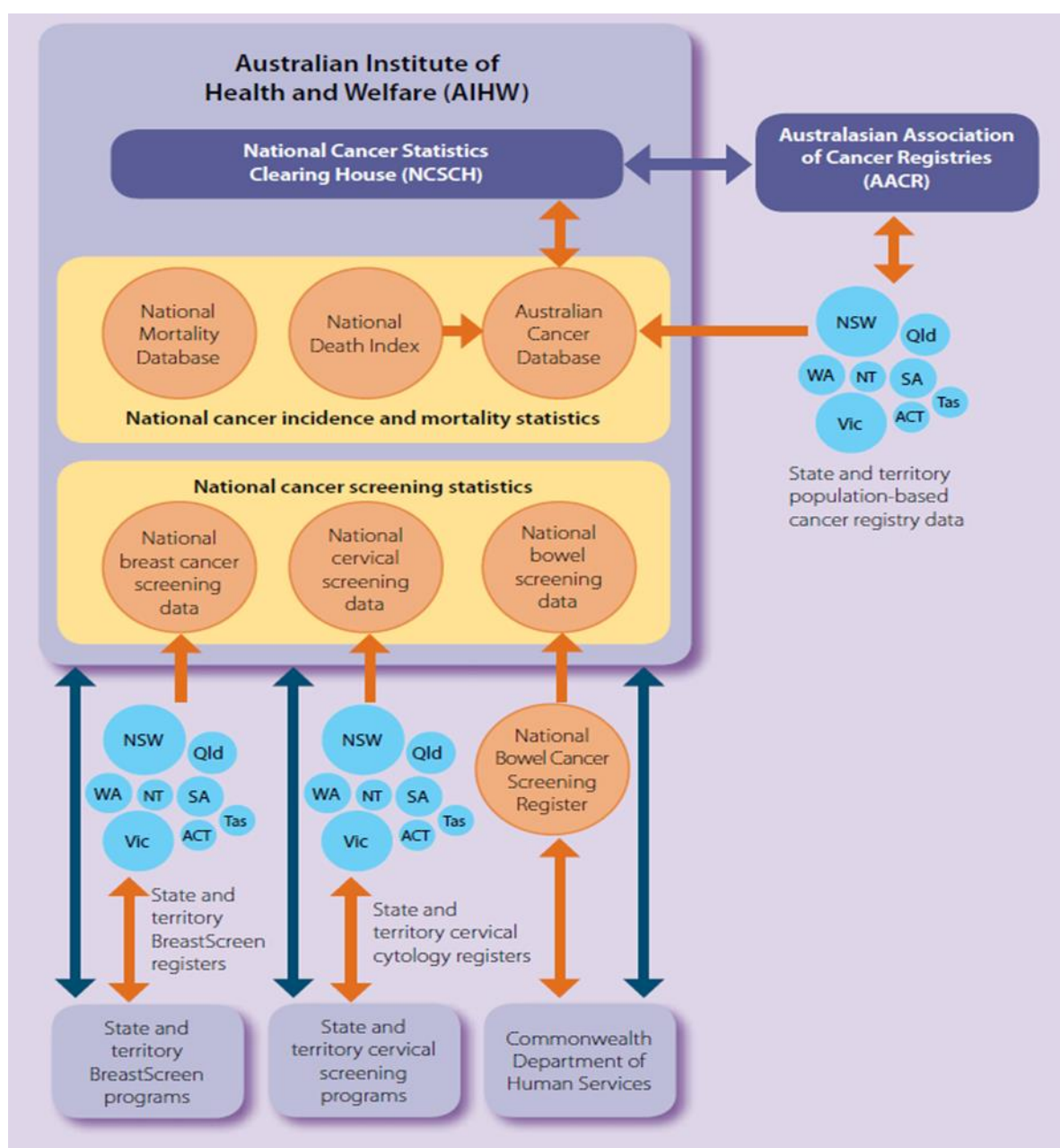
jurisdictional residence at diagnosis; tumour identification number (assigned by jurisdiction); date of diagnosis; date of diagnosis accuracy indicator (is the date of the pathology report, if any, that first confirmed the diagnosis of cancer) (Australian Institute of Health and Welfare 2016); age at diagnosis; ICD-O-3(a) topography code; ICD-O-3(a) morphology code; ICD-10(b) disease code; most valid basis of diagnosis; statistical local area at diagnosis; postcode at diagnosis; melanoma thickness (Breslow); and tumour size (breast cancer only) (Australian Institute of Health and Welfare 2015).

Data from the ACD are used to report on national cancer statistics such as incidence, trends, projections, survival and prevalence. The Australian Institute for Health and Welfare are custodians for the ACD data, and the data is provided by and owned by state and territory cancer registries through the AACR Registries. These population-based cancer registries receive information on cancer diagnoses from sources such as: public and private hospitals; pathology laboratories; radiotherapy centres; and the births, deaths and marriages registries (Australian Institute of Health and Welfare 2015).

Once collated at the jurisdictional cancer registry, cervical cytology registers, BreastScreen registers and the National Bowel Screening register are forwarded to the ACD.

A limitation of ACD data is the quality and coverage of data on Indigenous status, which prevents comparison of cancer incidence and survival at a national level. However, a subsection of registries provide data considered of sufficient quality to report Aboriginal and Torres Strait Islander status, limiting analysis (Australian Institute of Health and Welfare 2012).

Figure 13: Relationship flowchart of cancer data between State and Territory jurisdictions, cancer programs and the Australian Cancer Database (ACD), National Statistics Clearing House (NCSCH), Australasian Association of Cancer Registries (AACR) and the cancer data custodians the Australian Institute of Health and Welfare (AIHW)



Source: (Australian Institute of Health and Welfare, 2012)

3.3.3 National Aboriginal and Torres Strait Islander Cancer data

All state and territory cancer registries collect data on Aboriginal and Torres Strait Islander status however, in some States and Territories the quality of Aboriginal and Torres Strait Islander status data is inadequate for analyses (Australian Institute of Health and Welfare 2014). Information in the ACD on Aboriginal and Torres Strait Islander status is reported for New South Wales (NSW), Queensland

Chapter 3

Page 94

(Qld), Western Australia (WA) and the Northern Territory (NT). Data for these four jurisdictions are used to examine the incidence of cancer by Indigenous status. While the majority of Aboriginal and Torres Strait Islander people (83%) reside in these four jurisdictions, the level to which data for these jurisdictions are representative of data for all Aboriginal and Torres Strait Islander people is unknown (Australian Bureau of Statistics 2012, Australian Institute of Health and Welfare 2014).

The total level of missing data on Indigenous status for all cancers combined diagnosed between 2005 and 2009 was 12% (*Table 7*). (Australian Institute of Health and Welfare 2014).

Table 7: Availability of cancer data by Indigenous status and jurisdiction

Data Source	Measure	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	(a)
Australian Cancer database (2009 version, reporting years 2004-2008)	Incidence	✓	×	✓	✓	×	×	×	✓	12%
National Mortality Database (reporting 2007-2011)	Mortality	✓	×	✓	✓	✓	×	×	✓	0.08%
National Hospital Morbidity Database (b) 2006-07 to 2010-2011 financial years)	Hospitalisation	✓	✓	✓	✓	✓	×	×	✓	11%
BreastScreen Australia(c) (2 years 2010-2011)	BreastScreening	✓	✓	✓	✓	✓	✓	✓	✓	n.a.
National Bowel Cancer Screening Program(c) July 2011 and June 2012)	Bowel screening	✓	✓	✓	✓	✓	✓	✓	✓	n.a.
National Cervical Screening Program	Cervical screening	×	×	×	×	×	×	×	×	n.a.

(a) Refers to the percent of records with unknown Indigenous status.

(b) The Northern Territory data by Indigenous status considered acceptable for analysis purposes are restricted to public hospitals only.

(c) Information on the BreastScreen Australia and National Bowel Cancer Screening Program require people to self-report and therefore some Aboriginal and Torres Strait Islander people may choose to not identify.

Source: AIHW Australian Cancer Database 2009, AIHW National Mortality Database, AIHW National Hospital Morbidity Database, AIHW 2012e, AIHW 2013d and AIHW 2013f.

3.3.4 Description of the Queensland Cancer Registry

The QCR is a population-based registry operating under the *Public Health Act 2005* (QLD). QCR is a repository for information on cancer, registering all cases

of cancer diagnosed in Queensland since 1982. The registry collects data about new cases of cancer and is used to generate statistics about incidence, prevalence, survival and mortality. It is one of the larger population based cancer registries in Australia used in conjunction with other states and territories to compile national statistics on cancer incidence and mortality, and to support health service planning and cancer research (Queensland Government, 2013).

The QCR was initially established through community and other state organisations such as the Queensland Institute of Medical Research and the Cancer Council (formally known as the Queensland Cancer Fund), and is the result of a push for a state-wide information registry on cancer. Since 2000, the Cancer Council of Queensland has managed the processing operations of the QCR for Queensland Health (Queensland Government, 2015).

The main purpose of the QCR is to collect data to describe the nature and extent of cancer in Queensland. The data can be combined with related data to assist in the control and prevention of cancer.

Initially, Indigenous status was not collected and Qld Cancer Control Analysis Team (QCCAT) suggested that Indigenous status may have started being collected around the mid-1990s as this was when Indigenous incidence data seemed more consistent (Philpot, 2016).

Queensland Health contracts with Cancer Council Queensland (CCQ) to maintain the QCR under the QCR Maintenance Agreement. The QCR Maintenance Agreement is managed by the QCCAT under the auspices of the Metro South Hospital and Health Service (Queensland Government, 2013).

QCR data are accessible for use:

- in research projects on the causes, treatment and prevention of cancer;

- in the planning and assessment of cancer treatment and prevention services;
- in monitoring survival times of cancer patients; and
- for the education of health professionals and members of the general public (Queensland Government, 2015).

3.4 Objectives of the Queensland Cancer Registry

The main objective of the QCR as a repository is to collect data to describe the nature and degree of cancer in Queensland. The registry collects information on new cases of cancer in the state, and produces statistics about incidence, prevalence, survival and mortality.

3.5 Aims of the Evaluation

The aim of this evaluation was to:

- Assess the completeness of recording Indigenous status in the QCR;
- To assess QCR system attributes in relation to Indigenous cancer notifications; and
- Make recommendations for improving the system.

3.6 Methods

I undertook the evaluation of the Queensland Cancer Registry (QCR) using the Centers for Communicable Disease Control and Prevention (CDC) (2001), Updated Guidelines for Evaluating Public Health Surveillance Systems. Public Health surveillance is defined by the CDC as:

‘the ongoing systematic collection, analysis, interpretation and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health’ (Centers for Communicable Disease Control and Prevention, 2001).

This chapter comprises findings from my evaluation of the QCR applying a mixed methods approach using 2003 – 2012 QCR data, and a questionnaire (Appendix 1) which was electronically forwarded to the QCR for staff to complete. Three QCR staff participated, including the QCR data custodian at the time.

The system key attributes focused on for this evaluation were: simplicity, flexibility, data quality, acceptability, sensitivity, representativeness, timeliness, stability and usefulness.

The evaluation was undertaken in two stages:

1. Analysis of 2003-2012 QCR data
2. Survey of key QCR staff

3.6.1 Ethics

The evaluation was submitted and approved by the Australian National University Human Research Ethics Committee (HREC 2015/141), The Australian Institute of Aboriginal and Torres Strait Islander Studies Ethics Committee (EZ022/22052014) and Queensland Health (QCHO/009321/RD006511).

The QLD Health code of confidentiality was adhered to at all times during the extraction and analysis of QCR data and during the reporting of my findings.

3.6.2 Analysis of QCR data

The data analysis for this evaluation involved importing QCR data from Excel to StataSE 14®; inspecting and cleaning the data; and recoding data prior to analysis.

The QCR data available for analysis in this study includes Qld cancer notifications from 2003 to 2012 (n=209,725). For the purpose of this study persons identifying as Aboriginal, Torres Strait Islander, or both were combined into a single category (Indigenous). No distinction was made between those who did not, or declined to, state their Aboriginal status and for those whose information was not recorded or collected (for example, the question was never asked) – missing Aboriginal status due to any reason was coded as 'unknown'. I present data on those with

unknown Indigenous status by broad cancer diagnosis code (ICD-10 codes) using StataSE 14®.

3.6.3 QCR Staff Questionnaire

To gain an understanding of the QCR system and how Indigenous status is collected and managed, a brief questionnaire was provided electronically to the QCR data custodian (Appendix x). The questionnaire focused on:

- Internal and external quality assurance of Indigenous status data
- Analyses QCR perform using the Indigenous status variable
- Quality of Indigenous status data
- Completeness and usefulness of Indigenous status in QCR data

3.7 Stakeholders

Stakeholders of the QCR are:

- public hospitals
- private hospitals
- nursing homes
- pathology laboratories

The users of QCR data are:

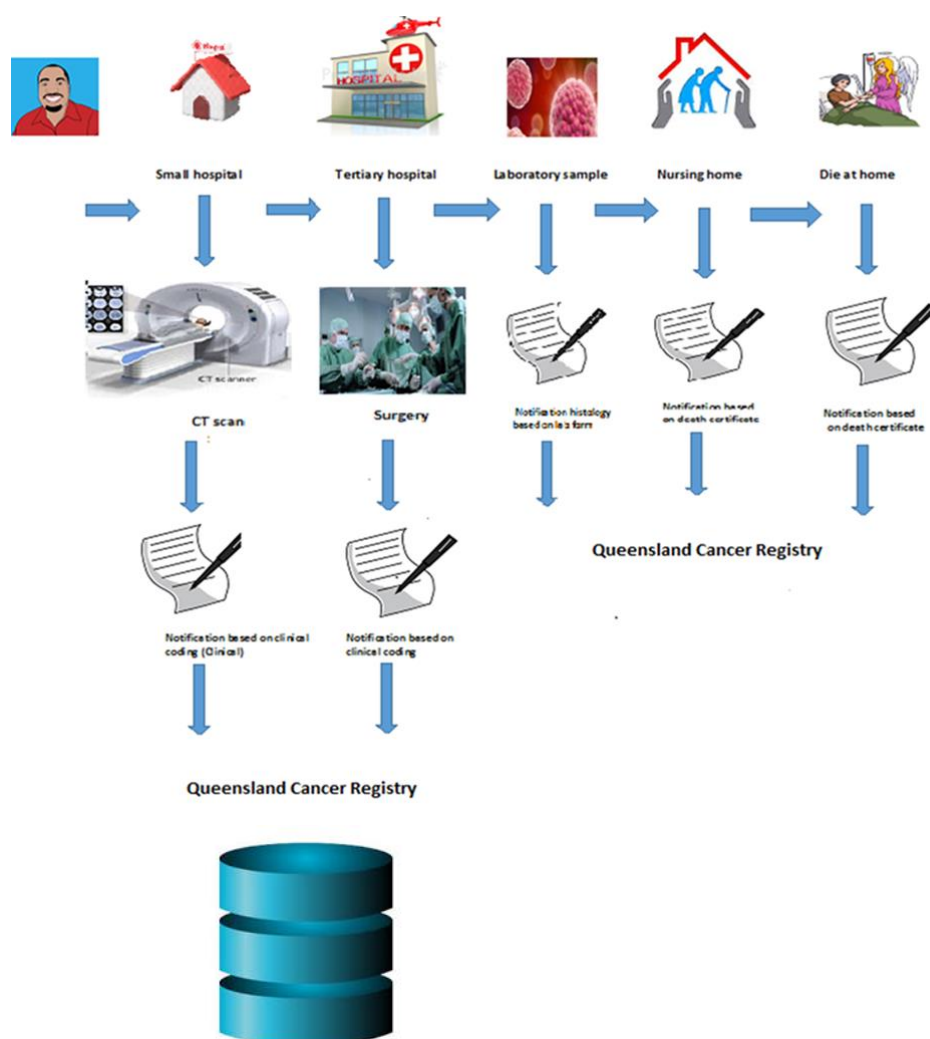
- Cancer Council
- Researchers and health professionals
- Australian Institute of Health and Welfare (AIHW)

3.8 Description of the QCR system

Notification of cancer is a statutory requirement for all public and private hospitals, nursing homes and pathology services in Queensland. Notifications are received for all persons with cancer separated from public and private hospitals and nursing homes (*Figure 14*). Queensland pathology laboratories provide copies of pathology reports for cancer specimens. Data on all people who die of cancer or cancer patients who die of other diseases are abstracted from the mortality files

of the Registrar of Births, Deaths and Marriages and linked to hospital and pathology data (Cancer Council Queensland, 2015).

Figure 14: QCR information flow chart



3.8.1 Information collected

QCR receives notifications at:

- first diagnosis of cancer or when a new site is diagnosed;
- patient's first date of attendance as an inpatient each calendar year (whether the cancer is current or history); and
- if a patient dies from cancer or has a history of cancer at death QCR is notified (Cancer Council Queensland, 2015).

The data collected for each cancer patient includes:

- patient name(s)
- usual residential address (at diagnosis and at last contact)
- date of birth/age
- occupation
- country of birth
- sex
- Indigenous status
- marital status
- date of last contact

- institution of last contact
- treating doctor
- date of diagnosis
- site of cancer
- cancer histology
- differentiation
- basis of diagnosis
- laterality
- date of death
- cause of death

(Cancer Council Queensland, 2015)

Additional information is collected breast cancer including:

- tumour size
- size complete
- number of nodes
- number of positive nodes
- nodes complete
- Melanoma
 - thickness
 - ulceration
 - Clark's level

(Cancer Council Queensland, 2015)

The QCR receive data on Indigenous status for all cancer notifications based on data supplied to the QCR from external data sources. According to the *Queensland Hospital Admitted Patient Data Collection (QHAPDC) manual of instructions and procedures*, Indigenous status must be assigned on the basis of self-identification or the identification by next-of-kin, close family member, carer, guardian, or power of attorney (Queensland Health 2013). The manual also advises that individual identification can be changed for each admission, and the individual or their spokesperson should be given the opportunity to identify each time they present. If patients have not already completed their details on the admission form they must be asked 'Are you of Australian Aboriginal or Torres Strait Islander origin?' (Queensland Health 2013).

3.8.2 Data storage

All information sent to the Registry is kept confidential, held under tight security and protected by the *Health Act 1937* (Australian Institute of Health and Welfare, 2016).

3.8.3 Data Analysis/Data quality

In addition to frequently providing data to the ACD, the Cancer Council QLD reports on cancer incidence, mortality, and survival and prevalence (Queensland Government, 2015). Three methods are utilised by QCR to assess data quality. These include:

1. Histological Verification (HV%) – the proportion of cases registered which had histological verification of diagnosis.
2. Death Certificate Only (DCO%) – the proportion of cases registered for which no information was available other than a statement on the death certificate that the deceased died from or with cancer.
3. Mortality to Incidence Ratio (M/I%) – the comparison of the number of deaths attributed to a specific cancer in a defined population with the

number of cases of the same cancer registered during the same period in the same population.

It is not known how often an assessment of the quality of Indigenous status in the QCR is undertaken.

3.8.4 Dissemination of results

A regularly produced fact sheet: *Cancer incidence, mortality, survival and prevalence* by the Cancer Council Queensland gives an overview of the Registry's data for the most recent year (Cancer Council Queensland, 2016a). The Cancer Council Queensland also provides data via their online cancer statistics portal (Cancer Council Queensland, 2016b). Trends in incidence, mortality, survival and prevalence are produced on a less frequent basis (Queensland Government, 2015).

3.8.5 QCR Classification and Coding

The QCR codes the site and the histology of the cancers to the International Classification of Diseases for Oncology, 3rd edition (ICD-O-3) (World Health Organisation, 2013). The change to ICD-O-3 was in response to an Australasian Association of Cancer Registries (AACR) recommendation.

3.9 Performance of QCR in relation to Indigenous notifications

This evaluation is focused on ensuring that practices concerning validity and integrity of Indigenous status in the QCR is enhanced.

3.9.1 Simplicity

Notification of cancer to QCR is a statutory requirement for all public and private hospitals, nursing homes and pathology services in the state of Queensland (*Figure 13*). The QCR provides a thorough instruction manual to guide notifications (Queensland Cancer Registry, 2009). Data is submitted to QCR for all persons

with cancer separated from public and private hospitals and nursing homes (Cancer Council Queensland, 2015). In relation to reporting of Indigenous status, clear guidance to reporting organisations includes:

‘Data providers should be aware that:

(1) Patients born outside Australia are unlikely to be of Australian indigenous status; and

(2) A person’s Indigenous status cannot be determined by observation.

For data accuracy, the patient, their carer, or next of kin must be asked the question directly.’ (Queensland Cancer Registry, 2009 pg 14)

3.9.2 Flexibility

While any number of variables can be added to the QCR system, adding one would adversely affect a number of other areas within the system.

Consequences would include modification to the design of data collection forms and computerised data entry packages and adjustments to the interface proforma that deliver these data. Any variation would require changes to the database and reporting prerequisites.

The system is flexible in that if Indigenous status is recorded through any of the reporting mechanisms, then the notification is treated as ‘Indigenous’.

Amendments to the notification are permitted if a registration is refilled.

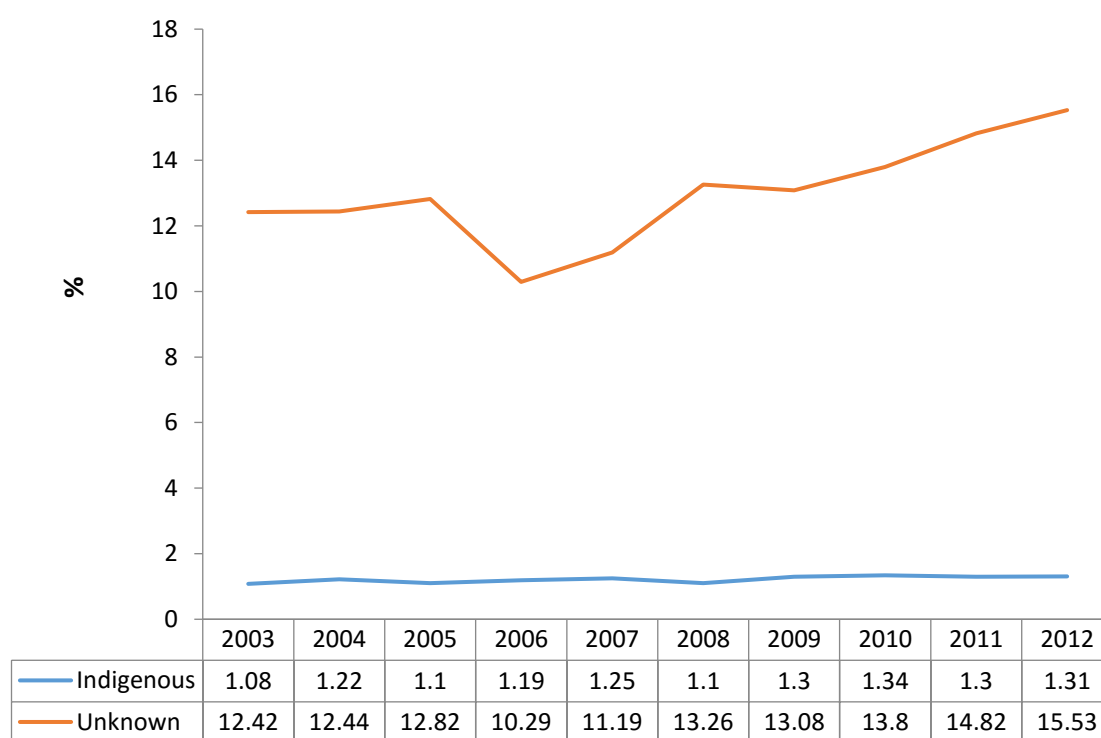
3.9.3. Data quality and Acceptability

Data quality reflects the completeness and validity of the data recorded in the public health surveillance system. This was assessed in this project as the proportion of Indigenous status recorded as unknown in the QCR data.

From QCR's inception (1982), Indigenous status was not collected. However, from personal communications with the QCR data custodians, Indigenous status data is thought to have commenced at some time during the mid-1990s (Philpot, 2016).

Figure 15 below indicates that for the period of the evaluation there were declines in the unknown status from 2003-2006 before increases in almost each year since 2006. There has been an increase in 'unknown' from around 10 to 16 percent over this period.

Figure 15: Proportion of Indigenous and unknown Indigenous status in QCR notifications 2003-2012



Quality of data is influenced by the performance of the screening and diagnostic tests (i.e., the case definition) for the health-related event, the clarity of hardcopy or electronic surveillance forms, the quality of training and supervision of persons who complete these surveillance forms, and the care exercised in data management.

The reporting process in terms of Indigenous status can be problematic due to a number of reasons:

- Training in system data entry;
- various stakeholder forms with a combination of coding;
- reliance on staff proficiency in collecting status;
- subject to human error based on physical attributes;
- staff ability to ask Indigenous status; and
- some private hospitals do not provide Aboriginal status when reporting (Philpot, 2016).

3.9.4. Acceptability

Due to reporting of cancer being legislated, organisations report cancer cases to the QCR within a specified time of usually less than one month. There are the previously mentioned instruction manual to guide notifications (Queensland Cancer Registry, 2009).

Collection of Aboriginal and Torres Strait Islander data by the QCR is reliant upon their stakeholder's full participation via Qld Health training using the *National best practice guidelines for collecting Indigenous status in health data sets* and *Making Tracks towards Closing the Gap Framework* (Australian Institute of Health and Welfare, 2010).

3.9.5 Sensitivity

QCR data is accumulated over the life (and death certificate) of the patient and is always updated (Scott, 2015). The algorithm used by QCR is one of 'progressive' positive identification in which a single notice from any notifying

source indicating more information on Aboriginal status overwrites less information (Cancer Institute NSW, 2012; Scott, 2015).

3.9.6 Representativeness

A public health surveillance system that is representative accurately describes the occurrence of a health-related event over time and its distribution in the population by place and person.

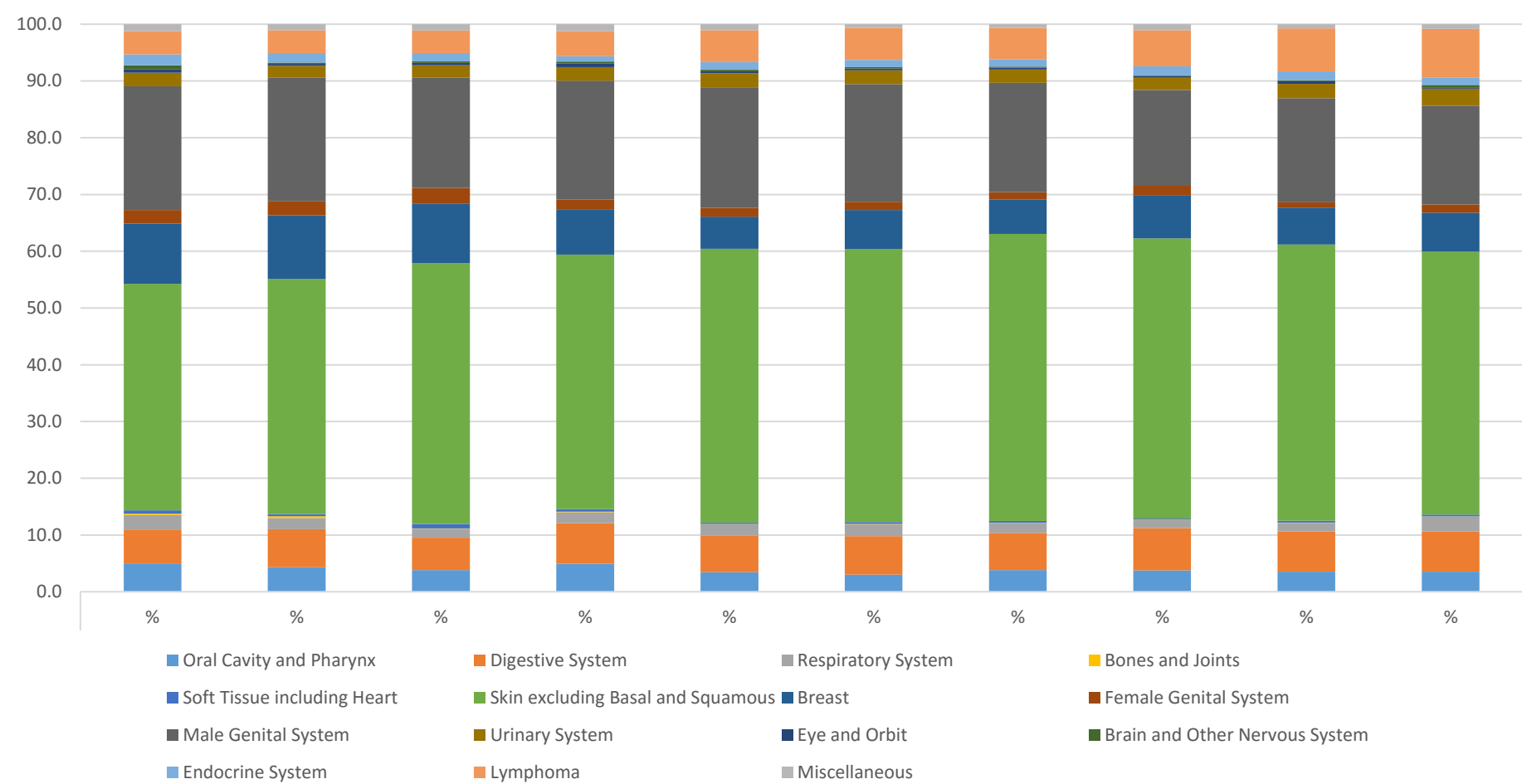
From 2003-2012 the level of 'unknown' Indigenous status has increased within Queensland Cancer Registry (QCR) data. From 2003 – 2005 the rate of 'unknown' Indigenous status has steadily increased from 12.42% to 12.82%.

In 2006 there was a sharp decline to 10.29% however, from 2007 (11.19%) the percentage rate of 'unknown' Indigenous status picked up momentum once again eventually increasing to 15.53% in 2012.

This level of 'unknown' reporting will likely affect rates of cancer diagnosed within the Indigenous population (*Figure 16*). As 75% of notifications are paper based, we were unable to identify any validation processes undertaken concerning Indigenous status. We also sought details on what constitutes 'representative' status of the data. QCR referred to national guidance, however when contact was made with the AIHW, they explained that the representative thresholds were determined by the jurisdictions.

The analysis of the unknown Indigenous status cancer notifications were largely for skin cancers (around 50%), male genital system cancers and breast cancer. Together these three cancers concerned almost 75% of the unknown Indigenous status cancers.

Figure 16: Proportion of cancers (by cancer type) notified to QCR with unknown Indigenous status 2003-2012, Queensland



3.9.7 Timeliness

Timeliness reflects the speed between steps in a public health surveillance system. Paper notifications from hospitals, pathology and nursing homes are posted to QCR; notification forms are scanned and the data is entered into the QCR system within a week. The system is timely.

QCR receives approximately 164,000 notifications per year, increasing by 2% annually. 75% of notifications are paper based. (Queensland Government, 2013)

It is legislated that cancer notifications are reported to QCR within one month.

3.9.8 Sources of Indigenous status recording in the QCR

Hospitals

The *Queensland Hospital Admitted Patient Data Collection (QHAPDC) manual of instructions and procedures* states that Indigenous status must be assigned on the basis of self-identification or the identification by next-of-kin, close family member, carer, guardian, or power of attorney (Queensland Health, 2013). The QHAPDC manual also states that individual identification can be changed for each admission, and the individual or their spokesperson should be given the opportunity to identify each time they present. If patients have not already completed their details on the admission form they must be asked 'Are you of Australian Aboriginal or Torres Strait Islander origin?' (Queensland Health, 2013)

The Queensland Health patient administration system, Hospital Based Corporate Information System (HBCIS) – pronounced 'hibiscus' by health workers – has been used by the state since 1991 (iTnews, 2016).

The hospital paper coding of Indigenous status is:

1. Aboriginal but not Torres Strait Islander origin

2. Torres Strait Islander but not Aboriginal origin
3. Both Indigenous origin
4. Neither Aboriginal or Torres Strait Islander origin
9. Not stated (This code should only be used in the event when a patient, or next of kin cannot answer this question)

As per the QCR *Instruction Manual for Notifying Cancer HBCIS Hospitals*, Indigenous status is located at status field (11) on the Patient Registration Screen, and states that they should be checked for accuracy.

The hospital electronic (HBCIS) coding of Indigenous status is:

Code	Description	Code	Extracted and mapped by HQI (Homer Qld Interface) as
11	Aboriginal but not Torres Strait Islander origin	1	Aboriginal but not Torres Strait Islander origin
12	Torres Strait Islander but not Aboriginal origin	2	Torres Strait Islander but not Aboriginal origin
13	Both Indigenous origin	3	Both Indigenous origin
14	Not Aboriginal nor Torres Strait Islander origin	4	Neither Aboriginal nor Torres Strait Islander origin
19	Not stated	9	Not stated

[Death registration/certificates](#)

As per personal correspondence with the QCR data custodian, data is accumulated over the life (and death certificate) of the patient and is constantly

updated, and QCR Aboriginal status information received from Qld Births, Deaths and Marriages can originate from either part of the death certificate, completed by the medical certifier or funeral director.

The death registration application form recording Indigenous status coding is:

No ☐ ; Yes (Aboriginal) ☐; Yes (Torres Strait Islander) ☐; Yes (Indigenous) ☐

QCR recording Indigenous status coding is:

1. Aboriginal
2. Torres Strait Islander
3. Both Indigenous
4. Neither Aboriginal or Torres Strait Islander
9. Unstated

Information on Indigenous status in cancer registration can come from several sources such as episodes of care to death registration. QCR accumulates data over the life and death of the patient and updates their records continuously. QCR does not receive Indigenous status from National Death Index (NDI) or the Australian Bureau of Statistics (ABS) however, if it is on Births, Deaths and Marriages (BDM) data it is used regardless of whether it is a cancer death or not. QCR uses data linkage with NDI to match Qld residents whose deaths may have been registered interstate.

3.10 Discussion and recommendations

The QCR provides a long standing framework for receiving cancer notifications in Queensland. The system appears effective overall, but some problems were identified with it in relation to Indigenous status:

- Unknown coding of Indigenous status is increasing;
- There is no data quality assessments being undertaken to resolve increasing unknown Indigenous status recording;

- There appears to be no national level agreement on what constitutes reliability of Indigenous status in these types of data sets (i.e. limits set at 70, 80, or 90%, for example); and
- Most notifications continue to be paper based (75%) and this may be contributing to unknown Indigenous status.

The proportion of people with cancer who have missing Indigenous status affects any interpretations of reporting of cancer morbidity, mortality, survival and prevalence in Indigenous populations. The higher proportions of Queensland notifications with unknown Indigenous status increases the likelihood of underestimation of cancer incidence in Indigenous peoples. In this study, proportions of cases with missing Indigenous status over time indicates a possibly large underestimation of Indigenous cancer notifications.

It is timely to assess the recording of Indigenous status for cancers in Queensland to determine if there are discrepancies in recording Indigenous status and if so, to make recommendations on how to further improve the recording of Indigenous status in the future. The ultimate aim in executing this task is to more accurately determine the burden of morbidity and mortality due to cancer among Indigenous peoples and to advance and better target prevention, diagnosis and treatment services.

Recommendations to improving Indigenous status in the QCR data are:

1. That all QCR stakeholders adopt a single format of coding for recording Indigenous status in documentation submitted to the QCR;
2. Implementing the mandatory use of *National best practice guidelines for collection Aboriginal and Torres Strait Islander status in health datasets*

across all health sectors, medical practitioners, coroners, funeral directors and undertakers responsible for registering death; and

3. Linking other health services data (i.e. Qld Hospital Admitted Patient Data Collection (QHAPDC), Qld Perinatal Data Collection (QPDC), Registrar General (RG) deaths, Emergency Department Information System (EDIS), Community Integrated Mental Health Application (CIMHA) with Medicare data to improve QCR data quality.

This undertaking would progress health services planning; enable constructive evaluations as to the effectiveness and quality of cancer services; informatively monitor the uptake of treatments and monitor the impact of screening and vaccination programs. These procedures would provide a more accurate picture of cancer mortality and morbidity in the Queensland Indigenous population.

The use of a national form for all states and territories, for all public and private hospitals, pathology labs and aged care facilities following the national guidelines in conjunction with cross-checking using Medicare data may improve data integrity.

3.11 Acknowledgements

I would like to thank Queensland Health staff and Queensland Cancer Registry staff, in particular, Ms Carly Scott who always found the time to answer my questions. I would also like to thank Dr Kerri Viney, Dr Phyll Dance for their valuable comments and contributions; and I would like to specifically thank Dr Ray Lovett for his patience, direction, encouragement, academic vision and support.

3.12 References

- Australian Institute of Health and Welfare. (2010). *National best practice guidelines for collecting Indigenous status in health data sets*. Canberra: AIHW.
- Australian Institute of Health and Welfare. (2012). *National Centre for Monitoring Cancer: Framework 2012*,. Canberra: AIHW.
- Australian Institute of Health and Welfare. (2014). *Cancer in Australia: an overview 2014* (Vol. Cancer Series No. 90). Canberra: Australian Institute of Health and Welfare.
- Australian Institute of Health and Welfare. (2016). *Queensland Cancer Registry*, . from AIHW <http://www.aihw.gov.au/qld-cancer-registry/>
- Australian Institute of Health and Welfare & Australasian Association of Cancer Registries. (2014a). *Cancer in Australia 2014*,. Canberra: AIHW.
- Australian Institute of Health and Welfare & Australasian Association of Cancer Registries. (2014b). *Cancer in Australia: an overview, 2014*. Canberra: AIHW.
- Cancer Council Queensland. (2015). *Queensland Cancer Registry: research, prevention, support*,. Qld Cancer Registry. Brisbane.
- Cancer Council Queensland. (2016a). *Fact Sheets*. Retrieved from <https://cancerqld.org.au/research/queensland-cancer-statistics/fact-sheets/>
- Cancer Council Queensland. (2016b). *Queensland Cancer Statistics Online (QCSOL)*. Retrieved from <https://cancerqld.org.au/research/queensland-cancer-statistics/queensland-cancer-statistics-online-qcsol/>
- Cancer Institute NSW. (2012). *Cancer in NSW Aboriginal peoples: completeness and quality of Aboriginal status data on the NSW Central Cancer Registry*, . from Cancer Institute NSW,
- Centers for Communicable Disease Control and Prevention. (2001). *Updated Guidelines for Evaluating Public Health Surveillance Systems*, . from US Department of Health & Human Services, <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm>
- iTnews. (2016). *Qld Health to be tested by new system replacement project*,. Retrieved from <http://www.itnews.com.au/news/qld-health-to-be-tested-by-new-system-replacement-project-356047>
- Philpot, S., *Queensland Cancer Registry*, (2016, 21 December 2016). [Indigenous status,].
- Queensland Cancer Registry. (2009). *Queensland cancer registry instruction manual for notifying cancer hbcis hospitals (version 5)*. Online: https://cancerqld.blob.core.windows.net/site/content/uploads/2015/11/60014_QCR_public_hospital_notifications.pdf: QCR.
- Queensland Government. (2013). *Queensland Cancer Control Analysis Team*, . from Queensland Health, <https://qccat.health.qld.gov.au/QueenslandCancerRegistry>
- Queensland Government. (2015). *Cancer in Queensland 1982-2013, Incidence, Mortality, Survival and Prevalence*, . Brisbane: Cancer Council Queensland,.
- Queensland Health. (2013). *Queensland Hospital Admitted Patient Data Collection, Manual of Instructions and Procedures*,. Brisbane: Queensland Government,.
- Scott, C., *Queensland Cancer Registry*, (2015). [QCR Notifications].
- World Health Organisation. (2013). *International classification of diseases for oncology (ICD-O) – 3rd edition, 1st revision*. .

- ❖ These questions are by the Principal Researcher. By completing the questionnaire you give consent to participate in the research project: *An evaluation of the completeness of Aboriginal and Torres Strait Islander status in the Queensland Cancer Registry (QCR) Proposal*

Queensland Cancer Registry (QCR)

Your perspective of completeness and usefulness of Indigenous status in QCR data

Allocated ID Number

Name:

Department Section/Position:

Email:

1. Are you aware of any *external* quality assurance processes? If you are, is Indigenous status included as a data quality item?

.....
.....

2. Both internally and externally, how does QCR use and report the data that is reported to them? How is this data accessed?

.....
.....
.....

3. How does the QCR use Indigenous status data; and what analyses does QCR perform using this variable?

.....
.....

4. What processes does the QCR have to ensure data quality in general, and for Indigenous status in particular?

.....
.....

5. In your opinion how does completeness affect the usefulness of Indigenous status in the QCR data?

.....

.....
.....

6. In your opinion are there any other ways that completeness of Indigenous status may be improved?

.....
.....
.....

7. To your knowledge, has the QCR ever considered data linkage to improve completeness of Indigenous status? (i.e. ABS and/or Medicare)

.....
.....
.....

8. Is there anything else you would like to add?

.....
.....
.....
.....

Chapter 4: A community perspective of 'Burdekin rot'

'For a colonized people the most essential value, because the most concrete, is first and foremost the land: the land which will bring them bread and, above all, dignity' (Fanon, 1963).

Abbreviations

AIATSIS	Australian Institute of Indigenous Studies
ANU	Australian National University
Bur-del	Bur-del Co-operative Advancement Society Limited
CDC	Centre for Disease Control and Prevention
EPA	Environmental Protection Agency
GBR	Great Barrier Reef
Gudjuda	Gudjuda Reference Group Indigenous Corporation
MAE	Master of Philosophy in Applied Epidemiology
NCEPH	National Centre for Epidemiology and Population Health
QCR	Queensland Cancer Registry
Qld	Queensland
RUS	Restricted Use Pesticide

For the purpose of this study, Aboriginal and Torres Strait Islander peoples are respectfully referred to as “Indigenous”

4.1 Prologue

4.1.1. Role

When approached by Master of Applied Epidemiology (MAE) supervisors at the Australian Institute for Indigenous Studies (AIATSIS) and National Centre for Epidemiology and Population Health (NCEPH) to consider a topic for my major epidemiology project I seized the opportunity to conduct a study focusing on local community concerns within the small town where I was born and raised. I reflected on discussions over the years that I had with family, friends and community, and decided that my contribution would be concentrated on examining local concerns of the perceived high rates of cancer in the community and the causes of these perceived higher rates of cancer. I was also interested in people's experiences of diagnosis and management of their cancers. The result is a mixed methods study that looks at the geographical variation in notifications, rates of cancer and cancer survival across Queensland, combined with interviews of 14 local people in the Burdekin region about their experiences of cancer diagnosis and treatment.

As chief investigator I was responsible for developing the research questions and study design. The project required access to data on sensitive populations which necessitated writing three ethics applications; an interstate meeting with data custodians and working with and obtaining a letter of support for the project from a local Burdekin Indigenous community organisation – Bur-del.

4.1.2. Lessons Learnt

This study provided the opportunity to review and further develop data analysis skills using Stata, and improve my analytical skills, and working with a very large dataset (over 220,000 records over some 10 years). I learnt the importance of preliminary meetings with data custodians and community with respect to 'putting a name to a face', building rapport, and reconnecting with community. I learnt that regardless of time restrictions careful consideration must be given to the study question, design and methods. I gained experience in ethics applications, ethics committee process and project timeframes including allowing for timeframe adjustments with supervisors and stakeholders. I gained knowledge of conducting qualitative methods, specifically content analysis. This project also provided the opportunity for me to present at a

conference with other researchers (Appendix 1). I learnt the importance of writing consistently as the project evolves, and that not all mandatory data about Indigenous peoples is complete. I learnt the public health implications of 'unknown' and 'missingness' in terms of study power and how underreporting of Indigenous status impacts heavily on health data, policy, prevention, intervention, diagnosis and treatment of Indigenous peoples. The key issue I learnt is the crucial need for data collection and data linkage in terms of Indigenous status across all jurisdictions - State and Commonwealth, and mandatory reporting of Indigenous status as per the national guidelines as a necessary step in closing the gap in life expectancy and the cancer burden, and morbidity and mortality of Indigenous peoples.

4.1.3. Public Health Implications

The higher rates of some cancers are clearly related to exposures such as tobacco smoking. Poorer cancer outcomes are related to access and treatment, both of these disproportionately affect Indigenous peoples in QLD as evidenced by lower survival rates in rural and remote areas.

Public perceptions of cancer clusters due to environmental factors can be powerful within small community settings as an explanatory factor for health outcomes and especially for cancer, leading to high levels of psychological distress on a small, tight knit Indigenous community. It can also mask what is really going on.

The public health implications of recording of Indigenous status will better inform health policy specific to Indigenous people's needs. The ultimate aim in executing this task is to more accurately determine the burden of morbidity and mortality due to cancer among Indigenous peoples; to provide evidence to advance and better target intervention, prevention, diagnosis and treatment services; and to attempt to alleviate/explain anecdotal community perceptions of cancer in the Burdekin region.

4.1.4. Ethics

Three human research ethics committees reviewed and approved the applications for this project. Details of the ethics approvals are described in the methodology section.

4.1.5. Acknowledgements

I would like to acknowledge and thank Queensland Health Data Custodians; the Queensland Cancer Registry (QCR) Registrar and Data Custodian; the Australian Institute of Indigenous Studies (AIATSIS: Step Up program); the Australian National University (ANU) - National Centre for Epidemiology and Population Health (NCEPH); Dr Ray Lovett; Dr Kerri Viney; Dr Stephanie Davis; Dr Phyllis Dance; Gudjuda Reference Group Indigenous Corporation – Home Hill, North Queensland; and Bur-del Co-operative Advancement Society Limited – Ayr, North Queensland. I would also like to sincerely thank family and friends, and the community of the Burdekin region for supporting and participating in the study.

Master of Philosophy (Applied Epidemiology) requirement

The chapter meets the requirement for a conference presentation, major project, and peer reviewed publication

4.2. Abstract

Background

Cancer among Aboriginal and Torres Strait Islander peoples (hereafter respectfully referred to as “Indigenous”) is a concern in Australia with increasing prevalence and disproportionate mortality compared with other Australians. Indigenous peoples have poorer survival than their non-Indigenous counterparts after diagnosis of most cancer types.

Pseudomonas rubrilineans has been associated with the disease referred to in Queensland as ‘top rot’, ‘cane rot’ or ‘Burdekin rot’. Anecdotal reports of ‘Burdekin rot’ in the Burdekin River region of Queensland are commonplace. However, people are not talking about sugarcane - ‘Burdekin rot’ is an anecdotal term for cancer among people from the Burdekin. The term ‘Burdekin rot’ is commonly used, particularly among the Indigenous population of the region, in reference to the perceived higher rates of cancer among the population.

Aim

This study aimed to investigate if the concept of ‘Burdekin rot’ was real based on an examination of geographical variation in cancer notifications and mortality across Queensland (Part 1). Being my home area, I was also obliged to undertake a qualitative component in the study to understand the diagnosis and treatment experiences of some families from the area (Part 2).

Methods

I conducted a mixed methods study. The quantitative component included a descriptive analysis of 2003-2012 Queensland Cancer Registry (QCR) data to present rates of cancer notifications, mortality and survival by Indigenous status and Statistical Divisions (SD). Poisson regression was used to calculate rates of cancer mortality by Indigenous status and by geographical region (SD). Cox regression for survival analysis (Kaplan Meier function) was used to examine survival analysis by geographic region in QLD and to provide an overall hazards ratio of death between Indigenous and non-Indigenous people in QLD during the period 2003-2012.

The qualitative component included conducting interviews with Indigenous people residing in the Burdekin region to understand their experiences of

cancer diagnosis, treatment, and care. For the analysis of qualitative interview data, I used thematic content analysis.

Results

I found the number of cancer notifications for Indigenous status unknown (n=28,781) in QCR data 2003-2012 has been increasing, and since 2006 it has increased dramatically from 11% in 2006 to around 15.5% in 2012.

The rate of cancer deaths in the Indigenous population of Queensland 2003-2012 was 189 per 1,000 person years compared to the non-Indigenous rate of 123 per 1,000 person years. The ratio of cancer deaths for Indigenous compared to non-Indigenous people in Queensland is 1.5. Across the geographic regions rates of cancer varied, but for the area of the Burdekin, there is insufficient data to examine cancer deaths on a year-by-year basis. Despite this, rates of cancer deaths within the Northern region (which includes the Burdekin) are similar to other rural regions when looking at cancer rates among the Indigenous populations of those regions. Ratio of cancer deaths is 1.4 in this region, slightly lower than the overall Queensland ratio of 1.5.

People describe their cancer diagnosis as a confirmatory process, by doctors or of being 'told' they have cancer. Some people alluded to something being wrong (physical symptoms) before seeking this confirmation.

Treatment was often characterized in the physical sense and described the physical response primarily to chemotherapy. For some, this was related to decisions to stop treatment altogether due to the severe side effects of treatment.

When asked about contributing factors, over one-third of respondents mentioned water and chemical contamination as a contributing factor.

Conclusions

Perceptions of higher cancer rates (or clusters) can be powerful. Data at the finer geographic level are required to ensure appropriate monitoring is occurring for populations where rates are higher including Indigenous populations. To achieve this, data need to be reliable and more work on this needs to occur with this cancer registry and likely others.

4.3 Introduction

In this section I provide a brief overview of Indigenous cancer morbidity, mortality and survival at the national level, then at the Queensland level. Finally, I place the study in the context of cancer in the Burdekin region of Queensland.

4.3.1. Brief overview of Australian Indigenous health status

Indigenous health status is poor across many domains from cardiovascular diseases; diabetes; cancer, chronic respiratory, liver and renal diseases; trauma; and other causes when compared to the non-Indigenous population. Indigenous life expectancy at birth is on average 11 years less than for non-Indigenous Australians and Indigenous peoples mental and physical health routinely bears the brunt of social disadvantage and exclusion (Australian Institute of Health and Welfare, 2015; Brown et al., 2016).

Indigenous peoples of Australia have lived on their lands for many thousands of years prior to the European invasion and settlement, and have endured the impact and burden of colonisation with resilience. At the *International Symposium on the Social Determinants of Indigenous Health* in Adelaide, Australia (2007), the World Health Organisation's (WHO) investigation into health determinants recognises European colonisation as a common and central underlying determinant of Indigenous health (Freemantle et al., 2015).

Mortality lets a society know about its social advancement since mortality is a fundamental indicator of how effective public health policies and programs are. Mortality data, in particular the causes of infant and childhood mortality, also exposes the bigger picture of social, economic, and political issues (Freemantle et al., 2015).

The Close the Gap campaign launched in 2007 set a goal of raising the health and life expectancy of Indigenous peoples to that of the non-Indigenous population within a generation (Australian Human Rights Commission, 2016). However, cancer among the Indigenous population has become a growing area of concern in Australia with increasing prevalence and disproportionate mortality in comparison to other Australians (C. M. Bernardes, L. J. Whop, G. Garvey, & P. C. Valery, 2012).

4.3.2. National

A 2016 article analysing data from the *Indigenous Health Performance Framework 2014* report showed that the overall difference in death rates between Indigenous people and non-Indigenous Australians from 1998-2012 of 13.2 vs 7.5 deaths per 100,000 per year respectively, (both $P<0.001$) (Ring, Dixon, Lovett, & Al-Yaman, 2016).

For cancer, there was a considerable decline in the mortality rate for non-Indigenous Australians (1.3 deaths per 100,000; $P=0.009$) however, there was a significant increase in the Indigenous mortality rate (2.1 deaths per 100,000 per year; $P<0.001$). As a consequence, the rate difference for Indigenous peoples widened significantly by 3.4 deaths per 100,000 per year ($P<0.001$), and the rate ratio also rose significantly (by 0.02 per year; $P<0.001$) (Ring et al., 2016).

4.3.3. Queensland

Moore and colleagues conducted a study in 2010 on cancer incidence and mortality rates for cancers diagnosed among Indigenous Australians in Queensland from 1997-2006. The study found that Indigenous Queenslanders were 21% less likely to be diagnosed with cancer, and those who were diagnosed were 36% more likely to die (Rametta et al., 2013).

Overall incidence of cancer diagnosis is lower among Indigenous vs. non-Indigenous people of Queensland however, the question arises is there variation by regions? What were the rates?

4.3.4. Burdekin Region of north Queensland

Since the middle of the 19th century sugarcane production has been the main agricultural industry for coastal Queensland, and continues to be the economic mainstay of many coastal communities (Garside, 2003). More than 85% of sugarcane production in Queensland is concentrated in the Wet Tropics, Burdekin Dry Tropics and Mackay Whitsunday regions (Smith, Poggio, Thompson, & Collier, 2014).

Figure 17: Map of mainland Australia outlining the Burdekin region



Source: (Commonwealth of Australia, 2015)

The Burdekin shire consists of the towns/suburbs of Ayr, Home Hill, Brandon, Giru, Clare, Millaroo, Alva Beach, Airville, Fredericksfield, Inkerman, Jarvisfield, McDesme, Mt Kelly and Osbourne covering an area just over 5, 058 square kilometres. The shire's main towns of Ayr and Home Hill are just 12km apart and are linked by the Burdekin River Bridge. Located in the north-eastern section of Queensland, the Burdekin River is the heart to a whole network of rivers. This abundance of water allows Burdekin farmers to produce sugar cane, mangoes, melons, capsicums, zucchinis, tomatoes and many other small crops (Queensland Government, 2016e).

*The Burdekin River basin drains an area of about 130,000 square kilometres. Two main tributaries drain the catchment, the Burdekin River flowing from the north and the Belyando from the south, both join at the Burdekin Falls Dam (Figure 18). Downstream of the Dam, the Bowen and Bogie Rivers merge the Burdekin River before it flows into the sea near Ayr and Home Hill (Department of Health, 2010). The Burdekin River Delta covers an area of approximately 850 km², and represents one of the biggest unconfined coastal aquifer systems in eastern Australia (Cook, Stieglitz, & Clark, 2004).

Figure 18: Burdekin Dam



Source: (Budd, 2016)

As at 30 June 2015, the Burdekin regions population was 17,831 persons. It has a 20% aged between 0-14, 62% aged 15-64, and 18% aged 65 years and over (Queensland Government, 2016b). The median age is 41.4 years, and the Indigenous population is 5.1% (n~892). There are 19 schools and 2 hospitals in the region (Queensland Government, 2016a).

4.3.5. Pesticide use in the Burdekin region

Currently, there are stringent rules and regulations for the use of pesticides and herbicides in the catchments of the Wet Tropics, Burdekin and Mackay-Whitsundays. There is evidence that significant quantities of fertiliser, pesticides and sediment from sugarcane farms and grazing properties are entering the Great Barrier Reef (GBR) lagoon. Sugarcane farmers are encouraged by the Qld government authorities, the Department of Environment, Land and Water and the Department of Agriculture and Primary Industries to adopt farming practices that decrease the probability of nutrients and pesticide runoff into the GBR (Queensland Government, 2016d).

The 2010 reef protection requirements under the *Environmental Protections Act 1994* and the *Chemical Usage (Agricultural and Veterinary) Control Act 1988*, require all canefarmers in the Wet Tropics, Burdekin and Mackay-Whitsundays to:

- keep records of their use of fertilisers and agricultural chemicals;
- undertake soil tests, use the soil tests and the regulated method to calculate and apply no more than the ideal amount of fertiliser (nitrogen and phosphorus);

- follow product label instructions when using herbicides and insecticides; and
- follow specific controls when using herbicide products containing atrazine, ametryn, hexazinone and diuron including the stipulated user training criteria, spray-droplet size limits, no-spray windows, and restrictions on using prior to rainfall and near waterbodies (Queensland Government, 2016c).

4.3.6. Burdekin 'rot'

Bacterial red stripe (*Pseudomonas rubrilineans*) is a sugar cane leaf disease first described in Hawaii and later labelled 'red stripe' (Figure 19). *Pseudomonas rubrilineans* has been associated with the disease referred to in Queensland as 'top rot', 'cane rot' or 'Burdekin rot'. The mode of transmission is airborne and occurs where bacteria groups in large masses in the leaf tissues and oozes onto the leaf surface during periods of moist warm weather. The bacteria then readily spread plant to plant – even field to field (C Ricaud, Egan, Gillaspie Jnr, & Hughes, 1989).

Figure 19: Red Stripe *Pseudomonas rubrilineans*



Source: (American Phytopathological Society, 2016)

Anecdotal reports of 'Burdekin rot' in the Burdekin River region of Queensland are commonplace. However people are not only talking about sugarcane. 'Burdekin rot' is a colloquial term used to describe cancer among Indigenous people from the Burdekin. 'Burdekin rot' is commonly used in reference to anecdotal reports from the region such as:

- a higher incidence of cancer; and
- a relationship between chemical use and cancer diagnosis and death.

There are no currently available regional level reports to understand if there is variation in diagnosis and death at regional levels. Disaggregation is required to monitor cancer rates (or rates of any disease or health condition) at finer geographical areas.

4.4. Aims

1. My first aim was to undertake a finer geographical analysis of cancer rates in the Indigenous and Non-Indigenous population of Queensland.

This was to assess the variation in rates by cancer type, region and by Indigenous status.

2. My second aim was to undertake interviews in the Burdekin with cancer sufferers and their families to understand the cancer diagnosis and treatment process.

This was to shed light on what those experiences were.

4.5. Methods

I conducted a mixed methods study. The quantitative component included a descriptive analysis of 2003-2012 Queensland Cancer Registry (QCR) data using Cox regression survival analysis and Kaplan Meier to show rates of cancer notifications, rates of diagnosis, and mortality by Statistical Divisions (SD) and Indigenous status. The qualitative component included conducting one-on-one interviews within Indigenous people living in the Burdekin region to understand their experiences of cancer diagnosis and treatment. For the analysis of qualitative interview data I used content analysis.

4.5.1. Quantitative Analysis

The Queensland Cancer Registry (QCR) data from 2003-2012 (n=207,137 cancer diagnoses and 71,784 deaths from cancer) were analysed by Indigenous status, broad cancer diagnosis and statistical division. The original QCR data did not contain SD [only Statistical Local Area (SLA)], therefore the SD had to be generated from SLA codes using *Stata version 14*. The data were also recoded from site specific cancer code to broad cancer code categories (ICD 10) to ensure confidentiality was maintained. Data are presented as proportions of notifications by SD region, cancer type and age group over time; Cox proportional hazard rates, mortality; and survival rates (Kaplan Meier).

4.5.2. Qualitative Analysis

I conducted in-depth interviews with Indigenous cancer survivors and cancer carers (n=14) in relation to their experiences of cancer diagnosis, treatment and

care either from a personal perspective or interviewee experience of a family member with cancer.

Content analysis is a method for analyzing communication (Haslam & McGarty, 2009). I examined interview transcripts in *Wordstat*® text analysis software to extract themes on experiences told by respondents. My sampling domain was Aboriginal and Torres Strait Islander cancer survivors or family members of those who had passed away within the Burdekin region. The coding units were identified from the text analysis software by examining the interview transcripts and looking for the most common words mentioned in the text. The software then coded the text according to the order of the frequency of text. Data were then summarized into key themes and example quotes representing those themes are presented to contextualize (Haslam & McGarty, 2009).

4.6. Results

I first present a descriptive analysis of the QCR data (Part 1), and the second part of the results I will present the experiences of the Indigenous peoples on their perspective of cancer diagnosis, treatment and care (Part 2).

Part 1: Queensland Indigenous cancer notifications, deaths rates and survival

Cancer notifications QLD by Indigenous status

There were 209,725 cancer notifications recorded in Queensland from 2003-2012. Indigenous people accounted for 1.3% (n= 2,628) of these notifications (Figure 20)

The number of cancer notifications with Indigenous status unknown (n=28,781) has been increasing since 2006 (from 11% to 15.6% in 2012) (Figure 21).

From 2003-2012 the level of unknown Indigenous status has increased within Queensland Cancer Registry (QCR) data. In 2003 the rate of unknown Indigenous status was 12.42%, and there was a drop from 12.82% in 2006 to 10.29% however, from 2007 (11.19%) the percentage rate of unknown status had increased dramatically to 15.53% in 2012 (*Figure 21*).

Figure 20: Queensland cancer notifications 2003-2012 by Indigenous status.

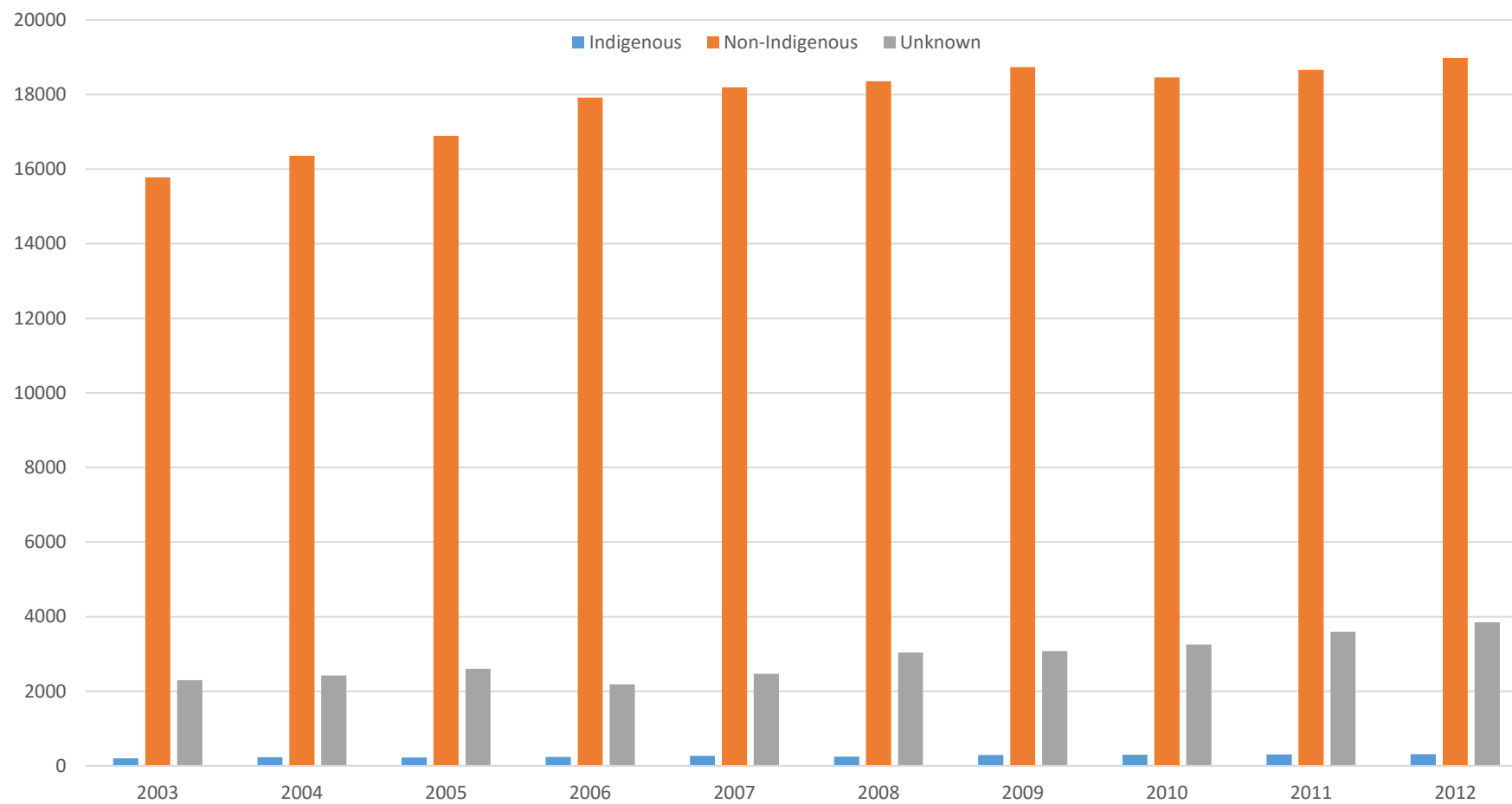
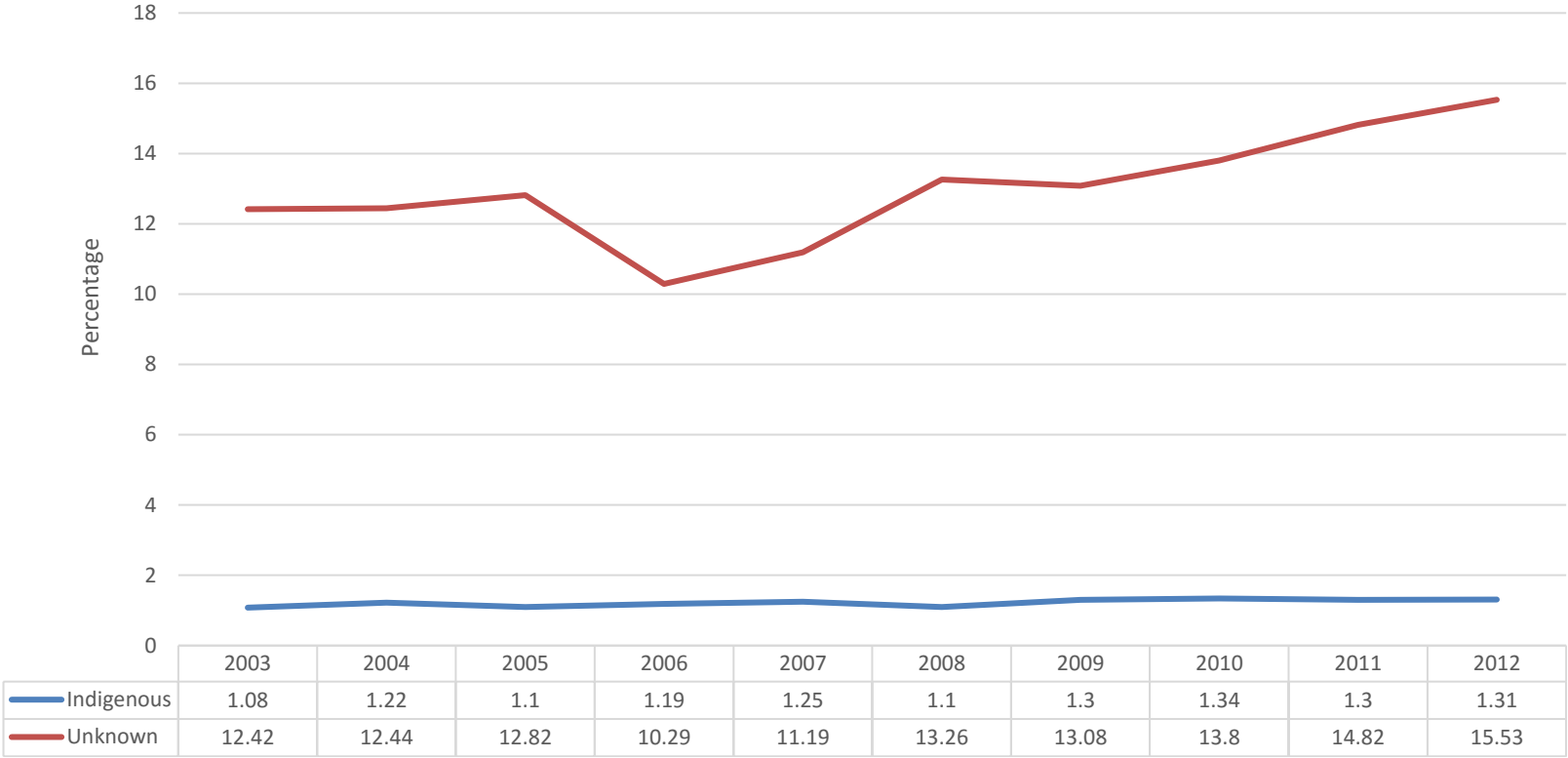


Figure 21: Cancer cases with missing/unknown Indigenous status in QCR data 2003 – 2012



4.6.1. Cancer notifications by broad cancer ICD code

Table 8: Cancer notifications (%) by broad ICD 10 code and Indigenous status 2003-2012, Queensland

	2003		2004		2005		2006		2007		2008		2009		2010		2011		2012	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Oral Cavity and Pharynx	14	7.0	15	6.4	11	4.9	11	4.5	15	5.6	13	5.2	15	5.1	18	6.0	13	4.3	10	3.2
Digestive System	49	24.5	44	18.8	57	25.6	51	21.1	64	23.9	60	24.0	65	22.2	62	20.7	57	18.8	66	20.9
Respiratory System	31	15.5	38	16.2	33	14.8	42	17.4	51	19.0	31	12.4	52	17.7	55	18.4	51	16.8	58	18.4
Bones and Joints		0.0	2	0.9	1	0.4	1	0.4	1	0.4		0.0		0.0	2	0.7	2	0.7	0	0.0
Soft Tissue including Heart Skin excluding Basal and Squamous	3	1.5	2	0.9	2	0.9	4	1.7	2	0.7		0.0	3	1.0	2	0.7	5	1.7	1	0.3
	2	1.0	6	2.6		0.0	8	3.3	7	2.6	3	1.2	7	2.4	10	3.3	3	1.0	6	1.9
Breast	29	14.5	28	12.0	36	16.1	24	9.9	30	11.2	36	14.4	26	8.9	35	11.7	42	13.9	47	14.9
Female Genital System	20	10.0	23	9.8	27	12.1	32	13.2	20	7.5	23	9.2	37	12.6	34	11.4	32	10.6	26	8.2
Male Genital System	9	4.5	19	8.1	15	6.7	19	7.9	20	7.5	25	10.0	29	9.9	26	8.7	39	12.9	35	11.1
Urinary System	9	4.5	8	3.4	6	2.7	14	5.8	12	4.5	4	1.6	8	2.7	11	3.7	16	5.3	13	4.1
Eye and Orbit Brain and Other Nervous System		0.0		0.0		0.0		0.0		0.0	1	0.4		0.0		0.0	1	0.3	0	0.0
	1	0.5	2	0.9	3	1.3	1	0.4	3	1.1	6	2.4	6	2.0	3	1.0	3	1.0	5	1.6
Endocrine System	3	1.5	9	3.8	6	2.7	6	2.5	8	3.0	14	5.6	11	3.8	7	2.3	7	2.3	7	2.2
Lymphoma	20	10.0	33	14.1	16	7.2	22	9.1	25	9.3	24	9.6	26	8.9	25	8.4	20	6.6	33	10.4
Miscellaneous	10	5.0	5	2.1	10	4.5	7	2.9	10	3.7	10	4.0	8	2.7	9	3.0	12	4.0	9	2.8
Total	200		234		223		242		268		250		293		299		303		316	

The 5 most common cancer notifications among the Indigenous population accounted for around 80% of all cancers in

Queensland 2003-2012. These were: cancers of the digestive system (around 25% of all cancers), followed by cancers of the respiratory system (around 20% of all cancers), breast cancer (around 14% of all cancers), followed by both female and male genital system cancers (both around 11% of all cancers) Table 8.

Table 9: Cancer notifications by broad ICD 10 code and Non-Indigenous status 2003-2012, Queensland

Cancer type Non- Indigenous	2003		2004		2005		2006		2007		2008		2009		2010		2011		2012	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Oral Cavity and Pharynx	418	2.6	434	2.7	494	2.9	482	2.7	501	2.8	449	2.4	475	2.5	498	2.7	505	2.7	454	2.4
Digestive System	3461	21.9	3623	22.1	3726	22.1	3858	21.5	3904	21.5	3903	21.3	3830	20.4	3966	21.5	3990	21.4	4032	21.2
Respiratory System	1711	10.8	1901	11.6	1888	11.2	2024	11.3	1955	10.7	2045	11.1	2051	10.9	2083	11.3	2027	10.9	2004	10.6
Bones and Joints	32	0.2	43	0.3	35	0.2	43	0.2	48	0.3	45	0.2	38	0.2	49	0.3	56	0.3	35	0.2
Soft Tissue including Heart	64	0.4	89	0.5	84	0.5	75	0.4	69	0.4	72	0.4	80	0.4	103	0.6	103	0.6	113	0.6
Skin excluding Basal and Squamous	1641	10.4	1461	8.9	1575	9.3	1554	8.7	1595	8.8	1546	8.4	1517	8.1	1459	7.9	1483	7.9	1563	8.2
Breast	1949	12.4	2001	12.2	2108	12.5	2294	12.8	2257	12.4	2453	13.4	2523	13.5	2561	13.9	2547	13.7	2701	14.2
Female Genital System	631	4.0	689	4.2	725	4.3	735	4.1	761	4.2	745	4.1	784	4.2	833	4.5	842	4.5	924	4.9
Male Genital System	2319	14.7	2593	15.9	2576	15.2	2902	16.2	3158	17.4	3256	17.7	3414	18.2	3105	16.8	3247	17.4	3247	17.1
Urinary System	880	5.6	876	5.4	881	5.2	981	5.5	861	4.7	829	4.5	945	5.0	878	4.8	914	4.9	967	5.1
Eye and Orbit	63	0.4	46	0.3	53	0.3	56	0.3	46	0.3	57	0.3	44	0.2	45	0.2	37	0.2	42	0.2
Brain and Other Nervous System	231	1.5	244	1.5	285	1.7	276	1.5	268	1.5	267	1.5	329	1.8	302	1.6	319	1.7	286	1.5
Endocrine System	271	1.7	277	1.7	326	1.9	357	2.0	432	2.4	380	2.1	412	2.2	423	2.3	394	2.1	401	2.1
Lymphoma	1691	10.7	1637	10.0	1698	10.1	1825	10.2	1855	10.2	1822	9.9	1798	9.6	1704	9.2	1764	9.5	1796	9.5
Miscellaneous	414	2.6	444	2.7	439	2.6	453	2.5	481	2.6	485	2.6	494	2.6	450	2.4	429	2.3	414	2.2
Total	15776	100	16358	100	16893	100	17915	100	18191	100	18354	100	18734	100	18459	100	18657	100	18979	100

Table 9 indicates that the most common cancer notifications during 2003-2012 for non-Indigenous people of QLD were cancers of the digestive system (around 22% of all cancers), followed by male genital cancers (around 17% of all cancers),

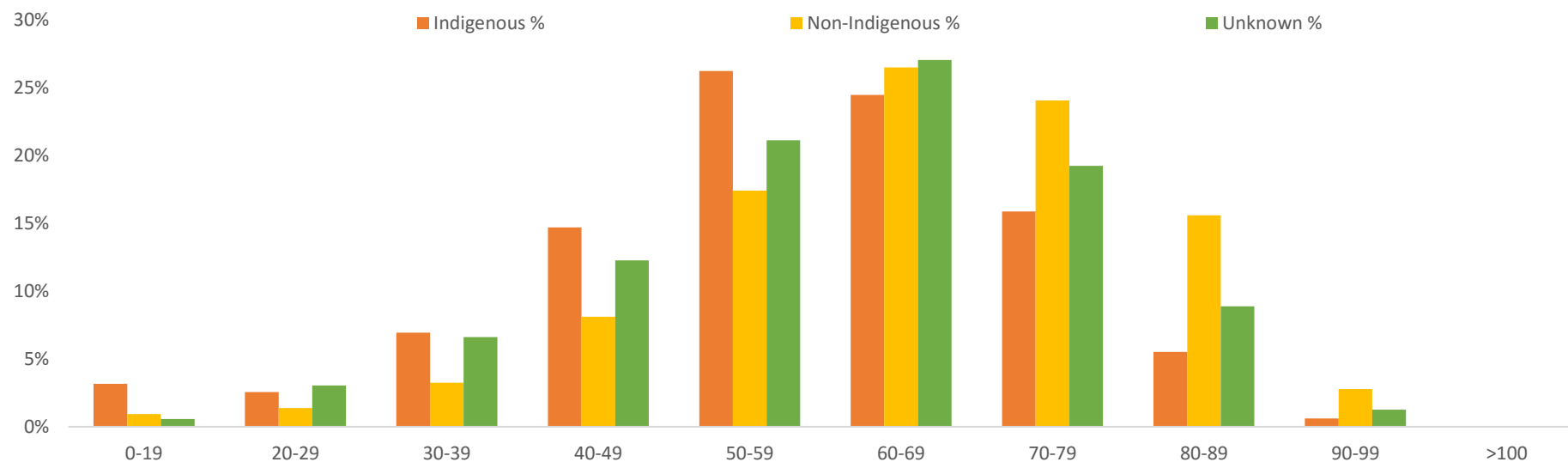
breast cancer (around 14% of all cancers), respiratory system cancer (around 11% of all cancers), and lymphoma (around 10% of all cancers).

Table 10: Cancer notifications (n & %) by broad ICD code by unknown Indigenous status 2003-2012, Queensland

Cancer type (unknown Indigenous status)	2003		2004		2005		2006		2007		2008		2009		2010		2011		2012	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Oral Cavity and Pharynx	114	5.0	105	4.3	99	3.8	108	4.9	85	3.4	91	3.0	118	3.8	122	3.7	127	3.5	135	3.5
Digestive System	138	6.0	162	6.7	149	5.7	156	7.1	159	6.5	206	6.8	201	6.5	243	7.5	255	7.1	272	7.1
Respiratory System	59	2.6	48	2.0	41	1.6	42	1.9	50	2.0	62	2.1	53	1.7	47	1.4	54	1.5	105	2.7
Bones and Joints	6	0.3	7	0.3	2	0.1	2	0.1	1	0.0	3	0.1	2	0.1	2	0.1	2	0.1	0	0.0
Soft Tissue including Heart	12	0.5	9	0.4	21	0.8	10	0.5	5	0.2	9	0.3	10	0.3	6	0.2	12	0.3	10	0.3
Skin excluding Basal and Squamous	917	39.9	1003	41.4	1197	46.0	978	44.8	1190	48.3	1454	48.1	1555	50.6	1607	49.4	1749	48.7	1783	46.4
Breast	244	10.6	273	11.3	271	10.4	175	8.0	139	5.6	208	6.9	187	6.1	244	7.5	234	6.5	264	6.9
Female Genital System	55	2.4	61	2.5	74	2.8	38	1.7	38	1.5	44	1.5	39	1.3	57	1.8	34	0.9	55	1.4
Male Genital System	501	21.8	526	21.7	506	19.4	456	20.9	522	21.2	627	20.7	593	19.3	550	16.9	659	18.3	670	17.4
Urinary System	55	2.4	51	2.1	56	2.1	52	2.4	63	2.6	73	2.4	72	2.3	70	2.2	92	2.6	116	3.0
Eye and Orbit	13	0.6	7	0.3	12	0.5	13	0.6	8	0.3	10	0.3	10	0.3	11	0.3	18	0.5	9	0.2
Brain and Other Nervous System	17	0.7	6	0.2	7	0.3	8	0.4	7	0.3	7	0.2	7	0.2	4	0.1	5	0.1	15	0.4
Endocrine System	44	1.9	41	1.7	38	1.5	21	1.0	33	1.3	39	1.3	39	1.3	51	1.6	55	1.5	49	1.3
Lymphoma	95	4.1	97	4.0	103	4.0	97	4.4	139	5.6	171	5.7	171	5.6	206	6.3	272	7.6	331	8.6
Miscellaneous	27	1.2	26	1.1	29	1.1	26	1.2	26	1.1	19	0.6	19	0.6	35	1.1	27	0.8	32	0.8
Total	2297	100	2422	100	2605	100	2182	100	2465	100	3023	100	3076	100	3255	100	3595	100	3846	100

Table 10 above shows the most common cancer notifications in the unknown Indigenous status category 2003 – 2012 were skin cancers (around 46% of all cancers), followed by male genital system (around 20% of all cancers), breast cancer and lymphoma (around 8% of all cancers), and digestive system cancer (around 7% of all cancers).

Figure 22: Cancer notifications (%) by Indigenous status and age group Queensland, 2003-2012



The 0-19 age group for Indigenous people shows they are 3.4 times more likely to be notified of a cancer than non-Indigenous. Indigenous people in the 30-39 age group, 40-49 age group, and 50-59 age group are around 2 times more likely to be notified of a cancer than non-Indigenous Queenslanders (not age standardized) (Figure 22).

Table 11: Cancer notifications (%) by Indigenous status, sex, marital status and statistical division (SD)
2003-2012 Queensland.

	Indigenous		Non-Indigenous Australian		Unknown		Total
	n	%	n	%	n	%	
Sex							
Male	1252	47.64	99,283	55.68	17,330	60.21	117,865
Female	1376	52.36	79,033	44.32	11,451	39.79	91,860
Marital status							
Single	1378	52.44	64,751	36.31	2,927	10.17	69,056
Partner	1173	44.63	111,058	62.28	8,697	30.22	120,928
Unknown	77	2.93	2,507	1.41	17,157	59.61	19,741
Statistical Division							
Brisbane	597	0.67	77,682	86.95	11,065	12.38	89,344
Gold Coast	88	0.32	22,602	82.69	4,645	16.99	27,335
Sunshine Coast	46	0.26	15,530	86.67	2,343	13.08	17,919
West Moreton	32	0.75	3,635	85.71	574	13.53	4,241
Wide Bay – Burnett	150	0.85	15,407	87	2,152	12.15	17,709
Darling Downs	118	1.07	9,251	84.12	1,628	14.8	10,997
South West	64	4.82	1,112	83.8	151	11.38	1,327
Fitzroy	160	1.72	8,321	89.59	807	8.69	9,288
Central West	16	3.21	427	85.74	55	11.04	498
Mackay	128	1.8	5,874	82.79	1,093	15.41	7,095
Northern	282	2.82	7,584	75.89	2,127	21.28	9,993
Far North	758	6.78	8,508	76.07	1,918	17.15	11,184
North West	185	7.33	2,129	84.32	211	8.36	2,525
Offshore	4	1.49	253	94.05	12	4.46	26

More Indigenous people were notified of cancer in the North West and Far North SD's of Queensland (7.3% and 6.78%) respectively. The gender balance for Indigenous people was similar (48% male vs. 44% female) however, non-Indigenous had 12% more males than females (56% male vs. 44% female). More non-Indigenous people (62%) had partners than Indigenous people (45%) (Table 11).

Figure 23: Indigenous cancer notifications (%) by age group and year (QLD) 2003-2012

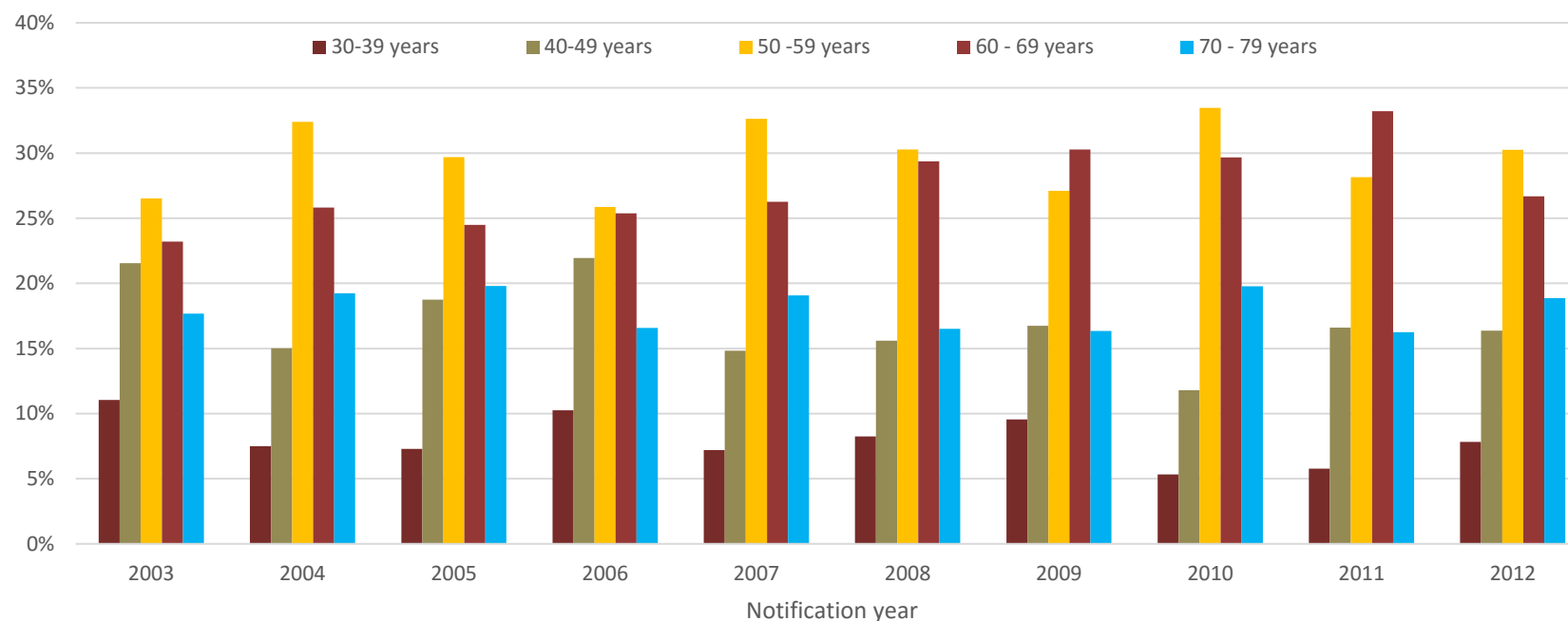
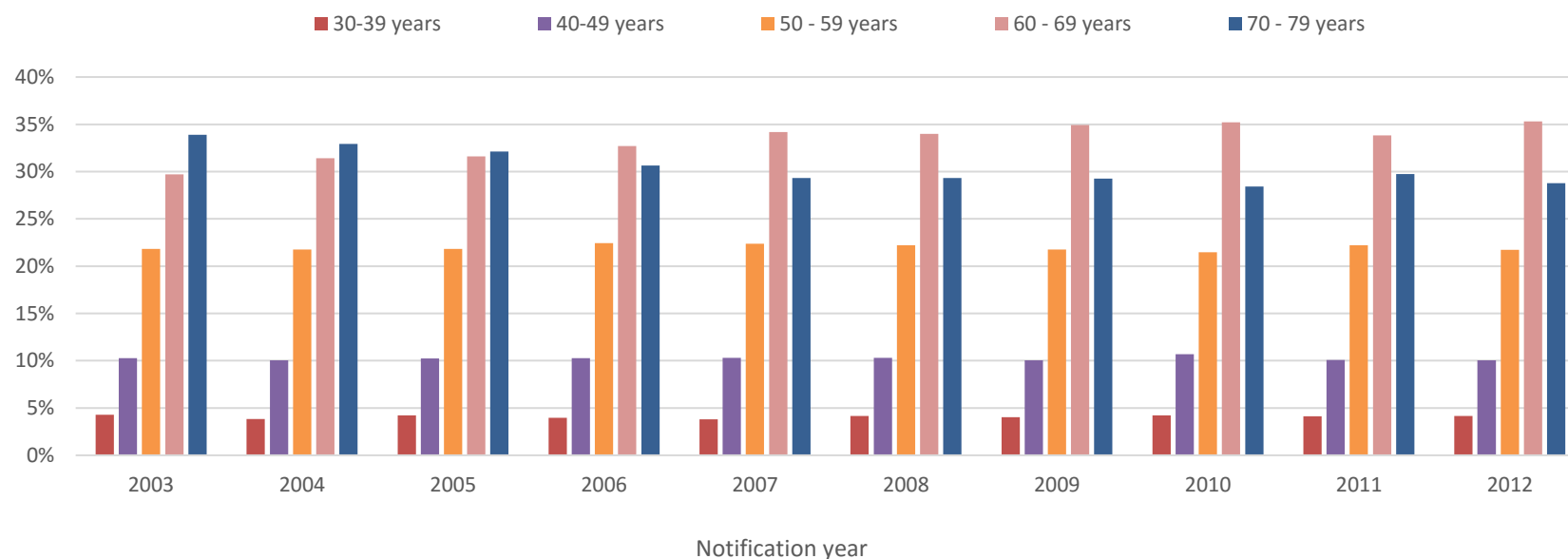


Figure 23 above displays cancer notifications for Indigenous people in Qld are consistently higher than those of their non-Indigenous counterparts. In the period 2003-2012 Indigenous cancer notifications have consistently remained around 30% in the 50-59 year age group vs. non-Indigenous (around 22%). The rate of notifications per year in the 60-69 age group has steadily increased from 2008 -2012.

Figure 24: Non-Indigenous cancer notifications (%) by age group and year QLD 2003-2012



Non-Indigenous cancer notifications for all age groups 2003-2012 have followed a consistent trend. Non-Indigenous people in Qld in the 70-79 year age group rate of cancer notifications have around 10% less notifications of cancer than Indigenous peoples (Figure 24). Indigenous people in the 30-39 year age group are notified of cancer around 1.5 times more than non-Indigenous people at aged 30-39 years (Figure 24).

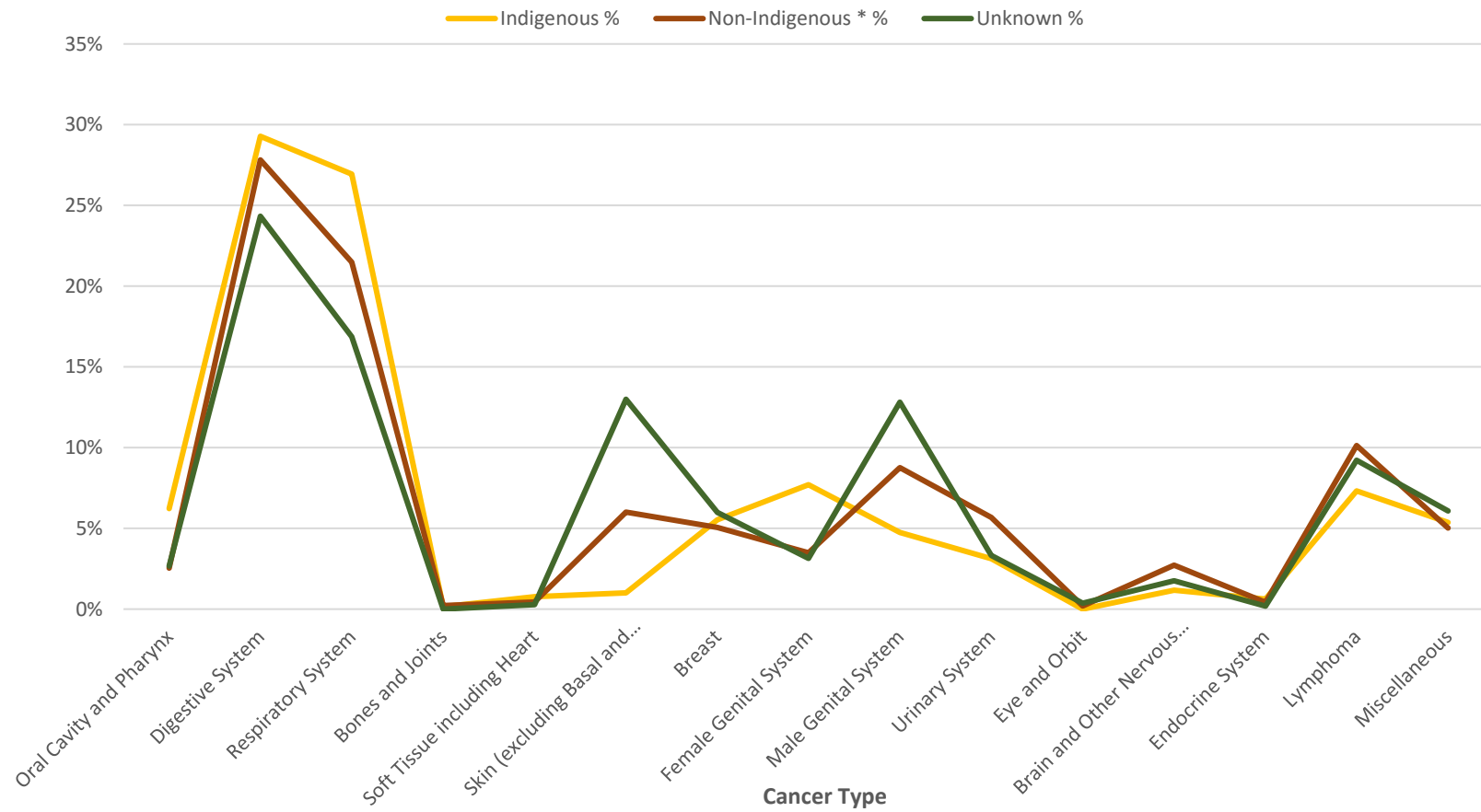
4.6.2. Cancer mortality

Table 12: Rate of all cancer deaths by Indigenous status and Statistical Division (SD) Queensland, 2003-2012

	Non-Indigenous					Indigenous				
	Person-Time	Deaths	Rate	Lower	Upper	Person-time	Deaths	Rate	Lower	Upper
Brisbane	254200.7	29172	114.76	113.45	116.08	1675.35	239	142.66	125.67	161.94
Gold Coast	70411.79	9120	129.52	126.89	132.21	251.89	35	138.95	99.77	193.53
Sunshine Coast	48699.9	5715	117.35	114.35	120.43	114.25	21	183.82	119.85	281.92
West Moreton	11653.12	1374	117.91	111.84	124.31	81.91	13	158.71	92.16	273.33
Wide Bay, Burnett	46797.31	6418	137.14	133.83	140.54	370.14	71	191.82	152.01	242.06
Darling Downs	29916.8	3624	121.14	117.26	125.14	377.45	45	119.22	89.01	159.68
South West	3384.45	499	147.44	135.05	160.96	148.39	33	222.39	158.11	312.82
Fitzroy	25953.13	3287	126.65	122.39	131.06	437.44	74	169.17	134.7	212.45
Central	1194.58	182	152.36	131.75	176.18	27.72	10	360.74	194.1	670.45
Mackay	18461.49	2294	124.26	119.28	129.45	304.97	60	196.74	152.76	253.39
Northern	23264.7	3178	136.6	131.93	141.43	701.48	138	196.73	166.5	232.45
Far North	24194.44	3630	150.03	145.23	155	1641.89	406	247.28	224.36	272.54
North West	6741.75	1028	152.48	143.44	162.09	437.38	99	226.35	185.88	275.63
Offshore	775.79	62	79.92	62.31	102.51	10.54	0	0	.	.
Total	565649.94	69583	123.01	122.1	123.93	6580.8	1244	189.03	178.82	199.84

In every Statistical Division of Queensland the rate of cancer deaths are higher for Indigenous people compared to non-Indigenous people. In the Central SD of Qld the rate of cancer deaths is nearly double for Indigenous, 361 per 1,000 person years vs. 182 per 1,000 person years for non-Indigenous people. Mackay SD the rate of cancer deaths is 63% higher between Indigenous 197 vs. 124 person years; Northern SD the rate of cancer deaths around 70% higher for Indigenous people 137 vs. 197 person years; and Far North SD Indigenous people had a higher rate of cancer death than non-Indigenous 247 vs. 150 person years (Table 12).

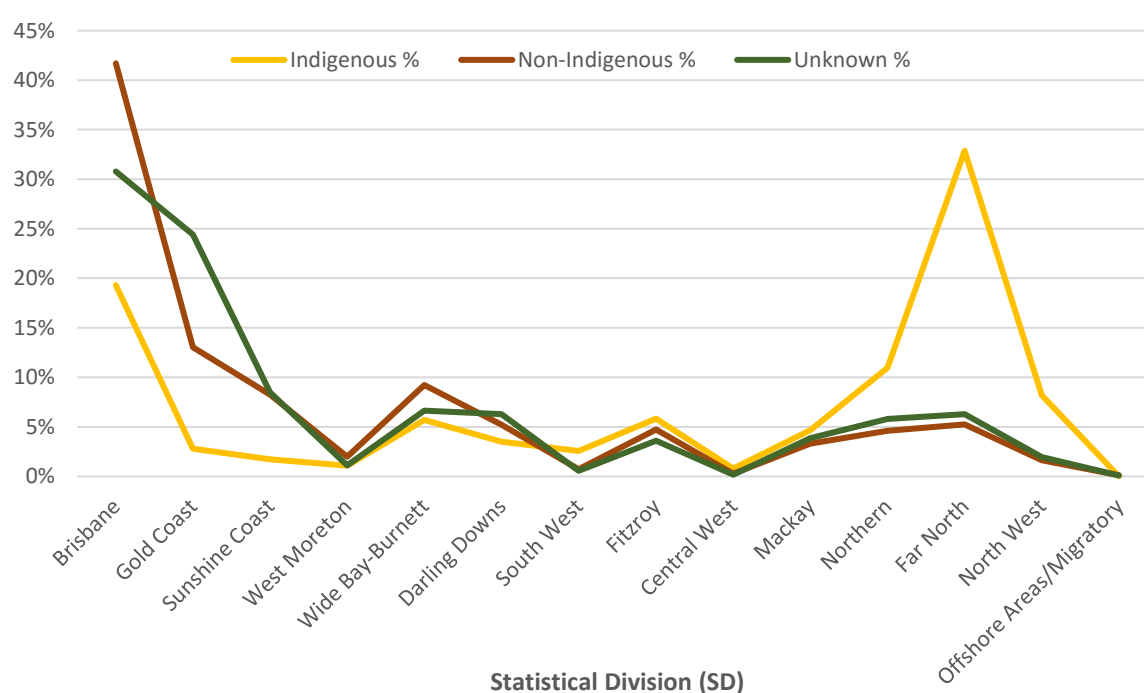
Figure 25: Cancer deaths (%) by broad ICD 10 code by Indigenous status Queensland 2003 - 2012



*One entry missing in non-Indigenous

Respiratory system cancer deaths are around 5% higher for Indigenous peoples than non-Indigenous people of Queensland (26.9% vs 21.5%) respectively. Female genital system cancer deaths for Indigenous females are more than double that of non-Indigenous females (7.7% vs. 3.1%). Most other causes of cancer deaths followed similar trends for Indigenous and non-Indigenous people except for skin cancers (1% vs. 6%) respectively. Male genital system cancer deaths for Indigenous men (4.8%) was lower than non-Indigenous men (8.8%). There was a high proportion of unknown Indigenous status for skin cancer deaths (13%) and male genital system cancer deaths (13%) (*Figure 25*).

Figure 26: Cancer deaths by Indigenous status and Statistical Division (SD) Queensland 2003



Although Metropolitan QLD accounted for 19% of Indigenous cancer deaths 2003 – 2012, considering the population, this may be due to the increased proportion of unknown Indigenous status (31%, n=10,731) in the urban SDs which could impact the higher proportion of cancer deaths for the Far North SD (Indigenous 33% vs. non-Indigenous 6.3%). The proportion of Indigenous cancer deaths in the Northern SD was more than double (11%) that of non-Indigenous cancer deaths (4.6%) (*Figure 26*).

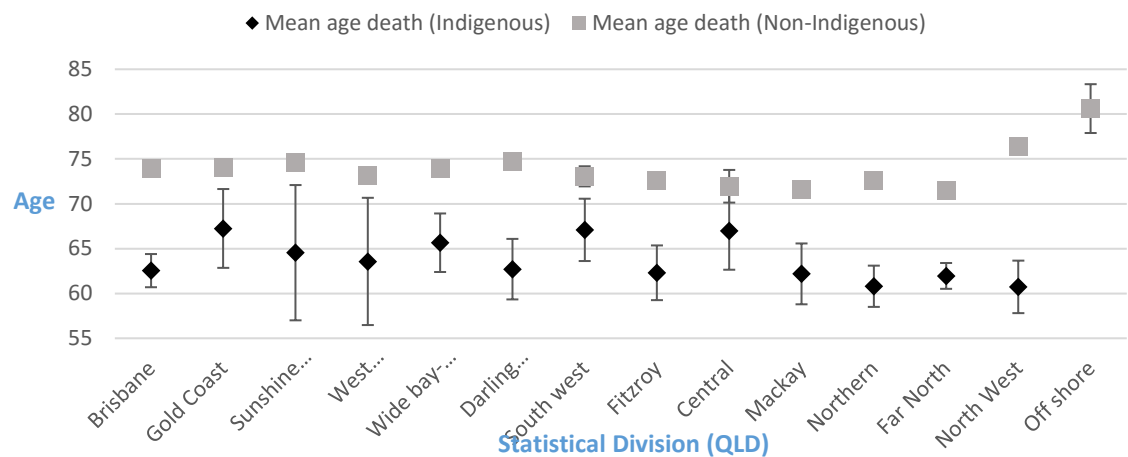
Table 13: Qld cancer 2003-2012 mortality rates by Indigenous status and age group

Age group	Indigenous					Non-Indigenous					
	Person years	Deaths	Rate	CI Lower	CI Upper	Person-years	Deaths	Rate	CI Lower	CI Upper	Ratio
0-9	122.33	6	49.05	22.03	109.17	2485.07	124	49.9	41.84	59.5	0.98
10-19	183.42	7	38.16	18.19	80.05	2959.5	121	40.89	34.21	48.86	0.93
20-29	224.57	10	44.53	23.96	82.76	8468.34	249	29.4	25.97	33.29	1.51
30-39	490.24	49	99.95	75.54	132.25	20416.65	647	31.69	29.34	34.23	3.15
40-49	1077.66	135	125.27	105.83	148.29	47478.15	2478	52.19	50.18	54.29	2.40
50-59	1708.59	316	184.95	165.64	206.51	100575.23	6984	69.44	67.83	71.09	2.66
60-69	1549.52	340	219.42	197.3	244.03	157668.83	14267	90.49	89.01	91.98	2.42
70-79	908.2	269	296.19	262.83	333.79	137963.92	19650	142.43	140.45	144.43	2.08
80-89	289.26	96	331.89	271.71	405.38	76604.37	20115	262.58	258.98	266.24	1.26
90-99	27.01	16	592.34	362.88	966.87	10895.3	4856	445.7	433.34	458.41	1.33
100+						135.51	93	686.28	560.06	840.95	
Total		1244					69584				

Death rates from cancer in the 20-29 age group, is about 1.5 times that of the non-Indigenous population. From the 30-39 age group the rate ratio increases substantially to over 3 times that of non-Indigenous people compared to non-Indigenous Queenslanders in the same age group.

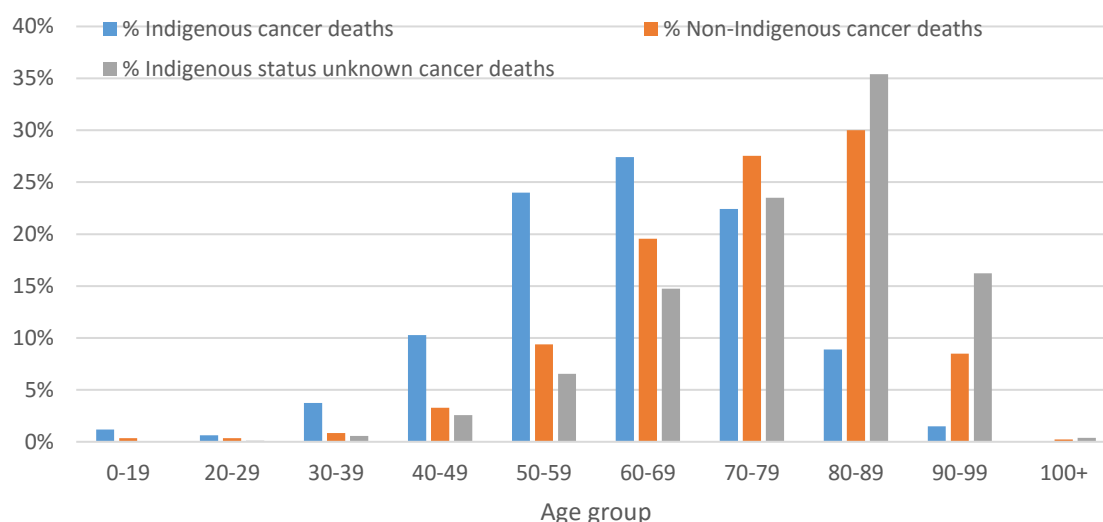
Even in the age groups: 40-49, 50-59, and 60-69 the death rate for Indigenous people is about 2.5 times that of non-Indigenous people in Qld. In the 70-79 age group the death rate is still 2 times that of Indigenous people compared to non-Indigenous people (Table 13). The overall rate of all cancer deaths in the QLD Indigenous population 2003-2012 was 189 per 1,000 person years compared to the non-Indigenous population rate of 123 per 1,000 person years.

Figure 27: Mean age at death Indigenous compared to non-Indigenous by Queensland Statistical Division (SD)



Indigenous and Torres Strait Island peoples in the Queensland overall die at an earlier age than Non-Indigenous people. Generally those from more rural and remoter areas (Indigenous and Non-Indigenous will die at an earlier age than their metropolitan counterparts. The North West and North statistical divisions have the poorest mean age of death at around 61 years (Figure 27).

Figure 28: Cancer mortality by Indigenous status and age group



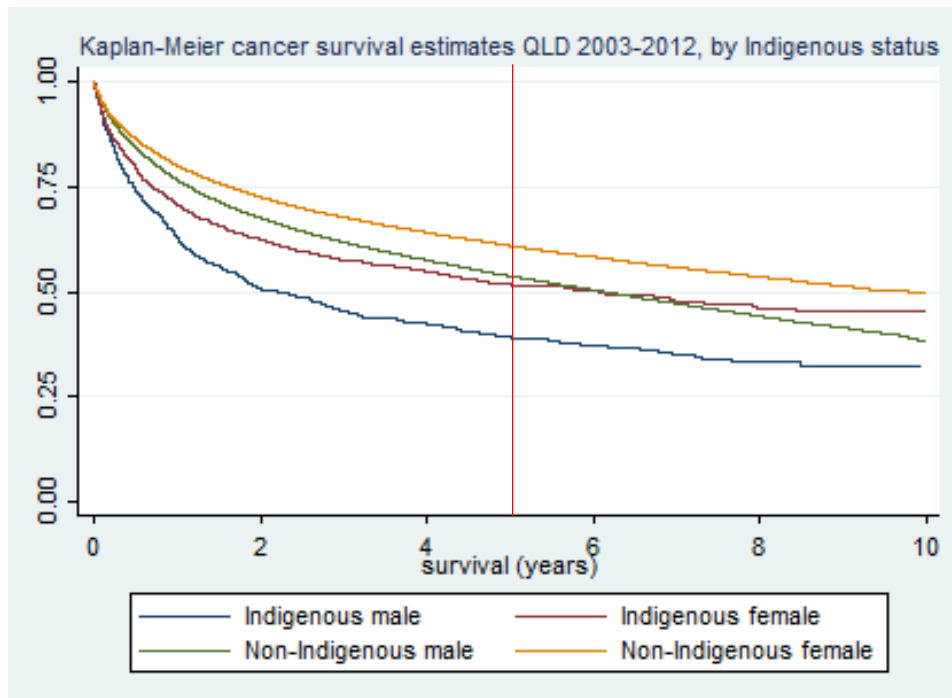
Cancer deaths for Indigenous people in Qld are much higher than non-Indigenous across all age groups. The rate of cancer death is around 1.5 times that of the non-Indigenous population of Qld in the 20-29 year age group. Between 30-40 years death from cancer for Indigenous peoples is just over 3 times the rate of non-Indigenous Queenslanders.

In the 50-59 age group 24% die compared to 9% of the non-Indigenous people in Queensland. In the 60-69 age group 7% more Indigenous peoples die than their non-Indigenous counterparts (27% vs. 20%) respectively. From the 70-79 age group to 80-89 age group Indigenous deaths drop considerably from around 23% to 9% indicative of the small number of Indigenous peoples aged over 70 years (*Figure 28*).

4.6.3 Cancer survival

I examined crude survival rates at the 5 year point. The results show that around 32% of Indigenous males survive past 5 years after diagnosis. About 50% of Indigenous females and non-Indigenous males survive past 5 years after diagnosis and Non-Indigenous women have the best 5 year survival with almost 65% alive after diagnosis (*Figure 29*).

Figure 29: Kaplan-Meier cancer survival estimates QLD 2003-2012, by Indigenous status



Part 2: Experiences of the Indigenous people with cancer or their experience with a family's members cancer diagnosis and treatment in the Burdekin region of QLD

In this section I present the results of interviews with 14 people that respondents describe the experience of cancer diagnosis (sometimes as told by another family member) and then treatment.

4.7.1 Experience of cancer diagnosis

Interviewees (57%, n=8/14) spoke of being 'told' that they had cancer by a doctor and in some cases used this as a confirmatory way of informing family members of their diagnosis:

*'after they did a couple of tests and they found out, then she called us all together and **told** us what it was and that she had cancer' (No.3)*

The word 'doctor' was in relation to who was undertaking investigations, confirming the diagnosis and informing the person about the final cancer diagnosis:

*'So then we decided to go to another **doctor** in the same area, he sent her straight to Townsville to have ultrasounds done'.
(No. 11)*

*'But when the **doctor** did the ultrasound he said, "Yeah, its cancer" and when they rang back with the results, it was' (No.6)*

Being 'diagnosed' and 'told' also related to post treatment and preparing for death:

*'Because 2013 I was **diagnosed** with five spots on my lungs'
(No.2)*

*'He called me into an office and **told** me that we had to prepare now, there is no cure, no more now. He's got six months to live' (No.4)*

The 2nd most common word extracted from the data was 'sick' (n=6). The experience of being 'sick' related to pre diagnosis of cancer and what prompted people to seek medical treatment or advice:

*'She was just nauseous all the time, feeling **sick** all the time and then they had the MRI done and that's when they picked up all the spots in her liver' (No.9)*

4.7.2. Experiences of cancer treatment

'Treatment', 'cancer' and 'chemo' were terms used by 43% of interviewees in relation to questions asked about their treatment or the treatment received by their family members. Five (36%) said the treatments made them very 'sick', and two (2/14, 14%) ceased treatment altogether. Two (14%) had treatments at early stages of their cancers. Nine people (64%) interviewed stated that their family member were too late to receive any form of treatment. Three (21%) of the cancer survivors gave interviews however, one passed away in 2016. All persons interviewed had minimal care (2/14) from outside of their immediate families – with (14%) receiving intermittent transport assistance from an Indigenous community organization:

*'I suppose you try and prepare as much as you can in anticipation, but nothing prepares you for **chemo**, I tell you that'. (No. 2)*

*'1997 I had **chemo**therapy and I had radiation for six weeks after. And then 2008 I only had **chemo**, but I was supposed to have six and I only had four because the **chemo** alone I felt would have killed me'. (No. 4)*

*'He had two **chemo** treatments. Yeah and then they told him that he was going to wait for? ... what's the word? ... when you tell the people where they are going to wait until they die' (No. 8)*

*'She was having **chemo**. She didn't have any radiation, just **chemo**'.(No. 15).*

*'Chemo and a bit of radiation. A bit of radiation then I think she said enough. She was very sick with the **chemo**. She stopped the **chemo**, and came home'. (No.16)*

*'Yeah whilst she was in hospital she was going through all that **chemo** treatment. Three or four months she was having that treatment, going through that'. (No. 18)*

*'We didn't even get **treatment**. They said it was too far gone. They sent her home to die with us'. (No.9)*

*'She had no **treatment**'. (No.13)*

*'They kept her in. She didn't stick to the **treatment** because it made her sick and just too far. When she (sic) getting the **treatment** it reduced it, but when it stopped the mass just got bigger and bigger'. (No. 16)*

*'No, she didn't receive **treatment** until she went to Townsville. She had six treatments and she could only do four because it was making her too sick'. (No.17)*

The common experiences of treatment focused on the unpleasant physical after-effects of treatment and the reluctance of people to continue cancer treatment, or it was too late for treatment:

'And then 2008 I only had chemo, but I was supposed to have six and I only had four because the chemo alone I felt would have killed me ...'(No.2)

*'My mum had bowel **cancer** and she was treated at the Townsville Hospital. She was losing weight and had a lot of pain in the bowel area and...It was a very aggressive **cancer** like they were talking about chemo, but a week later when she went back for them to sort out something for her chemo, they said it was too late.' (No.7)*

The other most common word extracted from the transcripts in terms of cancer experiences was 'cancer' (n=9).

*'the oncologist spoke to me about having chemo, and I said no way I was going to have chemo. I just kept taking my **cancer tablets**' (No.2)*

4.7.3. Diagnosis journey

Overwhelmingly the story of diagnosis was of frustration about knowing that something was wrong, delays for treatment and of limited communication between the medical profession and clients:

*'I just don't know how they never picked it up because she used to go have top and bottoms done regularly. She'd have it every six months. Yes. Because she's had **cancer** before. She had cervical **cancer**. They gave her a complete hysterectomy. I think she was about 37 years of age when that happened, and I don't know how they missed it? ... I don't know how they missed it?' (No. 7)*

Delays between tests and treatment:

*'They didn't treat him early when he had that little spot. If they had given him the right medicine when the doctor told him he had a little spot there, but they were waiting for **tests** and they waited too long for his **tests**. Nearly a year.'* (No. 4)

*'He thought it was the flu and then they kept saying its pneumonia, but nobody done any **tests**. I said to mum, because mum had been going with him and making appointments for him and he'd come out with the same thing; it's a cold or it's pneumonia. It was a good four months before I went up with him to say what **tests** have you done?' (No. 14)*

Communication:

*'They'd done some blood **tests** and they said that she had a fatty liver and she was still having pains in her stomach. No one had actually mentioned to her really that it was cancer too until she went to a chemist to pick up some painkillers and the chemist guy said to her because he knew her, "... we only give*

these tablets to people who have got cancer and have you been diagnosed" and she said "oh no, I just have terrible pains in my stomach.' (No. 11)

4.7.4. Contributing factors to cancer diagnosis

The most common words extracted from the data in terms of cancer in the area were 'water' (n=14, 5/14 respondents), and 'cancer' (n=12, 7/14 respondents). People's experiences of working in the sugar cane industry and their subsequent exposure to chemicals were perceived as related to cancer diagnosis, as was water runoff associated with the agricultural industry:

*'I mean I worked out picking vegies and they sprayed so I didn't know if it was that or the **water**. From that time on I started drinking filtered **water**.' (No. 8)*

*'I believe that the **water** here in the Burdekin may be contaminated with cane fertiliser runoff maybe getting into the **water**. I know of families from out of town that come to Ayr, they tell their families, "Don't drink the **water**. Buy bottled **water** if you're coming here to Ayr.' (No.7)*

Problems with water in the region appear to have been reinforced by commentary by medical staff and others in the area:

*'I suspected as well that the **water** was an issue in the Burdekin because of the spraying of the sugar cane. So some doctors even commented on that too; so that was back in 1990.' (No. 9)*

*'Well I'm only going by what doctors said then too and I agree with the doctors that it was something like chemicals being sprayed. Maybe releasing a chemical there, settling in the **water** or whatever, however it poisoned...' (No.10)*

'I did hear that there was something in the Burdekin. Over in Home Hill they said there was a whole street full of people just with cancer, like there was something wrong with something around there. I don't know whether they thought it was the

water or what. The **water** has gone down because of no rain.
The **water** table has gone down, unclear **water** and that...' (No.
13)

4.7 Discussion

The *Cancer in Aboriginal and Torres Strait Islander People in Queensland 1997-2006 Incidence and Mortality* study reported 955 Indigenous deaths (495 men and 460 women) from cancer in the period 1997-2006 (Moore et al., 2010b)..

In this current study QCR data 2003-2012 there were 209, 725 cancer notifications recorded. Indigenous peoples although around 4.2% of the Queensland population (Queensland Government, 2013), only accounted for 1.3% (n=2628) of cancer notifications in the State during this period. Indigenous deaths have increased, but so has the Indigenous population of Qld.

In the same period (2003-2012), there were 28, 781 deaths in the State of which Indigenous status is unknown – 60% male (n=17, 350) and 40% female (n=11,451). The list of Australian cancer databases indicates jurisdictions and the rate of missing data for Indigenous status (*Table 14*).

Table 14: Availability of cancer data by Indigenous status and jurisdiction

Data Source	Measure	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	^a
Australian Cancer Database (2009 version, reporting years 2004-2008)	Incidence	✓	X	✓	✓	X	X	X	✓	12%
National Mortality Database (reporting 2007-2011)	Mortality	✓	X	✓	✓	✓	X	X	✓	0.08
National Hospital Morbidity Database ^(b) (2006-07 to 2010-2011 financial years)	Hospitalisation	✓	✓	✓	✓	✓	X	X	✓	11%
BreastScreen Australia (c) (2years 2010-2011)	Breast screening	✓	✓	✓	✓	✓	✓	✓	✓	n.a.
National Bowel Cancer Screening Program ^(c) (July 2011 and June 2012)	Bowel screening	✓	✓	✓	✓	✓	✓	✓	✓	n.a.
National Cervical Screening Program	Cervical screening	X	X	X	X	X	X	X	X	n.a.

(a) Missing data refers to the percent of records with unknown Indigenous data

(b) The Northern Territory data by Indigenous status considered acceptable for analysis purposes are restricted to public hospitals only

(c) Information on the BreastScreen Australia and National Bowel Cancer Screening Program require people to self-report and therefore some

Aboriginal and Torres Strait Islander people may choose to not identify.

Source: AIHW Australian Cancer Database 2009, AIHW National Mortality Database, AIHW National Hospital Morbidity Database, AIHW 2012e and AIHW 2013d and AIHW 2013f.

This unknown Indigenous status severely impedes correct validation of Indigenous incidence, mortality and survival data in Qld.

A Queensland study reported five year cancer survival (all sites combined) was considerably lower for Indigenous (50.3%) than non-Indigenous people (61.9%) (Cramb, Garvey, Valery, Williamson, & Baade, 2012).

Several Australian jurisdictions report cancer rates are greater for Indigenous people than other Australians for all cancers combined and for other numerous cancer sites. The increase in Indigenous mortality rates are partially due to higher incidence rates for some (but not all cancer sites) and partially due to lower survival rates for many cancer sites (Condon et al., 2014).

The Condon et al study validated findings from another study that analysed data on survival trends from the Queensland Cancer Registry and found that age-standardised incidence rates for female breast, colorectal and prostate cancers among Indigenous people had increased between 1991 and 2012 (Baade et al., 2016; Condon et al., 2014; Roder & Buckley, 2016).

European colonisation is a routine and central underlying determinant of Indigenous health. Indigenous peoples of Australia share the experience of being marginal populations in economically thriving populations.

‘The quality of Indigenous data that informs mortality statistics are similarly connected to these distal processes which began with colonisation’ (Freemantle et al., 2014).

While there have been improvements in survival outcomes for Indigenous peoples diagnosed with cancer, there has been minimal reduction in the survival inequalities compared to non-Indigenous cancer survival.

Improvements to cancer care for Indigenous peoples requires timely access to medically effective and culturally acceptable diagnostic, treatment and support services need to be provided within the first year of diagnosis (Baade et al., 2016).

Attempts to reduce the disparity in cancer outcomes for Indigenous peoples and their families include national policy initiatives and community awareness programs. However a better understanding at a finer population level of what is driving the poorer survival and avoidable deaths faced by Indigenous cancer patients will provide evidence to direct efforts for early diagnosis and care, and unnecessary Indigenous cancer deaths (Baade et al., 2016).

Indigenous people in Queensland have lower overall incidence rates than non-Indigenous people, although the rates are higher for some of the more fatal cancer types (Baade et al., 2016). Many studies have documented lower Indigenous survival once diagnosed however, varying completeness and misclassification of Indigenous status across organisational and governmental administrative data collections over time have restricted researchers ability to investigate chronological changes in the level of the survival inequality faced by Indigenous peoples diagnosed with cancer compared to non-Indigenous Australians (Baade et al., 2016).

Notifications

This study found the most common cancer notifications for all cancers among the Indigenous population of Queensland 2003-2012 were for:

- cancers of the digestive system (around 25% of all cancers vs. 22% non-Indigenous)
- cancers of the respiratory system (around 20% of all cancers vs. 11% non-Indigenous)
- breast cancer (around 14% of all cancers vs. 14% non-Indigenous) and
- female genital system cancers (around 7.7% vs. 3.1% non-Indigenous)
- male genital system cancers (around 4.8% of all cancers vs. 8.8% non-Indigenous).

On a national level the most commonly diagnosed cancers for Indigenous peoples were cancers of the lung (603 cases), breast in females (438), bowel (348), prostate (291) and unknown primary site (167) (Australian Institute of Health and Welfare & Cancer Australia 2013).

According to the Australian Cancer Database (ACD) report, Indigenous people were more likely to be diagnosed with all cancers at a younger age than non-Indigenous Australians, results reflected in this analysis. However, the ACD age-specific incidence rates for all cancers combined increased with age for both groups and were higher for Indigenous people than non-Indigenous in all age groups except for those aged less than 45 (Australian Institute of Health and Welfare & Cancer Australia 2013).

Mortality

The rate of cancer death in the Indigenous population of Queensland 2003-2012 was 189 per 1,000 person years compared to the non-Indigenous rate of 123 per 1,000 person years.

In this study, the most common cause of all cancer deaths for Indigenous peoples was respiratory system cancer. Respiratory system cancers were 5% higher for Indigenous people than non-Indigenous people of Queensland (26.9% vs. 21.5%). Indigenous people are 1.5 times more likely to die than non-Indigenous people in the 20-30 age group, but overall were 2.2 times more likely to die from cancer than non-Indigenous people in the State. This result likely reflects the much higher level of daily smoking within the population (Australian Institute of Health and Welfare, 2015).

From an early age the rate of cancer death for Indigenous peoples is about 1.5 times that of the non-Indigenous population of Queensland. The largest disparity includes cancer notifications and deaths observed in the 30-40 year age group where death from cancer for Indigenous peoples is just over 3 times the rate of non-Indigenous people.

National statistics show that between 2007-2011, the most common causes of cancer death among Indigenous peoples were cancers of the lung (549 deaths), liver (145), breast in females (140), unknown primary site (131) and bowel (118) (Australian Institute of Health and Welfare & Cancer Australia 2013). These results are consistent with these national data.

Information in the National Mortality Database (NMD) 2007-2011 in terms of Indigenous status is only considered to be of sufficient completeness for reporting for New South Wales, Queensland, Western Australia, South Australia and the Northern Territory (Australian Institute of Health and Welfare & Cancer Australia 2013). With almost 16% of cancer notification having unknown Indigenous status in the QCR dataset, questions about reliability of these data must be asked.

Survival

Reports sourced from the Australian Cancer Database (ACD) and the National Death Index (NDI) give a 5 year crude survival rate for Indigenous people of 40% for all cancers combined, which is significantly lower for non-Indigenous

Chapter 4

(52%). The comparative 5 year crude survival rate is lower for Indigenous people:

- for all age groups,
- for both males and females,
- for living in remote areas, and
- for lung cancer (7% vs 11%), breast cancer in females (70% compared with 81%), bowel cancer (47% compared with 53%), prostate cancer (63% compared with 72%) and cervical cancer (51% compared with 67%) (Australian Institute of Health and Welfare & Cancer Australia 2013).

Five-year survival rates observed in this analysis for Indigenous (32% male and 50% female) were consistent with the National 5 year crude survival rate of 40% for all cancers combined.

The results of a 2016 study suggests that the survival disadvantage faced by Indigenous people after diagnosis of cancer was decreasing, but the decrease in the inequality was not statistically significant, which means around one in five cancer-related deaths among Indigenous peoples is more than likely attributed to Indigenous survival disadvantage. Indigenous peoples diagnosed with cancer still face a poorer survival outlook than non-Indigenous Australians, particularly in the first year after diagnosis (Baade et al., 2016).

[Experiences of cancer diagnosis and treatment](#)

Qualitative research concerning cancer diagnosis and treatment for Indigenous people has found that many Indigenous peoples view cancer as an always terminal illness or a 'death sentence'. Fear of cancer for Indigenous people can also mean that people may prefer to 'not know' (Thompson, Shahid, Greville, & Bessarab, 2011).

In this study some participants did not perceive the seriousness of their symptoms, stating that they felt 'a sharp pain', 'thought it was muscle strain' or wonder why they have a 'loss of appetite' or are 'losing weight'.

Some participants reacted urgently and others felt they had more pressing duties in their day to day lives i.e. work, children etc. One female participant although unable to digest food and experiencing stomach pain put her doctor's appointment off for a few months, and did not consider her symptoms serious

enough to take time off work and/or her community calendar responsibilities to present straight away.

Communication in terms of medical language was confusing and people wanted more laymen's language used. They also wanted time to take in the full story of what was wrong and why. Another aspect of communication or miscommunication especially in the earlier experiences of diagnosis and treatment of family members was either 'shame' or a 'secretiveness' of their diagnosis and/or the use of bush medicine. Many of the women worked full time and the majority were diagnosed alone, and had treatment on their own. In terms of bush medicine, one study found a statistically significant relationship between the use of bush medicine complementary and complementary medicine and report delay in seeking assistance from clinical medicine ($p < 0.001$) (Broom et al., 2009).

Most of the women had negative experiences with chemotherapy treatment and some just stopped their treatment because it made them so sick - which likely may explain overall poorer survival outcomes.

In contrast the few who did have hospital/nurse support in treatment reported positive experiences, and all participants had extended family support in taking care of their own families.

Strength and limitations

A major strength of this study is that QCR carries out systematic and legislated reporting of cancers in Queensland, and data collection of diagnosis and treatment. Although the study aim was about cancer diagnosis, treatment and care, a limitation of the study was that the interview questions did not ask cancer sufferers/carers of their smoking and/or alcohol status. Nor does QCR record information of smoking and/or alcohol status of cancer patients.

A major concern and potential limitation of the study is the increasing unknown Indigenous status in QCR data, which is approaching 16% of all notifications.

Another strength of this study is the inclusion of a qualitative component in an attempt to examine the client and family journey and the cancer diagnosis and treatment journey. It appears that people still find it hard to speak about their cancer diagnosis and treatment journey, but those who did have provided valuable insights into fears, communication and the often mentioned tensions

between symptomology of both reasons for seeking help and adverse symptoms of treatment itself.

4.8 Implications for public health

Inaccuracies in the identification of Indigenous status and the collection of and access to important statistics data undermine the implementation and execution of evidence based public health initiatives (for example, Closing the Gap initiative) and policies in ending avoidable cancer deaths of Indigenous peoples.

Finer geographic analysis of cancer rates is required to ensure that perceived higher cancer rates can be monitored and compared.

Understanding the client cancer journey provides valuable insights into why people may delay seeking help, how communication occurs between medical professionals and Indigenous people and how people navigate the tensions between fatalism of a cancer diagnosis and the potential of survival.

4.9 Conclusion

Cancer is a significant contributor to Indigenous morbidity and mortality and rates nationally are increasing. Finer geographic analysis is required to prioritise areas for action and or prevention activity.

For the aim of this paper I was unable to cannot say that rates of cancer death are higher in the Burdekin region. Indications are that they are not. Inaccurate data may be contributing to perceptions of higher cancer rates (notifications) due to the uncertainty of the data. It might also be that because there is no community feedback on Indigenous cancer in Queensland (other than a few journal articles), these perceptions can persist.

Rates of mortality and survival and vastly different and public health approaches to smoking cessation will in the longer term reduce disparities across a number of cancers.

4.10 Recommendations

That:

- Indigenous identification is routinely monitored to assess reliability

- That more routine training is provided to ensure the integrity of the Indigenous status variable is enhanced;
- The reporting of cancer incidence and mortality by geographic region and Indigenous status is conducted on a routine basis for QLD
- That a public education campaigns around tobacco use continue to inform Indigenous people how to reduce their chances of developing cancers
- Undertake national data linkage to improve recording of Indigenous status necessary to provide a comprehensive evidence base for informing improvement of all services (Roder & Buckley, 2016).
- Ensure all jurisdictions have the same documentation/forms and processes across notification systems.
- Investigate data linkage of Medicare to jurisdictional health sector data as a method of decreasing disparities in the recording of Aboriginal and Torres Strait Islander status in datasets.

4.11 References

- American Phytopathological Society. (2016). Syllabus: Diseases Pests, and Nonnutrient Disorders of Sugarcane, . Retrieved 13 September, 2016, from APS <http://www.apsnet.org/publications/imageresources/Pages/SyllabusSugarcane.aspx>
- Australian Human Rights Commission. (2016). Close the Gap: Indigenous Health Campaign, . from Australian Government, <http://www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/projects/close-gap-indigenous-health>
- Baade, P. D., Dasgupta, P., Dickman, P. W., Cramb, S., Williamson, J. D., Condon, J. R., & Garvey, G. (2016). Quantifying the changes in survival inequality for Indigenous people diagnosed with cancer in Queensland, Australia. *Cancer Epidemiology*, 43, 1-8. doi:<http://dx.doi.org/10.1016/j.canep.2016.05.002>
- Bernardes, C., Whop, L., Garvey, G., & Valery, P. (2012). Health service utilization by indigenous cancer patients in Queensland: a descriptive study. *International Journal for Equity in Health*, 11(1), 57.
- Bernardes, C. M., Whop, L. J., Garvey, G., & Valery, P. C. (2012). Health service utilization by indigenous cancer patients in Queensland: a descriptive study. *Int J Equity Health*, 11, 57. doi:10.1186/1475-9276-11-57
- Bristow, K. L., Charlesworth, P. B., McMahon, G. A., Arunakumaren, J., Bajracharya, K., Ham, G., . . . Eldridge, S. (2000). *Towards a more integrated approach to water management in the Burdekin Delta irrigation area*,. Paper presented at the Australian Society of Sugar Cane Technology,, Toowoomba, Australia.
- Brodie, J. E., Hicks, W. S., Richards, G. N., & Thomas, F. G. (1984). Residues related to agricultural chemicals in the groundwaters of the Burdekin River Delta, North Queensland. *Environmental Pollution Series B, Chemical and Physical*, 8(3), 187-215. doi:[http://dx.doi.org/10.1016/0143-148X\(84\)90017-X](http://dx.doi.org/10.1016/0143-148X(84)90017-X)
- Brown, A., Roder, D., Yerrell, P., Cargo, M., Reilly, R., Banham, D., . . . the CanDAD Aboriginal Community Reference Group and other CanDAD Investigators. (2016). Cancer Data and Aboriginal Disparities Project (CanDAD) – an overdue cancer control initiative,. *European Journal of Cancer Care*, 25(2), 208-213. doi:10.1111/ecc.12466
- Budd, R. (2016). Budd Photography,. Retrieved from <http://www.buddphotography.com.au/burdekin-falls-dam/>
- Centers for Disease Control and Prevention. (2016). Uranium and Your Health, . from CDC <https://ephtracking.cdc.gov/showUraniumHealth>
- Centers for Disease Control and Prevention, E. H. (2009). *Arsenic Factsheet*,. Atlanta.
- Centre for Disease Control and Prevention. (2016). *Community Water, Atrazine and Your Health*,. Atlanta: CDC Retrieved from <https://ephtracking.cdc.gov/showAtrazineHealth>.

- Chong, A., & Roder, D. (2010). Exploring differences in survival from cancer among Indigenous and non-Indigenous Australians: implications for health service delivery and research. *Asian Pac J Cancer Prev*, 11(4), 953-961.
- Commonwealth of Australia. (2005). *Forty-First Parliament, Parliamentary Debates, House of Representatives, Official Hansard*,. Canberra: Commonwealth of Australia, Retrieved from <https://www.google.com.au/webhp?sourceid=chrome-instant&ion=1&espv=2&ie=UTF-8#q=House+of+Representatives+Official+Hansard+No.+18%2C+2005+Tuesday%2C+1+November+2005+FORTY-FIRST+PARLIAMENT+FIRST+SESSION%E2%80%94FOURTH+PERIOD>.
- Commonwealth of Australia. (2015). Burdekin, Physical information, . from BOM https://www.google.com.au/search?q=map+of+mainland+australia+burdekin+region&espv=2&biw=1680&bih=965&source=lnms&tbm=isch&sa=X&ved=0ahUKEwiJtJ_x3uXOAhWFjpQKHWh1C30Q_AUIBygC&dpr=1#tbm=isch&tbs=rimg%3ACU0HSQc8G_1V7Ijhm7wDBA4VjCDIdQXFcFOZWEUmb3YlmbR2SfQotxNqAnaUi-XtwbK7coBm64aYB9FfZnfDeevUMmyoSCWbvAMEDhWMIEQiRCEodj6C1KhIJMh1BcVwU5IYRrge61GFRa24qEgkRSZvdiWZtHREd5Yh2AoVFtyoSCZJ9Ci3E2oCdEf vJYYGzlorrKhIJpSL5e3BsrtwRrdE3jCN-d50qEgmgGbrhpgH0VxHEdk1LgEr5QioSCdmd8N569QybEcC0IEBCDn8&q=map%20of%20burdekin%20region&imgsrc=xbgNBqpNnCL_0M%3A
- Condon, J. R., Zhang, X., Baade, P., Griffiths, K., Cunningham, J., Roder, D. M., . . . Threlfall, T. (2014). Cancer survival for Aboriginal and Torres Strait Islander Australians: a national study of survival rates and excess mortality. *Population Health Metrics*, 12(1), 1.
- Cook, P. G., Stieglitz, T., & Clark, J. (2004). *Groundwater Discharge from the Burdekin Floodplain Aquifer, North Queensland*, . Retrieved from <https://publications.csiro.au/rpr/download?pid=procite:a1c8b068-52a8-4771-95f8-1fe8acc2eb2&dsid=DS1>
- Cramb, S. M., Garvey, G., Valery, P. C., Williamson, J. D., & Baade, P. D. (2012). The first year counts: cancer survival among Indigenous and non-Indigenous Queenslanders, 1997–2006,. *Medical Journal of Australia*, 196(4), 270-274.
- Cunningham, J., Rumbold, A. R., Zhang, X., & Condon, J. R. (2008). Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia. *The Lancet Oncology*, 9(6), 585-595. doi:[http://dx.doi.org/10.1016/S1470-2045\(08\)70150-5](http://dx.doi.org/10.1016/S1470-2045(08)70150-5)
- Department of Health. (2010). Monitoring the incidence and causes of diseases potentially transmitted by food in Australia: Annual report of the OzFoodNet network, 2009, . Retrieved 23 January 2016, from Australian Government,
- Fanon, F. (1963). *The Wretched of the Earth*, . France: Grove Press,.
- Freemantle, J., Ring, I., Arambula Solomon, T. G., Gachupin, F. C., Smylie, J., Cutler, T. L., & Waldon, J. A. (2014). Indigenous Mortality (Revealed): The Invisible Illuminated. *American Journal of Public Health*, 105(4), 644-652. doi:10.2105/AJPH.2014.301994

- Freemantle, J., Ring, I., Solomon, T. G. A., Gachupin, F. C., Smylie, J., Cutler, T. L., & Waldon, J. A. (2015). Indigenous Mortality (Revealed): The Invisible Illuminated,. *American Journal of Public Health*, 105(4), 644-652.
- Garside, A. L. (2003). *Sustainable sugarcane farming systems: Developments to date*, . Paper presented at the ABARE Outlook Conference Notes,.
- Gibberd, A., Supramaniam, R., Dillon, A., Armstrong, B. K., & O'Connell, D. L. (2015). Are Aboriginal people more likely to be diagnosed with more advanced cancer? *Med J Aust.*, 202. doi:10.5694/mja14.00701
- Klok, J., & Ham, G. (2004). *A pilot study into pesticides and the Burdekin delta aquifer system*,. Paper presented at the PROCEEDINGS-AUSTRALIAN SOCIETY OF SUGAR CANE TECHNOLOGISTS,, Toowoomba, Australia.
- Moore, S. P., O'Rourke, P. K., Mallitt, K.-A., Garvey, G., Green, A. C., Coory, M. D., & Valery, P. C. (2010a). Cancer incidence and mortality in Indigenous Australians in Queensland, 1997-2006. *Medical Journal of Australia*, 193(10), 590.
- Moore, S. P., O'rourke, P. K., Mallitt, K.-A., Garvey, G., Green, A. C., Coory, M. D., & Valery, P. C. (2010b). Cancer incidence and mortality in Indigenous Australians in Queensland, 1997-2006,. *Medical Journal of Australia*, 193(10).
- Mortimer, M. R. (2000). Pesticide and Trace Metal Concentrations in Queensland Estuarine Crabs. *Marine Pollution Bulletin*, 41(7–12), 359-366.
doi:[http://dx.doi.org/10.1016/S0025-326X\(00\)00136-3](http://dx.doi.org/10.1016/S0025-326X(00)00136-3)
- O'Shea, J. (1967). Replenishment of underground water supplies-Burdekin Delta, Queensland. *Civil Eng Trans, IE Aust.* CE9(1), 117-126.
- Queensland Government. (2013). *Population, Aboriginal and Torres Strait Islander Queenslanders, 30 June 2011*,. Brisbane: Qld Government, Retrieved from <http://www.qgso.qld.gov.au/products/reports/pop-atsi-qld-2011/pop-atsi-qld-2011.pdf>.
- Queensland Government. (2016a). Queensland Health, South West Hospital and Health Service,. Retrieved from <https://www.health.qld.gov.au/southwest/>
- Queensland Government. (2016b). *Queensland Regional Profiles, Resident Profile - people who live in the region, Burdekin State Electoral District (SED)*,. Brisbane: Queensland Treasury Retrieved from <http://www.qgso.qld.gov.au>.
- Queensland Government. (2016c). *Reef protection regulations, How does this impact cane farmers?*,. Brisbane: Qld Government, Retrieved from <http://www.qld.gov.au/environment/agriculture/sustainable-farming/cane-farmers/>.
- Queensland Government. (2016d). *Reef protection regulations, Managing agricultural chemicals*,. Brisbane: Qld Government, Retrieved from <https://www.qld.gov.au/environment/agriculture/sustainable-farming/chemicals/>.
- Queensland Government. (2016e). Visitor Information, About the Area, . from Burdekin Shire Council, <http://www.burdekin.qld.gov.au/community/visitor-information/about-the-area/>

- Rametta, S., Grosso, G., Galvano, F., Mistretta, A., Marventano, S., Nolfo, F., . . . Biondi, A. (2013). Social disparities, health risk behaviors, and cancer. *BMC Surgery*, 13, S17. doi:<http://dx.doi.org/10.1186/1471-2482-13-S2-S17>
- Ricaud, C., Egan, B., Gillaspie Jnr, A., & Hughes, C. (1989). *Diseases of Sugarcane, Major Diseases*, : Elsevier Publishing Company,.
- Ricaud, C., Egan, B., Gillaspie Jr, A., & Huges, C. (Eds.). (1989). *Diseases of Sugarcane: Major Diseases*. Amsterdam: Elsevier Publishers B. V.
- Ring, I. T., Dixon, T., Lovett, R. W., & Al-Yaman, F. (2016). Are Indigenous mortality gaps closing: how to tell, and when? *Medical Journal of Australia*, 205(1).
- Roder, D. M., & Buckley, E. (2016). High quality data are the key to understanding inequalities in cancer outcomes for Aboriginal and Torres Strait Islander Australians,. *Medical Journal of Australia*, 205(10), 451-452.
- Shahid, S., Teng, T.-H. K., Bessarab, D., Aoun, S., Baxi, S., & Thompson, S. C. (2016). Factors contributing to delayed diagnosis of cancer among Aboriginal people in Australia: a qualitative study. *BMJ Open*, 6(6). doi:10.1136/bmjopen-2015-010909
- Smith, M., Poggio, M. J., Thompson, M., & Collier, A. (2014). *The Economics of Pesticide Management Practices on Sugarcane Farms: Final Synthesis Report*, . Retrieved from Brisbane:
- Thompson, S., Shahid, S., Greville, H. S., & Bessarab, D. (2011). "A whispered sort of stuff" A community report on research round Aboriginal people's beliefs about cancer and experiences of cancer care in Western Australia, . Retrieved from Perth:
- Volker, R., & Stark, K. (1973). *Development of a numerical model of a coastal aquifer subject to recharge*. Paper presented at the Hydrology Symposium, Perth.



A mixed methods study: The truth about 'Burdekin rot'

Leone Malamoo
Master of Philosophy, Applied Epidemiology
National Centre for Epidemiology and Population Health
Research School of Population Health
The Australian National University and
The Australian Institute of Aboriginal and Torres Strait Islander Studies



Presentation Outline

- Background
- Aims
- Methods
- Results
- Discussion and Conclusions



<http://www.burdekin.qld.gov.au/wp/media/2011/06/BurdekinMap.16x9.gif?81eba0>

NIRAKN Conference, Adelaide 2015

Burdekin Rot

Anecdotal reports of 'Burdekin rot' in the Burdekin River region of Queensland are commonplace. However people are not talking about sugarcane top rot. 'Burdekin rot' is commonly used, particularly among the Aboriginal and Torres Strait Islanders of the region, in reference to the perceived higher incidence of cancer among the population.

NIRAKN Conference, Adelaide 2015

Burdekin River



NIRAKN Conference, Adelaide 2015

Aims

- i. To determine whether cancer rates vary between the Aboriginal and Torres Strait Islander population within Queensland; and
- ii. To determine Aboriginal and Torres Strait Islander experiences with cancer diagnosis and treatment in the Burdekin district.

NIRAKN Conference, Adelaide 2015

Method

Quantitative

- QLD cancer registry, 2003-2012 (n=207,137 cancer diagnoses and 71,784 deaths from cancer)
- QLD Cancer deaths by Indigenous status and ages
- Cox regression model (rates of death), controlled for sex
- Survival time after diagnosis by sex

Qualitative

- In-depth interviews (n=14)
- Thematic analysis
 - Experiences of cancer treatment
 - Experiences of exposure

NIRAKN Conference, Adelaide 2015

Preliminary Results

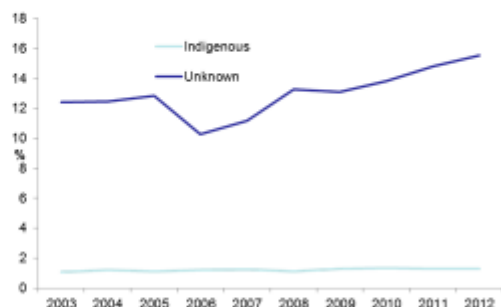
NIRAKN Conference, Adelaide 2015

Preliminary results: rates of cancer diagnosis and missing data 2003-2012

Cancer cases QLD 2003-2012

Indigenous status	n	%
Indigenous	2,748	1.23
Non-Indigenous	192,116	85.71
Unknown	29,275	13.06
Total	224,139	100

Missing Indigenous status by year



NIRAKN Conference, Adelaide 2015

Preliminary results: Cancer death rates QLD

Indigenous Status	person-time	Indigenous Deaths	Rate (per 1,000 person years)	95% CI lower	95% CI upper	Rate Ratio
Indigenous (age groups)						
20 - 30	224.57	10	44.53	23.96	82.76	1.5
30 - 40	490.24	49	99.95	75.54	132.25	3.2
40 - 50	1077.66	135	125.27	105.83	148.29	2.4
50 - 60	1708.59	316	184.95	165.64	206.51	2.7
60 - 70	1549.52	340	219.42	197.30	244.03	2.4
70 - 80	908.20	269	296.19	262.83	333.79	2.1
80 - 90	289.26	96	331.89	271.71	405.38	1.3
90 - 100	27.01	16	592.30	362.88	966.87	1.3

NIRAKN Conference, Adelaide 2015

Preliminary results: rate of death from cancer QLD Cox regression

	RR	P	CI lower	CI upper
Non-Indigenous (reference)	1			
^a Indigenous	2.26	<0.001	2.09	2.35
[*] Indigenous	1.46	<0.001	1.39	1.55

^aunadjusted

^{*}adjusted for sex

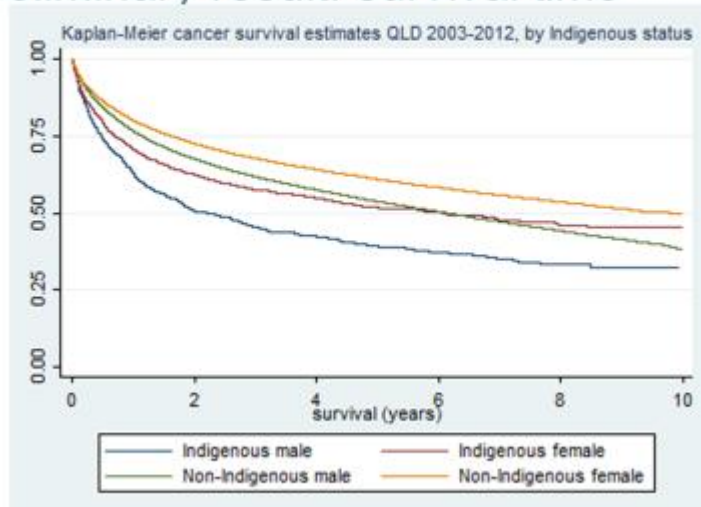
NIRAKN Conference, Adelaide 2015

Preliminary results: rates of cancer per 1000 person years QLD 2003-12

Indigenous status	Deaths	Person years	Rate	Lower	Upper
Indigenous	1181	6.12	192.87	182.17	204.18
Non-Indigenous	63457	507.94	124.93	123.96	125.91
Unknown	914	121.50	7.52	7.05	8.03

NIRAKN Conference, Adelaide 2015

Preliminary result: survival time



NIRAKN Conference, Adelaide 2015

Preliminary results: Experiences of cancer treatment

- People were aware of 'something being not right'
- Stunned at how quickly after diagnosis they had were undertaking treatment;
- Most considered the cancer nurses helpful and informative;
- Many were so focused on treatment that little information was sought about treatment processes;
- High levels of support provided by family; and
- Chemotherapy made people so ill – issues of treatment completion were often reported.

NIRAKN Conference, Adelaide 2015

Many Aboriginal people are “reserved” during their visits to doctors, and are reluctant to admit difficulties with understanding. This reticence could stem from believing that “the doctors know everything”, lack of confidence to ask questions, silence as part of their culture or a learned behaviour from previous encounters within mainstream institutions. Such silence could be easily misinterpreted by health care providers⁽²⁾.

2. (Shahid, Finn, & Thompson, 2009)

NIRAKN Conference, Adelaide 2015

What did participants think caused the cancer?

- Few respondents described ‘Burdekin rot’; and
- Respondents were aware of and mentioned environmental and other factors related to cancer:

“I think it’s the environment. I really think it’s the environment, because we know, you know it’s just natural - it’s just local information you know, that we live in a place where they have cane and that they use the chemicals they put on, it’s got to soak through the ground and run. It has to run off somewhere, so I say the environment and even food. But they say it’s hereditary, it’s because you’re - but nobody’s tested for that. And they - if it was a gene, I don’t know, it’s probably - I just think it’s a combination of stuff. Definitely all the rubbish we eat, and all the spray it to death”⁽³⁾.

3. Quote: SH_01 (Participant)

NIRAKN Conference, Adelaide 2015

Discussion and Conclusions

1. Missing data and reliability of rates
2. Date of death and cancer diagnosis
3. Late cancer diagnoses, treatment
4. Why it's important
5. Policy issue (screening), registry forms?
6. Treatment and survival gaps –
Implications?

NIRAKN Conference, Adelaide 2015

Discussion and Conclusion

In terms of planning and policy improvement, it is vital to expand the use of the available data. Data need to be consistently collected on a systematic basis using nationally agreed data definitions. Indigenous status needs to be purposely recorded in all cancer cytology registries. This information is essential for assessing the efficacy of preventive and screening programs and of clinical practice⁽⁴⁾.

If people are serious about Aboriginal health and CTG - adopt the national guideline identification recommendations nationally - ask the question and record it accurately!

“Are you Aboriginal and/or Torres Strait Islander?”

4. Stumpers S, Thomson N (2009) *Review of cancer among Indigenous peoples*. Australian Indigenous HealthInfoNet.

NIRAKN Conference, Adelaide 2015

GUDJUDA Reference Group Aboriginal Corporation - Home Hill



NIRAKN Conference, Adelaide 2015

Next steps

- Incidence and rates by statistical local area (hot spots)
- Thank you!



NIRAKN Conference, Adelaide 2015

Smoke from sugar cane burn-off at dusk in the Burdekin region



NIRAKN Conference, Adelaide 2015

AIATSIS RESEARCH ETHICS COMMITTEE

ETHICAL CLEARANCE PROPOSAL – AIATSIS RESEARCHERS

The Research Proposal

Background:

Cancer among the Aboriginal and Torres Strait Islander population has become an increasing area of concern in Australia with increasing prevalence and disproportionate mortality compared with other Australians (C. Bernardes, L. Whop, G. Garvey, & P. Valery, 2012; Chong & Roder, 2010; Moore et al., 2010a).

Bacterial red stripe (*Pseudomonas rubrilineans*) is a sugar cane leaf disease first described in Hawaii and later labelled 'red stripe' (C. Ricaud, Egan, Gillaspie Jr, & Huges, 1989). *Pseudomonas rubrilineans* has been associated with the disease referred to in Queensland as 'top rot', 'cane rot' or 'Burdekin rot'. The mode of transmission is airborne where bacteria groups in large masses in the leaf tissues and oozes onto the leaf surface during periods of moist warm weather. The bacteria then readily spread plant to plant even field to field (C. Ricaud et al., 1989).

Anecdotal reports of 'Burdekin rot' in the Burdekin River region of Queensland are commonplace. However people are not talking about sugarcane. 'Burdekin rot' is a euphemism for cancer among patients from the Burdekin. 'Burdekin rot' is commonly used, particularly among the Aboriginal and Torres Strait Islander population of the region, in reference to the perceived higher incidence of cancer among the population.

Moore and colleagues conducted a study in 2010 on cancer incidence and mortality rates for cancers diagnosed among Aboriginal and Torres Strait Islander Australians in Queensland from 1997-2006 - they found that Aboriginal and Torres Strait Islander Queenslanders were 21 per cent less likely to be diagnosed with cancer, but those who were diagnosed were 36 per cent more likely to die.

We know that overall incidence of cancer diagnosis is lower in Queensland, the question arises; is the incidence and mortality reported at the QLD level similar among the Burdekin. There are no currently available regional level reports to understand is the 'Burdekin rot' is truth or myth.

This research will undertake a regional level analysis using existing Queensland Cancer Registry data and report incidence by region and by Indigenous status to answer the research question.

Name of Researchers

1. Leone Malamoo and
2. Dr Ray Lovett

Positions at AIATSIS

1. MAE Student
2. Research Fellow

Title of Research Project

We are requesting an amendment to the title from: The truth about 'Burdekin Rot' to Peoples perspectives of 'Burdekin Rot'.

Aims of Research

Using the Centers for Disease Control and Prevention (CDC) guidelines for investigating clusters of health events (Centers for Disease Control, 1990), this research aims to:

- Ascertain whether cancer (by type) incidence differs between the Aboriginal and Torres Strait Islander population within each Statistical Local Area (SLA) of Queensland. (Part i)
- Understand the cancer processes surrounding diagnosis, treatment and treatment outcomes for people living in the Ayr region of North Queensland with cancer. (Part ii)
- Conduct an evaluation to assess the completeness of recording Aboriginal and Torres Strait Islander status in the Queensland Cancer Registry, to identify the usefulness of collecting this variable and to identify the barriers to recording Aboriginal and Torres Strait Islander status for people diagnosed with cancer in Queensland. (Part iii)

Research Methods and Techniques (Amended)

Part i

We will follow the Centers for Disease Control and Prevention (CDC) guidelines for investigating clusters of health events (Centers for Disease Control, 1990), with the additional reference material specific to investigation of potential cancer clusters (Centers For Disease Control, 2013). See **Appendix 1**.

Under step one of the four step process, an evaluation of the data available is required. This can be through the existing Queensland cancer registry data. We will undertake analysis of the Queensland cancer registry to determine standardised incidence rates (SIR's) by type(s) of cancer, for the period 1982-2012, by QLD region and by Indigenous status. The reference population will be background cancer incidence in the non-Indigenous population.

Part ii

The principal researcher will undertake a qualitative study in the Ayr community to assess and measure the local Aboriginal and Torres Strait Islander communities' knowledge and understanding of the anecdotal Burdekin rot and their experiences with cancer. The principal researcher will develop a small number of questions designed to elicit from participants information about experiences with cancer (**Appendix 2**). The principal researcher will collect the data, and thematically analyse and interpret the data. The results of all (Part i, Part ii, Part iii) of the study will be disseminated to the Ayr community and to other stakeholders such as AIATSIS, the Queensland Cancer Registry and the Australian National University.

Part iii

Using the existing Qld Cancer Registry data, the principal researcher will undertake an evaluation to ascertain the completeness of recording Aboriginal and Torres Strait Islander status for people diagnosed with cancer in Queensland, and determine how useful these data are, the principal researcher will:

- quantify how much missing data there is in the Aboriginal and Torres Strait Islander variable over time for the period 2003 - 2012 by assessing the proportion of notifications with this information missing;
- calculate the proportion of notifications for each year 2003 – 2012 by selected regions;
- use qualitative methods to survey a small number of QCR staff on their perspective of the completeness and usefulness of the Indigenous status variable in the QCR data to gauge what factors they think are important concerning the barriers and enablers of improving the completeness of these data (**Appendix 3**); and
- conduct a literature review to assess the barriers and or challenges to collecting data on Aboriginal and Torres Strait Islander status in health administrative datasets.

Confidentiality and Privacy

In Australia, cancer is a notifiable disease and is the only major disease where an almost complete coverage of incidence data is available. Current legislation requires health institutions in Queensland to notify the Registry about cancer diagnoses and deaths within one month.

The Public Health Act 2005 (Qld) establishes mechanisms for providing health information held by the Queensland Department of Health to approved research projects. We will utilise these procedures and processes in the analysis of the data. In summary the procedure for the research team to ensure confidentiality and privacy:

- Apply to the Chief Executive (Director-General) or delegate for access to the health information held by the department, providing certain criteria, processes

and confidentiality requirements are adhered to by successful applicants.
(Appendix 2)

- Access to and use of this information will only be approved for a specified time period, which must be clearly stated in the application.
- Researchers granted access under 63(2)(j) of the Health Services Act 1991 and S154M of the Health Act 1937 will only have access to the requested data for 2 years post-commencement of the Public Health Act 2005. (i.e. until 16 January 2008) (Section 489) (Note: S63 is now S62F in amended Health Services Act 1991)
- Details of approved applications and their studies will be kept in a register, known as “The Research Register” (the register) held by Queensland Health.
- Access to the register must, by law, be made available to anyone who requests it (S283 (3)).

Ethics and data access

Before access to the registry data is gained, researchers must have approval from a Human Research Ethics Committee (HREC) of their research proposal before applying for access to Queensland health information. Evidence of this approval must be provided in the application to the register. In addition, researchers must consult the data custodians to determine:

- whether the data fields being requested are available; and
- whether the data being requested can be provided in the timeframe being requested.

Evidence of this consultation should be included in the application. This may be in the form of a memo or copy of an email. Once ethics approval has been obtained from AIATSIS, we will commence communications with the registry.

Anticipated data items requested and received:

Demographic Information

- Date of Birth (or age in years)
- Statistical Locality Area (SLA)
- Occupation
- Sex
- Country of Birth
- Indigenous Status
- Marital Status
- Date of Death
- Cause of Death

For each Cancer the Person has:

- Site Code in ICDOv3
- Morphology in ICDOv3 (kind of tumour)
- Date of Diagnosis
- Basis of Diagnosis
- Suburb (where patient was living at when diagnosed)
- SLA (where patient was when diagnosed)

For each hospital or pathology lab who has notified to QCR

- Institution
- Admission Date
- Separation Date

Have you considered the potential impact of your research on culturally restricted information?

N/A

How will materials be stored and access moderated both during and at the conclusion of the project

All data will be stored in a de-identified password protected project folder on an internal AIATSIS network (s) drive, only accessible by the investigators. Upon completion of the research the data file will be stored for seven years then deleted or as per the legislative requirements of Queensland.

Are there any other ethical risks associated with this research?

No access is requested to biological samples.

- American Phytopathological Society. (2016). Syllabus: Diseases Pests, and Nonnutrient Disorders of Sugarcane, . Retrieved 13 September, 2016, from APS <http://www.apsnet.org/publications/imageresources/Pages/SyllabusSugarcane.aspx>
- Australian Human Rights Commission. (2016). Close the Gap: Indigenous Health Campaign, . from Australian Government, <http://www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/projects/close-gap-indigenous-health>
- Australian Institute of Health and Welfare. (2015). *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015*,. Canberra: AIHW.
- Australian Institute of Health and Welfare & Cancer Australia (2013). *Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview*,. Canberra: AIHW.
- Baade, P. D., Dasgupta, P., Dickman, P. W., Cramb, S., Williamson, J. D., Condon, J. R., & Garvey, G. (2016). Quantifying the changes in survival inequality for Indigenous people diagnosed with cancer in Queensland, Australia. *Cancer Epidemiology*, 43, 1-8. doi: <http://dx.doi.org/10.1016/j.canep.2016.05.002>
- Bernardes, C., Whop, L., Garvey, G., & Valery, P. (2012). Health service utilization by indigenous cancer patients in Queensland: a descriptive study. *Int J Equity Health*, 11(1), 57.
- Bernardes, C. M., Whop, L. J., Garvey, G., & Valery, P. C. (2012). Health service utilization by indigenous cancer patients in Queensland: a descriptive study. *Int J Equity Health*, 11, 57. doi: 10.1186/1475-9276-11-57
- Broom, A., Nayar, K., Tovey, P., Shirali, R., Thakur, R., Seth, T., & Chhetri, P. (2009). Indian cancer patients' use of Traditionak, Complementary and Alternative Medicine (TCAM) and delays in presentation to Hospital, . *Oman Medical Journal*, 24(2).
- Brown, A., Roder, D., Yerrell, P., Cargo, M., Reilly, R., Banham, D., . . . the CanDAD Aboriginal Community Reference Group and other CanDAD Investigators. (2016). Cancer Data and Aboriginal Disparities Project (CanDAD) – an overdue cancer control initiative,. *European Journal of Cancer Care*, 25(2), 208-213. doi: 10.1111/ecc.12466
- Budd, R. (2016). Budd Photography,. 2016, from <http://www.buddphotography.com.au/burdekin-falls-dam/>
- Centers for Disease Control. (1990). Guidelines for investigating clusters of health events. *MMWR*(1990;39), RR-11:11-23.
- Centers For Disease Control. (2013). Investigating Suspected Canver Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists. *MMWR*, 2013/62((RR08)), 1-14.

- Chong, A., & Roder, D. (2010). Exploring differences in survival from cancer among Indigenous and non-Indigenous Australians: implications for health service delivery and research. *Asian Pac J Cancer Prev*, 11(4), 953-961.
- Commonwealth of Australia. (2015). Burdekin, Physical information, . from BOM https://www.google.com.au/search?q=map+of+mainland+australia+burdekin+region&espv=2&biw=1680&bih=965&source=Inms&tbm=isch&sa=X&ved=0ahUKewiJtJ_x3uXOAhWFjpQKHWh1C30QAUIBygC&dpr=1#tbm=isch&tbs=rimg%3ACU0HSQc8G_1V7Ijhm7wDBA4VjCDIdQXFcfOZWEUmb3YlmbR2SfQotxNqAnaUi-XtwbK7coBm64aYB9FfZnfDeevUMmyoSCWbvAMEDhWMIEQiRCEodj6C1KhIJMh1BcVwU5lYRrge61GFRa24qEgkRSZvdiWZtHREd5Yh2AoVFtyoSCZJ9Ci3E2oCdEf vJYYGzlorrKhIJpSL5e3BsrtwRrdE3jCN-d50qEgmgGbrhpgH0VxHEdk1LgEr5QioSCdmd8N569QybEcC0IEBCDn8&q=map%20of%20burdekin%20region&imgsrc=xbgNBqpNnCL_0M%3A
- Condon, J. R., Zhang, X., Baade, P., Griffiths, K., Cunningham, J., Roder, D. M., . . . Threlfall, T. (2014). Cancer survival for Aboriginal and Torres Strait Islander Australians: a national study of survival rates and excess mortality. *Population health metrics*, 12(1), 1.
- Cook, P. G., Stieglitz, T., & Clark, J. (2004). Groundwater Discharge from the Burdekin Floodplain Aquifer, North Queensland, .
- Cramb, S. M., Garvey, G., Valery, P. C., Williamson, J. D., & Baade, P. D. (2012). The first year counts: cancer survival among Indigenous and non-Indigenous Queenslanders, 1997–2006,. *Medical Journal of Australia*, 196(4), 270-274.
- Department of Health. (2010). Monitoring the incidence and causes of diseases potentially transmitted by food in Australia: Annual report of the OzFoodNet network, 2009, . Retrieved 23 January 2016, from Australian Government,
- Fanon, F. (1963). *The Wretched of the Earth*, . France: Grove Press,.
- Freemantle, J., Ring, I., Arambula Solomon, T. G., Gachupin, F. C., Smylie, J., Cutler, T. L., & Waldon, J. A. (2014). Indigenous Mortality (Revealed): The Invisible Illuminated. *American Journal of Public Health*, 105(4), 644-652. doi: 10.2105/AJPH.2014.301994
- Freemantle, J., Ring, I., Solomon, T. G. A., Gachupin, F. C., Smylie, J., Cutler, T. L., & Waldon, J. A. (2015). Indigenous Mortality (Revealed): The Invisible Illuminated,. *American Journal of Public Health*, 105(4), 644-652.
- Garside, A. L. (2003). *Sustainable sugarcane farming systems: Developments to date*, . Paper presented at the ABARE Outlook Conference Notes,.
- Haslam, S., & McGarty, C. (2009). *Research Methods and Statistics in Psychology*. Thousand Oaks, California: SAGE Publications Inc.
- Moore, S. P., O'Rourke, P. K., Mallitt, K.-A., Garvey, G., Green, A. C., Coory, M. D., & Valery, P. C. (2010a). Cancer incidence and mortality in Indigenous Australians in Queensland, 1997-2006. *Medical Journal of Australia*, 193(10), 590.
- Moore, S. P., O'rourke, P. K., Mallitt, K.-A., Garvey, G., Green, A. C., Coory, M. D., & Valery, P. C. (2010b). Cancer incidence and mortality in Indigenous Australians in Queensland, 1997-2006,. *Medical Journal of Australia*, 193(10).

- Queensland Government. (2013). *Population, Aboriginal and Torres Strait Islander Queenslanders, 30 June 2011*,. Brisbane: Qld Government, Retrieved from <http://www.qgso.qld.gov.au/products/reports/pop-atsi-qld-2011/pop-atsi-qld-2011.pdf>.
- Queensland Government. (2016a). Queensland Health, South West Hospital and Health Service,. 2015, from <https://www.health.qld.gov.au/southwest/>
- Queensland Government. (2016b). *Queensland Regional Profiles, Resident Profile - people who live in the region, Burdekin State Electoral District (SED)*,. Brisbane: Queensland Treasury Retrieved from <http://www.qgso.qld.gov.au>.
- Queensland Government. (2016c). *Reef protection regulations, How does this impact cane farmers?*,. Brisbane: Qld Government, Retrieved from <http://www.qld.gov.au/environment/agriculture/sustainable-farming/cane-farmers/>.
- Queensland Government. (2016d). *Reef protection regulations, Managing agricultural chemicals*,. Brisbane: Qld Government, Retrieved from <https://www.qld.gov.au/environment/agriculture/sustainable-farming/chemicals/>.
- Queensland Government. (2016e). Visitor Information, About the Area, . from Burdekin Shire Council, <http://www.burdekin.qld.gov.au/community/visitor-information/about-the-area/>
- Rametta, S., Grosso, G., Galvano, F., Mistretta, A., Marventano, S., Nolfo, F., . . . Biondi, A. (2013). Social disparities, health risk behaviors, and cancer. *BMC Surgery*, 13, S17. doi: <http://dx.doi.org/10.1186/1471-2482-13-S2-S17>
- Ricaud, C., Egan, B., Gillaspie Jnr, A., & Hughes, C. (1989). *Diseases of Sugarcane, Major Diseases*, : Elsevier Publishing Company,.
- Ricaud, C., Egan, B., Gillaspie Jr, A., & Huges, C. (Eds.). (1989). *Diseases of Sugarcane: Major Diseases*. Amsterdam: Elsevier Publishers B. V.
- Ring, I. T., Dixon, T., Lovett, R. W., & Al-Yaman, F. (2016). Are Indigenous mortality gaps closing: how to tell, and when? *Medical Journal of Australia*, 205(1).
- Roder, D. M., & Buckley, E. (2016). High quality data are the key to understanding inequalities in cancer outcomes for Aboriginal and Torres Strait Islander Australians,. *Medical Journal of Australia*, 205(10), 451-452.
- Smith, M., Poggio, M. J., Thompson, M., & Collier, A. (2014). The Economics of Pesticide Management Practices on Sugarcane Farms: Final Synthesis Report, . Brisbane: Department of Agriculture, Fisheries and Forestry (DAFF), Queensland,.
- Thompson, S. C., Shahid, S., Greville, H. S., & Bessarab, D. (2011). *"A whispered sort of stuff" A community report on research around Aboriginal people's beliefs about cancer and experiences of cancer care in Western Australia*. Perth: Cancer Council Western Australia.



Queensland
Government

Public Health Act – Application and Information for Researchers

For the Release of Confidential Information for the Purposes of Research under the provision of Section 280 of the Public Health Act 2005

- Chapter 6 Part 4 of the *Public Health Act 2005* (PHA) establishes the process for accessing health information held by Queensland Health for approved research projects.
- The PHA requires researchers to apply to the Director-General of Queensland Health or his/her delegate, for access to health information held by Queensland Health.
- The Director-General or his/her delegate may grant access to health information for the purposes of research only if he/she are satisfied that the giving of health information held by the department is in the public interest: s.284 (2) and (3).
- Details of all applications approved to **access identifiable or potentially re-identifiable** health information for the purposes of research will be kept in a register, known as “*The Research Register*” (the register) held by Health and Medical Research, Preventive Health Unit. Access to the register must be made available to anyone who makes a request.

Data Custodian

- Researchers **must consult** with the information providers/data custodians prior to applying for ethics approval to ensure that relevant data items are available and that there are adequate local resources available to the data custodian to be able to provide that data for the specified study.
- Evidence of this consultation and confirmation that the necessary data is available, should be included in the application. See section (10) Authorisation from Data Custodian in the application form.
- Contact information for Queensland Health data custodians can be found at http://www.health.qld.gov.au/ohmr/documents/data_custodian_list.pdf

What Research requires a PHA Application?

- The PHA **applies** to all researchers (internal and external to Queensland Health) who are undertaking research using **identifiable or potentially re-identifiable** health information for which the researchers are **unable to obtain participant consent** to use their personal **or** identifying information for a clearly specified research study.

- This may also apply in circumstances in which it may be inappropriate or difficult to contact participants/patients for consent to access their health information. In these circumstances the **views of a Human Research Ethics Committee** should be taken into consideration when waiver of consent is required. See Chapter 2.3 '*Qualifying or Waiving Conditions for Consent*' of the *National Statement on Ethical Conduct of Research In Humans*.
- The PHA **does not apply** to health information held by Queensland Health if its disclosure is authorised under another Act. The most relevant exceptions are:
 - Where the disclosure is with the consent of the person to whom the information relates (s.139 *Hospital and Health Boards Act 2011*)
 - If the disclosure is in a form that could not or does not identify any person.
- In the case of 'Clinical Audit and Review' follow the procedures set out here: <http://www.health.qld.gov.au/psu/qac/default.asp>
- All confidential health information held in the private sector or by the Commonwealth is dealt with under the [Privacy Act 1988 \(Cth\)](#). Queensland Health has no jurisdictional authority or administrative responsibility for health information data held by the private health sector or the Commonwealth Government.

What decision may be given on your application?

- Provided the researchers provide adequate information, as detailed below, the Chief Executive or Delegated person may choose to:
 - grant approval,
 - grant approval subject to certain conditions (Section 284),
 - request additional information, or
 - deny approval. If approval is not granted or granted conditionally, the Chief Executive is required to provide the applicants with the reasons for this decision.
- In accordance with the *Public Health Act 2005*, the details of approved applications will be entered and stored in a designated database, known as the 'Research Registry'. The approval for release of data will only cover that study described in the NEAF/ LNR form and approved by a HREC. A change to the scope of data requested may necessitate a resubmission to the reviewing HREC for approval.
- A list of names and contact details for data custodians can be accessed at http://www.health.qld.gov.au/ohmr/documents/data_custodian_list.pdf. In some cases, a fee may be charged to recover the data.

How to Apply

- To apply for access to **identifiable or potentially re-identifiable** health information held by Queensland Health researchers need to meet the requirements in s282 of the PHA and must have **approval from a Human Research Ethics Committee (HREC)** prior to making application.
- The Application Form and all supporting documentation is emailed to PHA@health.qld.gov.au

Recovery of Costs

- In some instances, provision/extraction of health information or data may incur a fee. When consulting the information providers/data custodians, ensure you determine whether there is a cost associated for the extraction (Queensland Government)
- For **tissue samples** and data held by Pathology Queensland, contact the Coordination, Planning and Research Unit for more detail at <http://www.health.qld.gov.au/qhcss/research/resinfo.asp>

Notification of Approval/No Approval

- Applicants are notified by mail of the outcome of their application.
- The obligations when accessing **identifiable or potentially re-identifiable** confidential health information are outlined in the correspondence you receive, along with, the timeframe of access and reporting requirements.

Reporting requirements

- The Director-General may make it a condition when granting the application that researchers provide feedback on the progress and results of the research under s.284. Reporting templates may be accessed at: http://www.health.qld.gov.au/ohmr/html/regu/reporting_templates.asp

Useful Information

Health Information is not restricted simply to names and personal data but also includes tissues and tissue blocks.

Identifiable data are data that enables a person to establish the identity of a person or organisation to which some data relates. It is not necessary for the data to enable identification of all persons and organisations to which the data relate – only one or more persons or organisations.

Unidentifiable data are data that **do not contain** any identifiers such as **name, street, postal address** or **Medicare number**.

However when unidentifiable data are used in various combinations, it may reveal enough detail about the characteristics of a person or organisation to enable identification to be made. This becomes re-identifiable data. An example would be data that holds date of birth and an area code – in an area consisting of 200 – 300 residents. Researchers should consider the following factors when determining whether their research involves **potentially re-identifiable** data:

- Presence of rare characteristics in a statistical local area (SLA);
- Accuracy of the data;
- Age of the data;
- Coverage of the data (completeness);
- Presence of other information that can assist in identification, includes:
 - publicly available information;

- restricted access data holdings that a data user may have access to;
and
- personal knowledge that a user may have.

Dataset guidance

The Australian Institute of Health and Welfare (AIHW) has useful guidance on Health sector national minimum data sets and datasets specification. Visit the following site:
<http://meteor.aihw.gov.au/content/index.phtml/itemId/344846>

Documentation that is required prior to submission

1. Copy of the HREC approval
2. Evidence of Data custodian consultation
3. Completion of the application template
4. Email to PHA@health.qld.gov.au

PUBLIC HEALTH ACT – APPLICATION

Instructions: The information required from the researcher is provided in italics. This information should be inserted into the corresponding boxes, which may be expanded as required. **The data custodian/s must sign your application form before submission, or provide a letter/email of support.** Completed applications are to be submitted to Health and Medical Research at email: PHA@health.qld.gov.au with the relevant attachments.

1 Title of Research Project:

A community perspective of 'Burdekin rot'

2 HREC Number:

E022/22052014

3 Research Category:

Tick the research category to which the research proposal most closely aligns

☐ Biomedical Study
Epidemiological Study

☒ Evaluation and Planning Study;

☐

☐ Clinical and applied Study; ☐ Monitoring & Surveillance Study

4 Principal Investigator / Co-Investigator / Additional Applicants:

This section should list:

- The name/names of all the person/s proposing to conduct the research and who will be given or have access to the identifiable information for this research.*

Leone Malamoo, Principal Investigator

Dr Ray Lovett, Co-Investigator

5 Address of the Principal Investigator / Co-Investigator

Street: 51 Lawson Crescent, Acton ACT 2601

Postal: 51 Lawson Crescent, Acton ACT 2601

Telephone: (02) 6261 4222

Email: leonemalimu@y7mail.com

6 Location/s where project will be conducted

Ayr, North Queensland & Canberra, ACT

7 Description of the proposed research study

In this section please provide:

7.1 – Describe the research study including the research objectives, benefits and outcomes.

Cancer among the Aboriginal and Torres Strait Islander population has become an increasing area of concern in Australia with increasing prevalence and disproportionate mortality compared with other Australians (Bernardes et al., 2012, Chong and Roder, 2010, Moore et al., 2010).

Bacterial red stripe (*Pseudomonas rubrilineans*) is a sugar cane leaf disease first described in Hawaii and later labelled 'red stripe' (Ricaud et al., 1989). *Pseudomonas rubrilineans* has been associated with the disease referred to in Queensland as 'top rot', 'cane rot' or 'Burdekin rot'. The mode of transmission is airborne where bacteria groups in large masses in the leaf tissues and oozes onto the leaf surface during periods of moist warm weather. The bacteria then readily spread plant to plant even field to field (Ricaud et al., 1989).

Anecdotal reports of 'Burdekin rot' in the Burdekin River region of Queensland are commonplace. However people are not talking about sugarcane. 'Burdekin rot' is a euphemism for cancer among patients from the Burdekin. 'Burdekin rot' is commonly used, particularly among the Aboriginal and Torres Strait Islander population of the region, in reference to the perceived higher incidence of cancer among the population. Moore and colleagues conducted a study in 2010 on cancer incidence and mortality rates for cancers diagnosed among Aboriginal and Torres Strait Islander Australians in Queensland from 1997-2006 - they found that Aboriginal and Torres Strait Islander Queenslanders were 21 per cent less likely to be diagnosed with cancer, but those who were diagnosed were 36 per cent more likely to die.

We know that overall incidence of cancer diagnosis is lower in Queensland, the question arises; is the incidence and mortality reported at the QLD level similar among the Burdekin. There are no currently available regional level reports to understand if the 'Burdekin rot' is truth or myth.

This research will undertake a regional level analysis using existing Queensland Cancer Registry data and report incidence by region and by Indigenous status to answer the research question.

7.2 - Describe the methodology used in the research project.

We will follow the Centers for Disease Control and Prevention (CDC) guidelines for investigating clusters of health events (Centers for Disease Control, 1990), with the additional reference material specific to investigation of potential cancer clusters (Centers For Disease Control, 2013). See **Appendix 1** (previously provided to the Data Custodian).

Under step one of the four step process, an evaluation of the data available is required. This can be through the existing QLD cancer registry data. We will undertake analysis of the Queensland cancer registry to determine standardised incidence rates (SIR's) by type(s) of cancer, for the period 2003-2012, by QLD region and by Indigenous status. The reference population will be background cancer incidence in the non-Indigenous population.

7.3 – Describe the rationale for using identifiable confidential health information.

N/A

7.4 - Describe the benefits of this research study for the community.

As per attached community Letter of Support: 'informative for the future health and wellbeing of many locals living in the Burdekin.' The Ayr community is very much aware of the anecdotal 'Burdekin rot' and is most interested in the study outcome/findings.

7.5 - How do the benefits to the public outweigh the risks for the individuals' whose identifiable information will be used?

N/A

7.6 - What is the estimated duration of the research project?

1 year (1/1/2015 - 31/12/2015)

8 Name/Description of Database and Data Items required:

8.1. - What is the scope of the data that the applicant/s is requesting access to for the purposes of research?

- Applicant/s **must list specific data items** required to undertake the research study. This may include but is not limited to – demographics (eg. date of birth, sex), hospital episode information, details of diagnostic data and/or details relating to health services accessed by individuals.
- It is important that all items of data are listed to ensure that data custodians can determine the availability of data requested and/or time and resources required in providing the data.

Anticipated data items to be requested

Demographic Information

- Date of Birth (or age in years)
- Statistical Locality Area (SLA)
- Occupation
- Sex
- Country of Birth
- Indigenous Status
- Marital Status
- Date of Death
- Cause of Death

For each Cancer the Person has:

- Site Code in ICDOv3
- Morphology in ICDOv3 (kind of tumour)
- Date of Diagnosis
- Basis of Diagnosis
- Suburb (where patient was living at when diagnosed)
- SLA (where patient was when diagnosed)

8.2. - *What specific time period/s will this requested covers (e.g Jan 2000 – 2004)?*

Jan 2003 – Dec 2012

8.3 - *What are the requested data intervals (e.g once only, every 3 months etc)?*

Once only

9 Privacy and Confidentiality

9.1 - *Who is providing the confidential information and how will the disclosure take place?*

Data will be provided by Queensland Cancer Registry (QCR); and disclosed as per their discretion.

We have approval from the AIATSIS Human Research Ethics Committee (HREC) prior to applying for access to QLD health information. Evidence of this approval must be provided has been provided to QCR Data Custodian: Ms Carly Scott. In addition, we have met with and consulted with the data custodians to determine:

- whether the data fields being requested are available; and
- whether the data being requested can be provided in the timeframe being requested.

Evidence of this consultation is included in the application in the form of a copy of an email.

9.2 - *In what form will data be disclosed (electronic or paper)?*

Electronic data disclosure.

9.3 - *How will the security associated with the transfer of data be maintained?*

AIATSIS has secure government data transfer technology.

9.4 - *How will data security be maintained?*

All data will be stored in a de-identified password protected project folder on an internal AIATSIS network (s) drive, only accessible by the investigators. Upon completion of the research the data file will be stored for seven years then deleted or as per the legislative requirements of QLD.

10 Authorisation from Data Custodian:

I have considered this proposal and consulted the appropriate personnel and I confirm that I have seen all relevant documents that are required.

☐ able to confirm that the data services indicated will be provided, within the present resources;

☐ unable to provide data services indicated, on the following grounds:

The custodian has supplied these data for an approved research request, but makes no warranty as to the fitness of the data, nor of the proposed methods, for the purpose for which the data has been provided and do not necessarily represent those of Queensland Health.

Name

Date

Position

Hospital / HHS:

Signature

Authorisation from Data Custodian:

I have considered this proposal and consulted the appropriate personnel and I confirm that I have seen all relevant documents that are required.

☐ able to confirm that the data services indicated will be provided, within the present resources;

☐ unable to provide data services indicated, on the following grounds:

The custodian has supplied these data for an approved research request, but makes no warranty as to the fitness of the data, nor of the proposed methods, for the purpose for which the data has been provided and do not necessarily represent those of Queensland Health.

Name

Date

Position

Hospital / HHS:

Signature

*(Repeat "Authorisation from Data Custodian" if more than one required).
(A letter of support or email may be used, instead)*

11 Human Research Ethics Committee (HREC) Approval

11.1 - State the name of the Human Research Ethics Committee that approved this research proposal

Evidence should be provided as an attachment that the research proposal has been reviewed by a human research ethics committee, including the contact details for each committee this applies to.

As per attached HREC document:

AIATSIS Ethics Committee

51 Lawson Crescent

Acton ACT 2601

12 Undertaking of Confidentiality

- 12.1 In the course of using confidential information for research purposes, I acknowledge that I will be exposed to information which if inappropriately used or disclosed may impact on individuals, public or private facilities or communities, such as discrete non urban indigenous communities.
- 12.2 I will not disclose confidential information in any released output (eg in reports, publications).
- 12.3 I will not use this confidential information for purposes other than for performing the specific activities detailed in my application as approved by the Chief Executive under the Act.
- 12.4 I will not use the confidential information except during the defined time period for which access to and use of this information was approved.
- 12.5 I agree to take all the reasonable steps necessary to ensure that the confidential information is kept confidential, including storing or disposing of all data, information, documents and associated correspondence in a secure manner.
- 12.6 **I agree to re-apply for approval from the Chief-Executive if:**
12.6.1 - I require additional confidential information, or if
12.6.2 - I want to extend the approved time period for access to or use of the confidential information,
- 12.7 The declaration of my interests in Research Proposals and associated documents shall be held in strict confidence by the relevant Queensland Health Human Research Ethics Committee and Queensland Health employees, and it shall not be used or disclosed to any other person without my prior consent or when it is legally required to be disclosed.

In signing this declaration, I declare that all researchers accessing identifiable data described in this application will adhere to the obligations specified above.

Signed by Principal Investigator

Leone Malamoo

Principal Investigators Name

Date: 27 / 9 / 2016

Attachments:

Please complete all the details required and attach the relevant documents.

1. Evidence of Approval from HREC AIATSIS Dated: 24/ 4/ 2015
2. Evidence of Approval from the Data Custodian
3. Evidence of Approval from Pathology Queensland (if Pathology samples is required)



AIATSIS

AUSTRALIAN INSTITUTE OF ABORIGINAL
AND TORRES STRAIT ISLANDER STUDIES

51 Lawson Crescent
Acton Peninsula, Acton ACT 2601
GPO Box 553, Canberra ACT 2601

ABN 62 020 533 641

P | 02 6246 1111

F | 02 6261 4286

www.aiatsis.gov.au

24 April 2015

Leone Malamoo
MAE Student (AIATSIS 'Step Up' Program)

Dear Leone,

HREC Reference number: E022/22052014

Project title: People's Perspectives of 'Burdekin Rot'

Thank you for submitting the above research project for single ethical review. This project was considered by the AIATSIS Research Ethics Committee out-of-session.

I am pleased to advise you that the AIATSIS Research Ethics Committee has granted ethical approval of this research project.

The approved documents include:

Document	Version	Date
The Participant Information Sheet and Informed Consent Form	1.0	30 March 2015

Approval of this project from the AIATSIS Research Ethics Committee is valid from 23 April 2015 and subject to the following conditions being met:

- The Coordinating Principal Investigator will immediately report anything that might warrant review of ethical approval of the project.
- The Coordinating Principal Investigator will notify the AIATSIS Research Ethics Committee of any event that requires a modification to the protocol or other project documents and submit any required amendments in accordance with the instructions provided by the HREC.
- The Coordinating Principal Investigator will submit any necessary reports related to the safety of research participants in accordance with AIATSIS policy and procedures.



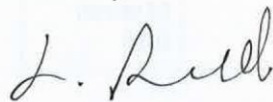
- The Coordinating Principal Investigator will report to AIATSIS annually in the specified format and notify the HREC when the project is completed at all sites.
- The Coordinating Principal Investigator will notify the AIATSIS Research Ethics Committee if the project is discontinued at a participating site before the expected completion date, with reasons provided.
- The Coordinating Principal Investigator will notify the AIATSIS Research Ethics Committee of any plan to extend the duration of the project past the approval period listed above and will submit any associated required documentation.
- The Coordinating Principal Investigator will notify the AIATSIS Research Ethics Committee of his or her inability to continue as Coordinating Principal Investigator including the name of and contact information for a replacement.

This letter constitutes ethical approval only. This project cannot proceed at any site until separate research governance authorisation has been obtained from the CEO or Delegate of the institution under whose auspices the research will be conducted at that site.

Should you have any queries about the AIATSIS Research Ethics Committee's consideration of your project please contact the Secretary of the AIATSIS Research Ethics Committee, ethics@aiatsis.gov.au. The AIATSIS Research Ethics Committee's Guidelines, Charter, membership and standard forms are available from <http://aiatsis.gov.au/research/ethical-research> or from the Secretary.

The AIATSIS Research Ethics Committee wishes you every success in your research.

Yours faithfully,



Lachlan Russell
Secretary of the AIATSIS Research Ethics Committee

For
Ms Christine Grant
Chair of the AIATSIS Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)* and the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) *Guidelines for Ethical Research in Australian Indigenous Studies (2012)*.



PARTICIPANT INFORMATION SHEET AND INFORMED CONSENT FORM

Project Title: A community perspective of 'Burdekin rot'

Researcher: Leone Malamoo

Organisations: The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and the Australian National University (ANU).

What is the project about?

- i. To determine whether cancer incidence (by type) varies between the Aboriginal and Torres Strait Islander population within each region of Queensland; and
- ii. To ask the community questions about their experience with cancer diagnosis and treatment in the Burdekin district.

Who is involved in the project?

This research project is being undertaken by Leone Malamoo. Leone is a Master of Applied Epidemiology student (ANU) based at AIATSIS. The research is supported by AIATSIS, the ANU, and The Bur-Del Co-Operative Advancement Society Limited.

Why have I been invited to participate?

You have been invited to participate because we would like to understand your perspectives and experience of cancer treatment in the Ayr/Burdekin district.

You do not have to participate, and it will not change your relationship with the researcher or anyone else. If you do decide to pull out of the project, you are able to do this at any stage of the study.

What will the researcher do and when?

The researcher will interview you about whether you or your family member have had experience with cancer. The interview will be digitally recorded.

- The research will happen from March to April 2015.
- The interview process will take the amount of time necessary to fully complete the interview questions.

What will happen to my information?

If you give your informed consent to participate in the study all information will be de-identified; it will be kept private and confidential and stored in locked cabinet at AIATSIS. Any electronic information is kept in a password protected folder on the AIATSIS database. This information is only accessed by the principal researcher or supervisors.

The study information is collected, analysed, and interpreted so that the outcome of the study will not identify any individual participant. The study results will be disseminated to the community and other stakeholders. The results will also be a chapter in the Principal

researchers Master's thesis and may be presented at conferences or published in a research journal.

What are the potential risks?

The potential risks are that the questions might cause distress to you or your family. If you or your family become distressed please be advised that the services listed below are available to you:

- Townsville Aboriginal and Torres Strait Islander Health Services Ltd (Social, Emotional Wellbeing) - (07) 4759 4000
- Ayr Health Service - (07) 4783 0855
- Beyondblue - 1300 224 636

Data storage and giving materials to AIATSIS

During the project, the data will be stored in a password protected computer and hard copies will be kept in a locked filing cabinet at AIATSIS. The information will be kept for seven (7) years.

Exclusion Criteria

People under 16 years of age will **NOT** be able to participate.

Contact

I know that if I am worried about the research I can contact the Principal researcher Leone Malamoo (02) 6261 4222 OR 0459 480 410

Complaints

If I have any concerns with this research I can speak to:

- Dr Lisa Strelein, Director of Research, AIATSIS, 51 Lawson Crescent, Acton ACT 2601, (p) 02 6246 1155, (e) lisa.strelein@aiatsis.gov.au
- Ms Chrissy Grant, Chair of the AIATSIS Research Ethics Committee by calling 02 6261 4251 or writing to the AIATSIS Research Ethics Committee, AIATSIS, 51 Lawson Crescent, Acton ACT 2601. This is an independent Committee whose members do not work for AIATSIS.

Ethics Committee Clearance

The ethical aspects of this research project have been approved by the AIATSIS Research Ethics Committee, and the ANU Research Committee.

PARTICIPANT INFORMATION SHEET AND INFORMED CONSENT FORM **(CONTINUED)**

Project Title: A community perspective of 'Burdekin rot'

Researcher: Leone Malamoo

Organisation(s): The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and the Australian National University (ANU)

DECLARATION BY PARTICIPANT

1 I understand what this project is about

I have read (or had it read to me), the Participant Information Sheet which explains what this research project is about, and I understand it.

I have had a chance to ask questions about the project, and I am comfortable with the answers that I have been given. I know that I can ask more questions whenever I like.

2 I have volunteered to participate

I agree to participate in the research. I know that I do not have to participate in it if I don't want to. I made up my own mind to participate and nobody is making me do it.

- a. I know that I don't have to answer any questions I don't like; and
- b. The researcher will turn off the digital recorder if I ask them to.

3 What will happen if I want to stop participating?

I know that I can pull out of the study at any time and it won't change my relationship with the researcher or anyone else.

If I pull out, none of the information I have given the researcher can be used in the research study.

4 How the research will happen

I agree that the researcher can interview me for the research.

- a. I understand the research will take place from March to April; and
- b. During that time the researcher will interview me once and the interview will last for as long as is necessary to fully complete the interview.

5 Having my interview recorded

I agree to the digital recording of my interview.

Yes ☐

No ☐

6 Getting paid for participating in the research

I know that I won't be paid for participating in the research project.

7 Risks and benefits of the research

- a. I understand that I can ask that the interview be stopped at any time that I want; and the researcher will provide information of a counselling support services in the local area.

- b. I understand that in talking about my recollections it may make me feel sad or angry. I know that I can stop the interview at any time.
- c. I understand that the research may have no benefit to the community however; the results of this study will still be disseminated to the community (including electronically to those participants who have provided the researcher with their email address).

8 Who will be the authors of the research?

I understand that the Principal researcher wants to write about the research in her thesis, and may present the information at a conference and/or publish a paper based on this study.

9 Will people find out personal things about me from the research?

I understand that my name will **NOT** be mentioned or written about in the research results. All information collected from the study will be de-identified. The researcher will keep a record of what I said during the research with my name on it, however this will be kept private and confidential and stored in a locked cabinet at AIATSIS and kept in a password protected folder on the AIATSIS database.

The information will be kept for seven (7) years.

If the researcher keeps a record of what I said with my name on it, or which might identify me, I want them to give it to AIATSIS for safekeeping. No other people will be allowed to access this information without my signed permission.

10 What about culturally restricted information or things?

I understand that no secret or sacred information will be collected by the researcher.

11 Who will have access to the research results?

I understand that the study results will be disseminated to participants and the community (including electronically to those participants who have provided the researcher with their email address).

12 Intellectual property and copyright

I understand that I will retain any Intellectual Property from my personal interview recordings.

I understand that the researcher will hold copyright in the analysis and interpretation and the report produced as a result of this research. This means that the researcher will be able to reproduce the information that is in the interviews in other places or for other purposes without asking for anyone else's permission. The researcher will be able to let other people reproduce that information without asking for anyone else's permission.

13 Complaints

I know that if I am worried about the research I can contact Leone Malamoo on (02) 6261 4222. I know that I can complain to:

- Dr Lisa Strelein, Director of Research, AIATSIS, 51 Lawson Crescent, Acton ACT 2601, (p) 02 6246 1155, (e) lisa.strelein@aiatsis.gov.au
- Ms Chrissy Grant, Chair of the AIATSIS Research Ethics Committee, by calling 02 6261 4251 or writing to the AIATSIS Research Ethics Committee, AIATSIS, 51 Lawson Crescent, Acton ACT 2601. This is an independent Committee whose members do not work for AIATSIS.
- If I think there has been a breach of my privacy I can write to the Office of the Australian Information Commissioner, GPO Box 5218 Sydney NSW 2001 or call 1300 363 992.

14 Signatures

Participant to complete:

- I have read the Participant Information Sheet and Informed Consent Form (or someone has read it to me in language I understand) and I agree with it.

Name: _____

Signature: _____

Date: / /

Researcher to complete:

- I have described the nature of the research to the Participant and I believe that he/she understood and agreed to it.

Name: _____

Signature: _____

Date: / /



**The Bur-Del Co-Operative
Advancement Society Limited**

ABN: 42 609 591 731

P.O. BOX 1060
AYR 4807

PHONE: (07) 4783 3680
FAX: (07) 4783 2416



Ethics Committee
Australian Institute of Aboriginal and Torres Strait Islander Studies
GPO Box 553
Canberra ACT
Australia 2601

LETTER OF COMMUNITY SUPPORT

Dear Committee Members

The Bur-del Co-operative Advancement Society supports Leone Malamoo with her research project "The truth about 'Burdekin Rot'" in relation to the incidence of cancers in the Burdekin region.

As a community organisation we are very much aware of the anecdotal 'Burdekin rot', and we would be most interested in the results of the study.

We wish Leone all the best with her research project and MAE studies, and trust that the project be informative for the future health and wellbeing of many locals living in the Burdekin.

Kind Regards,

Emene Monday
Chairperson

22/07/2014

Appendix 7: Participant recruitment flyer

Researcher: Leone Malamoo

Organisations: The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and the Australian National University (ANU).

What is the project about?

The aim of this research project is:

- i. To determine whether cancer incidence (by type) varies between the Aboriginal and Torres Strait Islander population within each region of Queensland; and
- ii. To ask the community questions about their experience with cancer diagnosis and treatment in the Burdekin district. (community to assess and measure the local Aboriginal and Torres Strait Islander communities' knowledge and understanding of the anecdotal Burdekin rot and their experiences with cancer)

Who is involved in the project?

This research project is being undertaken by Leone Malamoo who is a Master of Epidemiology student based at AIATSIS. The research is supported by AIATSIS, ANU, and The Bur-Del Co-Operative Advancement Society Limited.

Why have I been invited to participate?

You have been invited to participate because we would like to understand your perspectives and experience of cancer treatment in the Ayr/Burdekin district.

You don't have to participate, and it won't change your relationship with the researcher or anyone else. If you decide to participate and you decide to pull out of the project, you are able to do this at any stage of the study.

What will the researcher do and when?

The researcher will interview you about whether you or your family member experience with cancer. The interview will be digitally recorded.

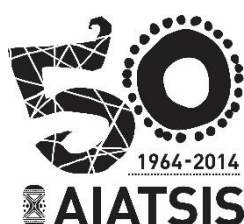
- The research will happen March to April 2015
- The interview should take as much time as required until completion

What will happen to my information?

If you give your informed consent to participate in the study all your information will be de-identified; it is kept private and confidential and stored in locked cabinet at AIATSIS. Any electronic information is kept in a password protected folder on the AIATSIS database. This information is only accessed by the principal researcher and the principal researcher's supervisor Dr Ray Lovett.

How to get involved? Contact: Leone Malamoo (02) 6261 4222 or Email: leone.malamoo@aiatsis.gov.au

[Appendix 8: Participant interview guide](#)



Appendix 2. (PROMPT SHEET)

Experiences of cancer in Ayr, North Queensland guiding questions for interview

These questions are to be asked by the Principal Researcher. Consent for participation and consent for digital recording of the interview will be completed prior to interview.

Will the participant be answering questions about themselves or a family member?

.....
.....

Allocated ID Number ☐ ☐

Email: (If available)

Age:

Gender: ☐ Male ☐ Female

Resident of Burdekin: ☐ Yes ☐ No **For how long?**

Household size: No. Adults:

No. Children:

Smoking status

Do you smoke? ☐ Yes ☐ No

Current: (no. per day)

Ex-Smoker: How long did they smoke (.....mths/yrs) How much (No. per day)

Never smoked ☐

Do you drink? ☐Yes ☐No

If yes, Alcohol consumption (AUDIT C)

How often do you drink?

☐ Never ☐ Monthly or less ☐ 2-4 times a month ☐ 2-3 times a week ☐ 4+ times a week

When you have a drink, how many do you have in one day?

☐ 1 or 2 ☐ 3 or 4 ☐ 5 or 6 ☐ 7-9 ☐ 10+

How often do you have six or more drinks on one day?

☐ Never ☐ Less than Monthly ☐ Monthly ☐ Weekly ☐ Daily

Total:

What type of cancer were you/they diagnosed with? (Cancer type):

.....

What stage was the cancer at diagnosis? (Cancer stage):

.....

Was this your/their first diagnosis of cancer? (If not list the previous cancer types/stage and dates of diagnosis).

.....

.....

Where did the participant/participants family member receive treatment (Treatment facility)?

.....

1. ***Please tell me about you/your families experiences of the cancer diagnosis*** (what was it that made them go to the Doctor/healthworker etc., did they have physical symptoms? did they have localised or general pain? How advanced was the cancer when diagnosed?)

.....

.....

.....

.....

2. ***Please tell me about your/your family members experiences of cancer treatment*** (What physical symptoms from treatment did they have? What care arrangements were made for treatment and who was this done by? Did they stick to the treatment? What did they not do? Did they try any alternative treatment? What made treatment

hard/easy? Who looked after kids and other family responsibilities while receiving treatment?)

.....

.....

.....

.....

3. **Please tell me about your/your families thoughts on what caused the cancer (Was it work exposures), smoking, drinking other/ what type of work did they do?)?**

.....

.....

.....

.....

4. **How long have you lived in Ayr? (where did they live/where they worked/ did they move away and return)**

.....

.....

.....

.....

5. **What do you believe was the key to you/your family member's success? Or why do you believe the treatment failed?**

.....

.....

.....

.....

6. **Which organisations were the most helpful?**

.....

.....

.....

.....

7. **Have you heard of 'Burdekin Rot'? If yes, what does this mean to you?**

.....

.....

NOTE:

The results of this study will be disseminated to the local community via Bur-Del Co-operative Advancement Society Limited; and electronically to those participants who provided their email address to the Researcher

Leone Malamoo

National Centre for Epidemiology and Population Health

The Australian National University, College of Medicine & Health Sciences,
Canberra

Dr Ray Lovett

National Centre for Epidemiology and Population Health

The Australian National University, College of Medicine & Health Sciences,
Canberra

Abstract

Objective

To take a finer geographical analysis of variations in cancer mortality by Indigenous status and Statistical Divisions (SD) in Queensland 2003-2012.

Methods

Descriptive analysis of Queensland Cancer Registry (QCR) 2003-2012 data to present rates of cancer mortality by Indigenous status and Statistical Divisions (SD). Poisson regression was used to calculate rates of cancer mortality by Indigenous status and by geographical region (SD).

Results

I found the number of cancer notifications for Indigenous status unknown (n=28,781) in QCR data 2003-2012 is increasing. Since 2006 Indigenous status unknown has increased from 11% to around 15.5% in 2012.

The rate of cancer deaths in the Indigenous population of Queensland 2003-2012 was 189 per 1,000 person years compared to the non-Indigenous rate of 123 per 1,000 person years. The ratio of cancer deaths for Indigenous compared to non-Indigenous people in Queensland is 1.5. Across the geographic regions rates of cancer varied, but for the area of the Burdekin, there is insufficient data to examine cancer deaths on a year-by-year basis. Despite this, rates of cancer deaths within the Northern region (which includes the Burdekin) are similar to other rural regions when looking at cancer rates among the Indigenous populations of those regions. Ratio of cancer deaths is 1.4 in the Northern region, slightly lower than the overall Queensland ratio of 1.5.

Conclusion

Data at the finer geographic level are required to ensure appropriate monitoring is occurring for populations where rates are higher including Indigenous populations. To achieve this, data need to be reliable and more work on this needs to occur with this cancer registry and likely others.

Introduction

Indigenous health status is poor across many domains from cardiovascular diseases; diabetes; cancer, chronic respiratory, liver and renal diseases; trauma; and other causes when compared to the non-Indigenous population. Indigenous life expectancy at birth is on average 11 years less than for non-Indigenous Australians and Indigenous people's mental and physical health routinely bears the brunt of social disadvantage and exclusion (Australian Institute of Health and Welfare, 2015; Brown et al., 2016).

Indigenous peoples of Australia have lived on their lands for many thousands of years prior to the European invasion and settlement, and have endured the impact and burden of colonisation with resilience. At the *International Symposium on the Social Determinants of Indigenous Health* in Adelaide, Australia (2007), the World Health Organisation's (WHO) investigation into health determinants recognises European colonisation as a common and central underlying determinant of Indigenous health (Freemantle et al., 2015).

Mortality lets a society know about its social advancement since mortality is a fundamental indicator of how effective public health policies and programs are. Mortality data, in particular the causes of infant and childhood mortality, also exposes the bigger picture of social, economic, and political issues (Freemantle et al., 2015).

The Close the Gap campaign launched in 2007 set a goal of raising the health and life expectancy of Indigenous peoples to that of the non-Indigenous population within a generation (Australian Human Rights Commission, 2016). However, cancer among the Indigenous population has become a growing area of concern in Australia with increasing prevalence and disproportionate mortality in comparison to other Australians (C. M. Bernardes et al., 2012)

Methods

Descriptive analysis of 2003-2012 Queensland Cancer Registry (QCR) data to present rates of cancer mortality by Indigenous status and Statistical Divisions (SD). Poisson regression was used to calculate rates of cancer mortality by Indigenous status and by geographical region (SD).

Results

I found the number of cancer notifications for Indigenous status unknown (n=28,781) in QCR data 2003-2012 has been increasing, and since 2006 it has increased dramatically from 11% in 2006 to around 15.5% in 2012.

The rate of cancer deaths in the Indigenous population of Queensland 2003-2012 was 189 per 1,000 person years compared to the non-Indigenous rate of 123 per 1,000 person years. The ratio of cancer deaths for Indigenous compared to non-Indigenous people in Queensland is 1.5 (Table 1.).

Across the geographic regions rates of cancer varied, but for the area of the Burdekin, there is insufficient data to examine cancer deaths on a year-by-year basis (Figure 1.).

Discussion

European colonisation is a routine and central underlying determinant of Indigenous health. Indigenous peoples of Australia share the experience of being marginal populations in economically thriving populations.

‘The quality of Indigenous data that informs mortality statistics are similarly connected to these distal processes which began with colonisation’ (Freemantle et al., 2014).

While there have been improvements in survival outcomes for Indigenous peoples diagnosed with cancer, there has been minimal reduction in the survival inequalities compared to non-Indigenous cancer survival.

Improvements to cancer care for Indigenous peoples requires timely access to medically effective and culturally acceptable diagnostic, treatment and support services need to be provided within the first year of diagnosis (Baade et al., 2016).

Attempts to reduce the disparity in cancer outcomes for Indigenous peoples and their families include national policy initiatives and community awareness programs. However a better understanding at a finer population level of what is driving the poorer survival and avoidable deaths faced by Indigenous cancer patients will provide evidence to direct efforts for early diagnosis and care, and unnecessary Indigenous cancer deaths (Baade et al., 2016).

Indigenous people in Queensland have lower overall incidence rates than non-Indigenous people, although the rates are higher for some of the more fatal cancer types (Baade et al., 2016). Many studies have documented lower Indigenous survival once diagnosed however, varying completeness and misclassification of Indigenous status across organisational and governmental administrative data collections over time have restricted researchers ability to investigate chronological changes in the level of the survival inequality faced by Indigenous peoples diagnosed with cancer compared to non-Indigenous Australians (Baade et al., 2016).

Limitations

A major concern and potential limitation of the study is the increasing unknown Indigenous status in QCR data, which is approaching 16% of all notifications.

Conclusions and Recommendations

Cancer is a significant contributor to Indigenous morbidity and mortality and rates nationally are increasing. Finer geographic analysis is required to prioritise areas for action and or prevention activity. Rates of mortality and survival are vastly different and public health approaches to smoking cessation will in the longer term reduce disparities across a number of cancers.

Recommendations to improve cancer registry data include:

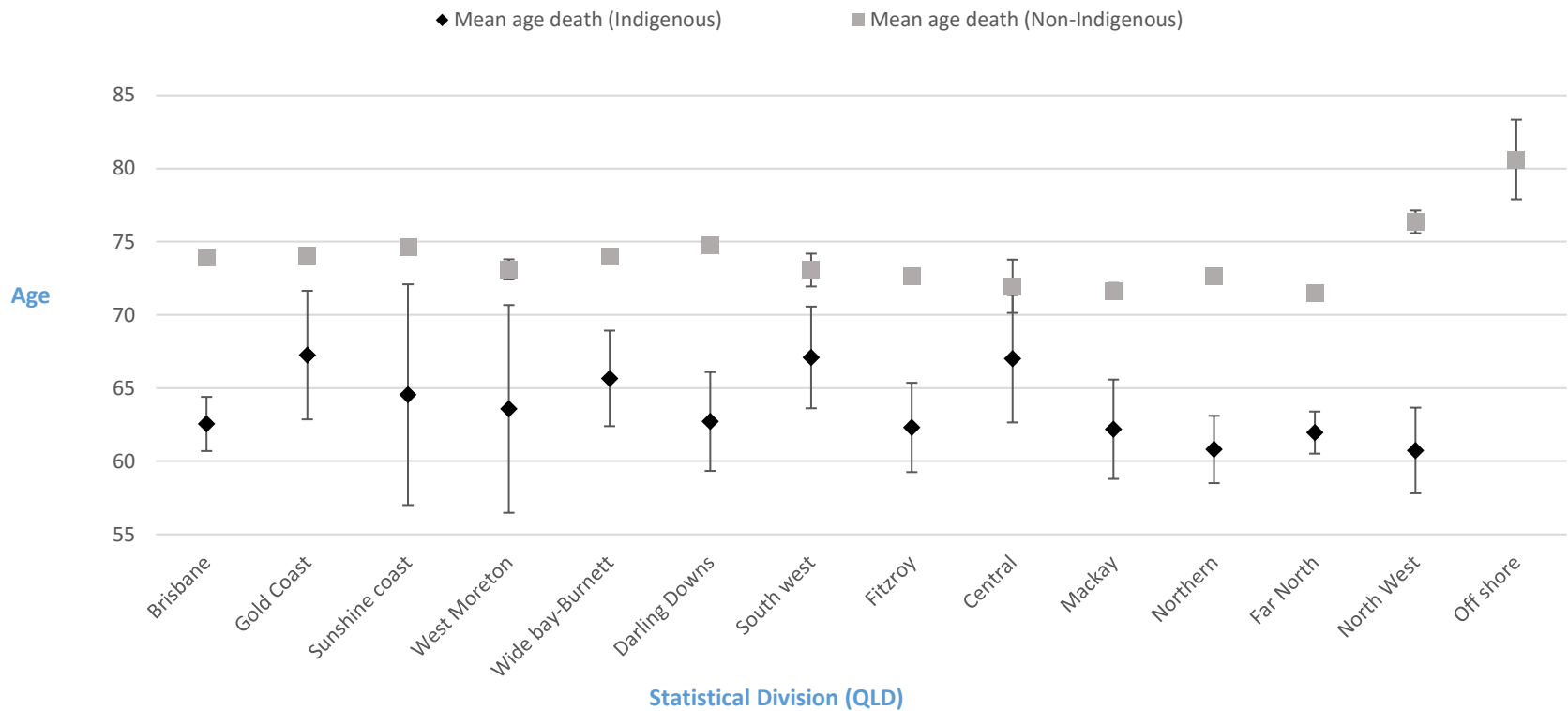
- Indigenous identification is routinely monitored to assess reliability
- That more routine training is provided to ensure the integrity of the Indigenous status variable is enhanced;
- The reporting of cancer incidence and mortality by geographic region and Indigenous status is conducted on a routine basis for QLD
- That a public education campaigns around tobacco use continue to inform Indigenous people how to reduce their chances of developing cancers
- Undertake national data linkage to improve recording of Indigenous status necessary to provide a comprehensive evidence base for informing improvement of all services (Roder & Buckley, 2016).
- Ensure all jurisdictions have the same documentation/forms and processes across notification systems.

- Investigate data linkage of Medicare to jurisdictional health sector data as a method of decreasing disparities in the recording of Aboriginal and Torres Strait Islander status in datasets.

Table 15: Qld cancer 2003-2012 mortality rates by Indigenous status and age group

Age group	Indigenous					Non-Indigenous					
	Person years	Deaths	Rate	CI Lower	CI Upper	Person-years	Deaths	Rate	CI Lower	CI Upper	Ratio
0-9	122.33	6	49.05	22.03	109.17	2485.07	124	49.9	41.84	59.5	0.98
10-19	183.42	7	38.16	18.19	80.05	2959.5	121	40.89	34.21	48.86	0.93
20-29	224.57	10	44.53	23.96	82.76	8468.34	249	29.4	25.97	33.29	1.51
30-39	490.24	49	99.95	75.54	132.25	20416.65	647	31.69	29.34	34.23	3.15
40-49	1077.66	135	125.27	105.83	148.29	47478.15	2478	52.19	50.18	54.29	2.40
50-59	1708.59	316	184.95	165.64	206.51	100575.23	6984	69.44	67.83	71.09	2.66
60-69	1549.52	340	219.42	197.3	244.03	157668.83	14267	90.49	89.01	91.98	2.42
70-79	908.2	269	296.19	262.83	333.79	137963.92	19650	142.43	140.45	144.43	2.08
80-89	289.26	96	331.89	271.71	405.38	76604.37	20115	262.58	258.98	266.24	1.26
90-99	27.01	16	592.34	362.88	966.87	10895.3	4856	445.7	433.34	458.41	1.33
100+						135.51	93	686.28	560.06	840.95	
Total		1244					69584				

Figure 30: Mean age at death Indigenous compared to non-Indigenous by Queensland Statistical Division (SD)



References

- American Phytopathological Society. (2016). Syllabus: Diseases Pests, and Nonnutrient Disorders of Sugarcane, . Retrieved 13 September, 2016, from APS <http://www.apsnet.org/publications/imageresources/Pages/SyllabusSugarcane.aspx>
- Australian Human Rights Commission. (2016). Close the Gap: Indigenous Health Campaign, . from Australian Government, <http://www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/projects/close-gap-indigenous-health>
- Australian Institute of Health and Welfare. (2015). *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015*,. Canberra: AIHW.
- Australian Institute of Health and Welfare & Cancer Australia (2013). *Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview*,. Canberra: AIHW.
- Baade, P. D., Dasgupta, P., Dickman, P. W., Cramb, S., Williamson, J. D., Condon, J. R., & Garvey, G. (2016). Quantifying the changes in survival inequality for Indigenous people diagnosed with cancer in Queensland, Australia. *Cancer Epidemiology*, 43, 1-8. doi: <http://dx.doi.org/10.1016/j.canep.2016.05.002>
- Bernardes, C., Whop, L., Garvey, G., & Valery, P. (2012). Health service utilization by indigenous cancer patients in Queensland: a descriptive study. *Int J Equity Health*, 11(1), 57.
- Bernardes, C. M., Whop, L. J., Garvey, G., & Valery, P. C. (2012). Health service utilization by indigenous cancer patients in Queensland: a descriptive study. *Int J Equity Health*, 11, 57. doi: 10.1186/1475-9276-11-57
- Broom, A., Nayar, K., Tovey, P., Shirali, R., Thakur, R., Seth, T., & Chhetri, P. (2009). Indian cancer patients' use of Traditionak, Complementary and Alternative Medicine (TCAM) and delays in presentation to Hospital, . *Oman Medical Journal*, 24(2).
- Brown, A., Roder, D., Yerrell, P., Cargo, M., Reilly, R., Banham, D., . . . the CanDAD Aboriginal Community Reference Group and other CanDAD Investigators. (2016). Cancer Data and Aboriginal Disparities Project (CanDAD) – an overdue cancer control initiative,. *European Journal of Cancer Care*, 25(2), 208-213. doi: 10.1111/ecc.12466
- Budd, R. (2016). Budd Photography,. 2016, from <http://www.buddphotography.com.au/burdekin-falls-dam/>
- Centers for Disease Control. (1990). Guidelines for investigating clusters of health events. *MMWR*(1990;39), RR-11:11-23.
- Centers For Disease Control. (2013). Investigating Suspected Canver Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists. *MMWR*, 2013/62((RR08)), 1-14.

- Chong, A., & Roder, D. (2010). Exploring differences in survival from cancer among Indigenous and non-Indigenous Australians: implications for health service delivery and research. *Asian Pac J Cancer Prev*, 11(4), 953-961.
- Commonwealth of Australia. (2015). Burdekin, Physical information, . from BOM https://www.google.com.au/search?q=map+of+mainland+australia+burdekin+region&espv=2&biw=1680&bih=965&source=Inms&tbm=isch&sa=X&ved=0ahUKEwiJtJ_x3uXOAhWFjpQKHWh1C30Q_AUIBygC&dpr=1#tbm=isch&tbs=rimg%3ACU0HSQc8G_1V7Ijhm7wDBA4VjCDIdQXFcfOZWEUmb3YlmbR2SfQotxNqAnaUi-XtwbK7coBm64aYB9FfZnfDeevUMmyoSCWbvAMEDhWMIEQiRCEodj6C1KhIJMh1BcVwU5lYRrge61GFRa24qEgkRSZvdiWZtHREd5Yh2AoVFtyoSCZJ9Ci3E2oCdEf vJYYGzlorryKhIJpSL5e3BsrtwRrdE3jCN-d50qEgmgGbrhpgH0VxHEdk1LgEr5QioSCdmd8N569QybEcC0IEEBcDn8&q=map%20of%20burdekin%20region&imgsrc=xbgNBqpNnCL_0M%3A
- Condon, J. R., Zhang, X., Baade, P., Griffiths, K., Cunningham, J., Roder, D. M., . . . Threlfall, T. (2014). Cancer survival for Aboriginal and Torres Strait Islander Australians: a national study of survival rates and excess mortality. *Population health metrics*, 12(1), 1.
- Cook, P. G., Stieglitz, T., & Clark, J. (2004). Groundwater Discharge from the Burdekin Floodplain Aquifer, North Queensland, .
- Cramb, S. M., Garvey, G., Valery, P. C., Williamson, J. D., & Baade, P. D. (2012). The first year counts: cancer survival among Indigenous and non-Indigenous Queenslanders, 1997–2006,. *Medical Journal of Australia*, 196(4), 270-274.
- Department of Health. (2010). Monitoring the incidence and causes of diseases potentially transmitted by food in Australia: Annual report of the OzFoodNet network, 2009, . Retrieved 23 January 2016, from Australian Government,
- Fanon, F. (1963). *The Wretched of the Earth*, . France: Grove Press,.
- Freemantle, J., Ring, I., Arambula Solomon, T. G., Gachupin, F. C., Smylie, J., Cutler, T. L., & Waldon, J. A. (2014). Indigenous Mortality (Revealed): The Invisible Illuminated. *American Journal of Public Health*, 105(4), 644-652. doi: 10.2105/AJPH.2014.301994
- Freemantle, J., Ring, I., Solomon, T. G. A., Gachupin, F. C., Smylie, J., Cutler, T. L., & Waldon, J. A. (2015). Indigenous Mortality (Revealed): The Invisible Illuminated,. *American Journal of Public Health*, 105(4), 644-652.
- Garside, A. L. (2003). *Sustainable sugarcane farming systems: Developments to date*, . Paper presented at the ABARE Outlook Conference Notes,.
- Haslam, S., & McGarty, C. (2009). *Research Methods and Statistics in Psychology*. Thousand Oaks, California: SAGE Publications Inc.
- Moore, S. P., O'Rourke, P. K., Mallitt, K.-A., Garvey, G., Green, A. C., Coory, M. D., & Valery, P. C. (2010a). Cancer incidence and mortality in Indigenous Australians in Queensland, 1997-2006. *Medical Journal of Australia*, 193(10), 590.
- Moore, S. P., O'rourke, P. K., Mallitt, K.-A., Garvey, G., Green, A. C., Coory, M. D., & Valery, P. C. (2010b). Cancer incidence and mortality in Indigenous Australians in Queensland, 1997-2006,. *Medical Journal of Australia*, 193(10).

- Queensland Government. (2013). *Population, Aboriginal and Torres Strait Islander Queenslanders, 30 June 2011*,. Brisbane: Qld Government, Retrieved from <http://www.qgso.qld.gov.au/products/reports/pop-atsi-qld-2011/pop-atsi-qld-2011.pdf>.
- Queensland Government. (2016a). Queensland Health, South West Hospital and Health Service,. 2015, from <https://www.health.qld.gov.au/southwest/>
- Queensland Government. (2016b). *Queensland Regional Profiles, Resident Profile - people who live in the region, Burdekin State Electoral District (SED)*,. Brisbane: Queensland Treasury Retrieved from <http://www.qgso.qld.gov.au>.
- Queensland Government. (2016c). *Reef protection regulations, How does this impact cane farmers?*,. Brisbane: Qld Government, Retrieved from <http://www.qld.gov.au/environment/agriculture/sustainable-farming/cane-farmers/>.
- Queensland Government. (2016d). *Reef protection regulations, Managing agricultural chemicals*,. Brisbane: Qld Government, Retrieved from <https://www.qld.gov.au/environment/agriculture/sustainable-farming/chemicals/>.
- Queensland Government. (2016e). Visitor Information, About the Area, . from Burdekin Shire Council, <http://www.burdekin.qld.gov.au/community/visitor-information/about-the-area/>
- Rametta, S., Grosso, G., Galvano, F., Mistretta, A., Marventano, S., Nolfo, F., . . . Biondi, A. (2013). Social disparities, health risk behaviors, and cancer. *BMC Surgery*, 13, S17. doi: <http://dx.doi.org/10.1186/1471-2482-13-S2-S17>
- Ricaud, C., Egan, B., Gillaspie Jnr, A., & Hughes, C. (1989). *Diseases of Sugarcane, Major Diseases*, : Elsevier Publishing Company,.
- Ricaud, C., Egan, B., Gillaspie Jr, A., & Huges, C. (Eds.). (1989). *Diseases of Sugarcane: Major Diseases*. Amsterdam: Elsevier Publishers B. V.
- Ring, I. T., Dixon, T., Lovett, R. W., & Al-Yaman, F. (2016). Are Indigenous mortality gaps closing: how to tell, and when? *Medical Journal of Australia*, 205(1).
- Roder, D. M., & Buckley, E. (2016). High quality data are the key to understanding inequalities in cancer outcomes for Aboriginal and Torres Strait Islander Australians,. *Medical Journal of Australia*, 205(10), 451-452.
- Smith, M., Poggio, M. J., Thompson, M., & Collier, A. (2014). The Economics of Pesticide Management Practices on Sugarcane Farms: Final Synthesis Report, . Brisbane: Department of Agriculture, Fisheries and Forestry (DAFF), Queensland,.
- Thompson, S. C., Shahid, S., Greville, H. S., & Bessarab, D. (2011). *"A whispered sort of stuff" A community report on research around Aboriginal people's beliefs about cancer and experiences of cancer care in Western Australia*. Perth: Cancer Council Western Australia.

Teaching Report: Bias in interpreting Aboriginal and Torres Strait Islander Health Data

Teaching Report

The one day teaching exercise facilitated by the MAE 2nd year cohort was an important part of the 2015 residential. It also provides an opportunity for 2nd year students to develop skills in adult teaching and to share aspects of the practical experiences and challenges they encountered in their 1st year of MAE learning.

For the 1st year MAE students it gave them the opportunity to interact with 2nd year peers and gain some insight of the MAE teaching component. Our aim was to provide experience in delivering education.

Our cohort found the teaching activity to be a challenging and positive team building activity that would hopefully provide a positive learning/teaching experience for the 1st year students and us.

The learning objectives of the teaching exercise were to:

- Design a structured teaching plan;
- Develop content and teaching materials to facilitate learning for individual topics;
- Deliver a teaching session in lively, learner friendly and participatory manner; and
- Evaluate the session and overall teaching exercise.

Planning and development

Time was allocated during our MAE classes and worked on after hours to plan and develop the teaching session in terms of structure and content. Agreement between our team was made on the structure and content and divided into three sections to be delivered to the 1st year MAEs.

My role

I was a co-presenter as part of a three person team to deliver the 'Bias in interpreting Aboriginal and Torres Strait Islander health data' teaching session.

The Aboriginal and Torres Strait Islander health data session was taught using examples of Indigenous mortality rates 1998-2013, data from the Close the Gap (CTG) report targets, the Qld Hepatitis A study and unpublished data from the Qld FluMum study.

The teaching session was divided into three sections:

Teaching report

1. Close the Gap report child mortality rates (is it real or artefact?); reasons why there is a spike in the Indigenous mortality rates displayed; where the information comes from; and potential limitations with Indigenous mortality data; systematic error; types of bias;
2. The definition of Aboriginal; why some jurisdictions are missing from CTG tables/figures; how much is incomplete Indigenous status data; what are some of the barriers to collecting Indigenous status; demonstrated steps identified in the Hepatitis A and FluMum studies process where Indigenous status may falter;
3. Implications of using results from the Hepatitis A study; how to identify bias in Indigenous data; implications of under-counting and inconsistencies; and reporting limitations when reporting your findings.

I co-facilitated the second section of the teaching session focussing the discussion on:

- Definition of Aboriginal;
- barriers to collecting Indigenous status;
- who should ask the question (i.e. coroners and funeral directors) as per the Australian Institute of Health and Welfare's *National best practice guidelines for collecting Indigenous status in health data sets*;
- Indigenous status not complete in data from jurisdictions such as the Australian Capital Territory (ACT), Tasmania and Victoria;
- Indigenous deaths incomplete in all State and Territory registration systems;
- only four jurisdictions assessed as 'complete' (complete only needs to be 90%), and Queensland, Western Australia(WA), South Australia (SA) and the Northern Territory (NT) representing 60% of Australia's Indigenous population.

Our teaching team encouraged interaction among the class groups via background information, involvement in discussion questions and a small group exercise.

Evaluation

An evaluation form was designed and distributed to the students at the end of the class for feedback on our teaching activity. Questions given to the students asked about the topic covered, was it presented in an easy to understand manner, what they got out of the activity, and whether it was useful to them. Students were also able to discuss positive and negative aspects of the teaching activity and further discussions took place at the end of the exercise.

I found the teaching activity rewarding from a team work perspective, constructive content and acquiring skills in adult instruction and learning.



Bias in interpreting Aboriginal and Torres Strait Islander Health data

Anna-Lena Arnold¹ Leone Malamoo² and Lisa McHugh³
MAE Scholars, National Centre for Epidemiology and Population Health
¹ Indigenous and Rural Health Division, Commonwealth Department of Health
² Australian Institute of Aboriginal and Torres Strait Islander Studies
³ QCMRI & Communicable Diseases Branch, Queensland Health



At the end of this session you should be able to.....

- Describe and interpret a graph
- Explain bias and the two major types of bias
- To identify biases in Aboriginal and Torres Strait Islander health data



Life expectancy

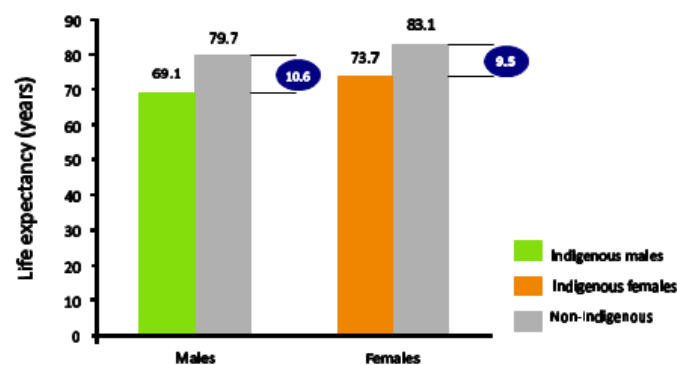
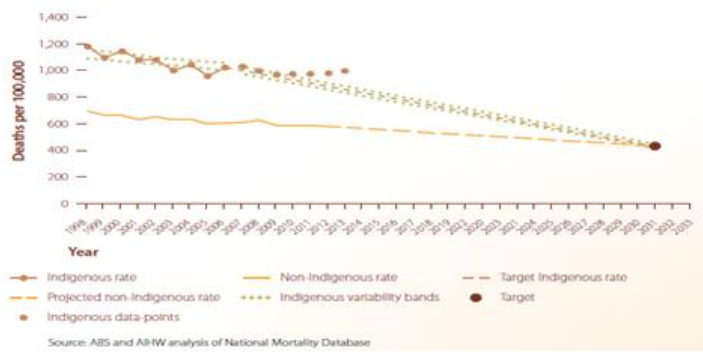


Figure 1:
Overall mortality rates by Indigenous status: NSW, QLD, WA, SA and the NT combined 1998-2031.



- Not on track to close the gap in life expectancy by 2031

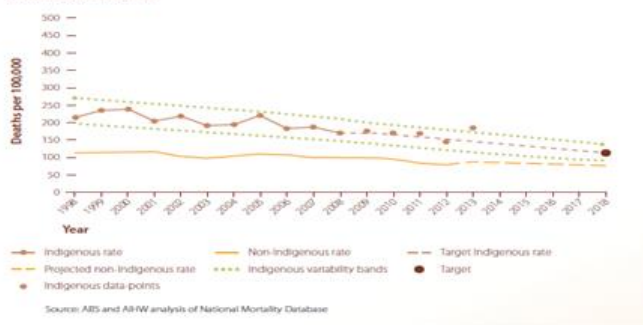
Figure 2: Child mortality rates by Indigenous status, NSW, QLD, WA, SA and the NT combined, 1998-2018



- On track to halve the gap in mortality rates for Indigenous children under five within a decade by 2018

Do you believe it?

Figure 2: Child mortality rates by Indigenous status, NSW, QLD, WA, SA and the NT combined, 1998-2018



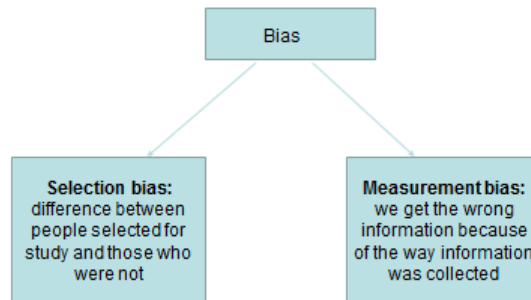
Questions to ask about the data

- Is this real?
 - Are the results statistically significant?
 - Is there confounding?
 - Are the results biased?

What is bias?

- Systematic error.
- Happens when there's a difference between survey results and what's happening in the real population

What are the two major types of bias?



What biases do you think are occurring in these mortality figures?

Figure 2: Child mortality rates by Indigenous status, NSW, QLD, WA, SA and the NT combined, 1998-2018

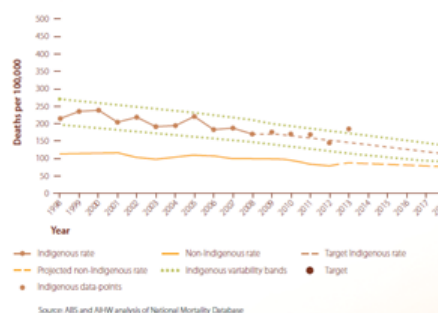
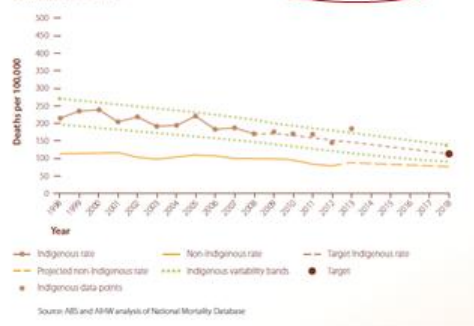


Figure 2: Child mortality rates by Indigenous status, NSW, QLD, WA, SA and the NT combined, 1999-2018



What kind of bias do you think this is?

- Is it selection or measurement bias?
 - Selection bias because ACT, VIC and TAS have been excluded i.e. we have selected a non-representative group into our study
- Why are these States and Territory not included?
 - They have been excluded because of an error in measurement (i.e. error in Indigenous status being recorded)

Incomplete identification of Indigenous status

- Under-reporting of Indigenous status
- Four jurisdictions (QLD, WA, SA and NT) assessed as 'complete'

Why?

- Clients are not asked about their Indigenous status
- The standard question is asked inconsistently
- The answer is recorded inaccurately by the interviewer
- The data are not entered into databases accurately
- People don't identify

Case Study - Hepatitis A

Hepatitis A positive cases who identify as being Aboriginal and/or Torres Strait Islander (unpublished data, 2015).

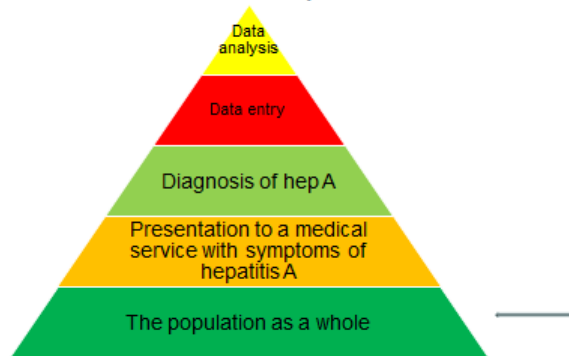
Aboriginal and/or Torres Strait	INDIG_STATUS						
Islander	Aborigine	Torres St	Both Abor	Non-Indig	Not state	.	Total
No	0	0	0	1,492	0	0	1,492
Yes	435	122	35	0	0	0	592
.	0	0	0	0	4,664	1	4,665
Total	435	122	35	1,492	4,664	1	6,749

Case Study - Hepatitis A

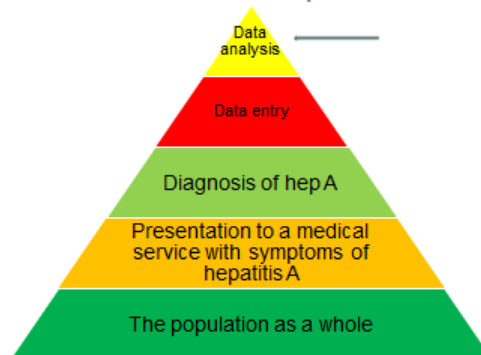
Hepatitis A positive cases who identify as being Aboriginal and/or Torres Strait Islander (unpublished data, 2015).

Aboriginal and/or Torres Strait Islander	INDIG_STATUS						
Islander	Aborigine	Torres St	Both Abor	Non-Indig	Not state	.	Total
No	0	0	0	1,492	0	0	1,492
Yes	435	122	35	0	0	0	592
.	0	0	0	0	4,664	1	4,665
Total	435	122	35	1,492	4,664	1	6,749

Steps where identification process falters



Steps where identification process falters



What type of bias do you think is happening in the Hep A study?

How do you ask the question?

Example of FluMum cohort study workbook/questionnaire for participants who are asked if they identify as being Aboriginal and/or Torres Strait Islander.

18.01	Are you of Aboriginal or Torres Strait Islander origin?	No	AB	TSI	B ^{oth}	DoI
(A1 210Mum)		0	1	2	3	10
18.02	Is your baby of Aboriginal or Torres Strait Islander origin?	No	AB	TSI	B ^{oth}	DoI
(A1 210Baby)		0	1	2	3	10

Case Study ii- Influenza in pregnancy

FluMum study participants who identify as being Aboriginal and/or Torres Strait Islander (unpublished data)2012-2014.

Aboriginal and/or Torres Strait Islander	Preg.	Percent	Con.
0	6,945	97.13	97.13
1	205	2.87	100.00
Total	7,150	100.00	

Case Study ii- Influenza in pregnancy

FluMum study participants who identify as being Aboriginal and/or Torres Strait Islander (unpublished data)2012-2014.

Aboriginal and/or Torres Strait Islander	Preg.	Percent	Con.
0	6,945	97.13	97.13
1	205	2.87	100.00
Total	7,150	100.00	

Measurement bias

- Data collection
- Tool (questionnaire)
- Person recording or interviewing
- Data entry

Group exercise

- What are the implications of using results from this Hep A study?
- Split into group and discuss

Some implications of under-reporting?

- Limits ability to compare across states and services
- We don't know if the characteristics of the people not being captured as Aboriginal and/or Torres Strait Islander are different
- Difficult to measure the gap between Indigenous and non-Indigenous Australians
 - Can lead to an underestimation of the gap difference
- Limits policy makers in understanding what works to overcome indigenous disadvantage and improve health outcomes

Recap

- What have you learnt in today's lesson?
- What was the most important thing you have learnt?
- What was the least important thing you learnt?

Recap – what does this all mean?

- Understand where your data are coming from
 - Bias
 - Chance
 - confounding

Recap – what does this all mean?

- All datasets have their limitations
- Be aware of the limitations that may come with the data
- Report limitations when reporting your findings

Think about selection and measurement bias...

Lessons From the Field (LFF): community
consultation for research with Indigenous
peoples and communities

LFF Objectives

The objective of my LFF to have a discussion centred on:

- Knowledge of community consultation for research with Indigenous peoples and communities
- Importance of collecting Indigenous status data
- Australian Bureau of Statistics (ABS) reports and Indigenous data

During the MAE personal individual and small group discussions often took place between myself and my cohort colleagues in terms of Aboriginality and my thoughts about research, community consultation, some States and Territories left out of government documents etc.

For my LFF I chose to have an informal discussion with my cohort on the importance of respectful interaction, consultation and community engagement with Indigenous people and communities in research; and a brief discussion on the barriers to collecting Indigenous status data, and ABS reports i.e. level of complete data in jurisdictions.

To assist my cohort with their responses, a few days prior to the teleconference I provided them with the Australian Human Rights Commission, *Aboriginal and Torres Strait Islander Peoples Engagement Toolkit 2012*; the National best practice guidelines for collecting Indigenous status in health data sets; and *Using a health promotion framework with an 'Aboriginal lens' – Making Two Worlds Work* which was for their thoughts on the topic. MAE cohort colleagues participated via teleconference, those unable to attend for various reasons had contacted me a couple of days earlier.

Questions and discussion topics

1. What community consultation processes were employed in their project experience?
2. How many of my cohort colleagues have worked in Indigenous communities or research projects involving Indigenous peoples?
3. In their experience do people identify and are they asked if they are Indigenous or not?
4. Why do you think it is important for government departments to record Indigenous status?
5. ABS – are their graphs/charts a true picture of Indigenous peoples?

Summary

Cohort individuals talked of their experiences working with Indigenous peoples from urban and remote areas. All cohort respondents considered the handouts valuable resources complemented by the class taught by Dr Guthrie and Dr Dance and the paper written by Drs Guthrie, Dance and Lovett et al - *Walan Girri: developing a culturally mediated case management model for problematic alcohol use among urban Indigenous people*.

Three of the nine people in my cohort were working on projects involving Indigenous peoples and/or with Indigenous data at the time (one in a remote community area of South Australia; another at the National Aboriginal Community Controlled Health Organisation (NACCHO); and the third with the Qld FluMum cohort). All three persons described their work; who the stakeholders in their projects were; what type of community consultation was undertaken and by whom. Through their projects we also talked about the problems around collecting Indigenous status data, and the barriers to acquiring the information. Discussions were had about why it is important to get it right; Indigenous people not trusting researchers; racism in government departments; and the implications of having to work with incomplete Indigenous data.

The group discussion format provided a collective view on the discussions at hand, and the students provided well developed and well thought out answers to the questions. Cohort colleagues responded in a timely and effective manner prior to and throughout the activity, and all in attendance provided reflective dialogue which proved a successful outcome.

The presenter provided the cohort with a concise summary of the LFF, and the identified objectives of the LFF achieved the desired outcome of this distance learning initiative.