Investigation and Surveillance of Infectious Diseases

Master of Philosophy in Applied Epidemiology Bound Volume

National Centre for Epidemiology and Population Health,
Australian National University

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November 2014

Field placement:

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Canberra

A thesis submitted for the degree of Masters of Philosophy in Applied Epidemiology of the Australian National University.

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Deceleration of work

This thesis is comprised of multiple discrete projects that were undertaken collaboratively with multiple stakeholders and the author acknowledges the contributions made by each of the stakeholders involved in the projects. Taken as a whole document, the author certifies that this thesis is an original work. None of the work has been previously submitted by me for the purpose of obtaining a degree or diploma in any university or other tertiary education institution. To the author’s best knowledge, this thesis does not contain material previously published by another person, except where a reference is made in the text. The author acknowledges that copyright of published works contained within this thesis resides with the copyright holders(s) of those works.

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Anna-Jane Glynn-Robinson

21/11/2014
Acknowledgements

To my husband Joseph Beckett, who helped me find the courage, strength and provided the support I needed to finish the masters. Thank you for being there for me when I need it most, and getting me to step back, breathe and clear my head.

To my mother Mary-Anne, thank you for your patience, for listening and taking my calls at all hours of the day and night.

To my brother Christopher, whose encouragement from the other side of the world always made me feel I could finish what I started. Our late night Skype chats gave me perspective and taught me to stop stressing about the small stuff.

To Noelle O’Hara, our weekly catch up over hot chocolate was more valuable then you’ll ever know.

To my supervisors:
Rhonda Owen, whose patience, insight, support and advice helped me see the wood from the trees. Thank you for getting me to stand back and look at how it all fits together. Martyn Kirk, whose knowledge, technical skills and attention to detail was so invaluable.

To my colleagues in the Vaccine Preventable Diseases Surveillance section, who listened, laughed and guided me through the world of national surveillance. In particular, Rachel de Kuyver who listened and advised me on all things academic; Lynne Hawker who made me laugh and made me feel so welcome; Amy Bright and Kate Pennington, who provided me with the support, encouragement and guidance I needed in the last few weeks of my placement.

To my fellow MAE cohort: thanks for the ride. I have learnt so much from all of you. Our chat’s and debriefs, via email, over drinks and on the phone, not only provided me with the answers to my burning issues, they made me laugh and smile.

To all those involved in my projects, thank you for taking the time to provide me with feedback and advice.

Finally, thank you to the National Centre for Epidemiology and Population Health, for the opportunity to undertake the MAE program, and the Australia Government Department of Health for providing me with the placement and funding to complete my Masters.
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Abstract

In this thesis, I present selected works I conducted in my Master of Philosophy Applied Epidemiology (MAE) placement at the Vaccine Preventable Disease Surveillance (VPDS) Section of the Office of Health Protection (OHP), at the Australian Government Department of Health from March 2013 to November 2014. The works presented comprise my MAE requirements and describe my experiences as an MAE.

I discuss my role in the day-the-day activities of the VPDS section, including the surveillance of notifiable diseases, being the secretariat for the rotavirus working group, writing annual reports and editing Communicable Disease Intelligence Journal submissions. I also describe my role as a Watch Officer for the National Incident Room within the OHP.

I investigated a foodborne outbreak of gastroenteritis at a Mother’s Day buffet luncheon in the Australian Capital Territory (ACT), where curried prawns and Caesar salad were the suspected cause of the outbreak. The investigation was unable to determine the aetiological cause of illness but highlighted the risk often associated with serving buffet style meals.

I present two epidemiological studies. The first is an analysis of notified Legionella infections from 2001 and 2012. Describing the epidemiology of legionellosis in Australia, the analysis found rates of infection are low and more likely to affect males and vulnerable populations such as the elderly. Comparing these results to a previous review of legionellosis in Australia (1991-2000), we found age, sex and season of infection were consistent, but notification rates were stable and higher compared with rates from 1991 to 2000, and Legionella longbeachae was notified more than Legionella pneumophila. I presented the findings of my analysis in an oral presentation at the 2014 Public Health Association of Australia 43rd Annual Conference in Perth.

The second epidemiological project I undertook examined why Indigenous status was underreported in National Human Papillomavirus Vaccination Register (NHVPR). Analysing female vaccination records from 2007 to 2012, we identified 46% were missing Indigenous status. We reviewed the literature, examined register data and consulted with jurisdictional health departments to identify what barriers exist that potentially prevent the reporting of Indigenous status to the NHVPR.
I evaluated the National Notifiable Diseases Surveillance System (NNDSS) as a surveillance system for influenza. The evaluation found that the NNDSS is an acceptable, simple and useable system that provides high quality data for the national surveillance of laboratory-confirmed influenza. However, improvements in the systems flexibility and sensitivity would ensure higher quality surveillance data continues to be available.

Lastly, to fulfil my teaching requirements I prepared a ‘Lessons From the Field’ case study on how to work with Aboriginal and Torres Strait Islander data and conducted a teaching session on measurement and information biases as part of a half day training session undertaken for the MAE cohort of 2014.

This thesis describes my experiences in my MAE placement, the fulfilment of requirements and the findings of my investigations. The work presented in this thesis contributes to the work of VPDS section by improving our understanding of communicable disease surveillance in Australia.
Abbreviations and Acronyms

Chapter 1
CDI Communicable Diseases Intelligence journal
Department of Health Australian Government Department of Health
HEMB Health Emergency Management Branch
NNDSS National Notifiable Diseases Surveillance System
NHVPR National HPV Vaccination Programme Register
OHP Office of Health Protection
PHAA Public Health Association of Australia
VCS Victorian Cytology Service
VPDS Vaccine Preventable Diseases Surveillance

Chapter 2
ACTGAL Australian Capital Territory Government Analytical Laboratory
ACT HPS Australian Capital Territory Health Protection Service
ART Acute Response Team
BDE Bacillus Diarrhoeal Enterotoxin
CDI Communicable Diseases Intelligence journal
EHO Environmental Health Officers
SPC Standard Plate Count
MDU Microbiological Diagnostic Unit
SET Staphylococcal Enterotoxin

Chapter 3
ABS Australian Bureau of Statistics
ASGS Australian Statistical Geography Standards
CDWG Case Definitions Working Group
Department of Health Australian Government Department of Health
NNDSS National Notifiable Diseases Surveillance System
PHAA Public Health Association of Australia

Chapter 4
ABS Australian Bureau of Statistics
AIHW Australia Institute of Health and Welfare
ASGS Australian Statistical Geography Standards
DEC Australian Government Department of Health Human Research Ethics Committee
DERC Australian National University Science and Medical Delegated Ethics Review Committee
Department of Health Australian Government Department of Health
GP    General Practitioner
HPV   Human Papillomavirus
LCG   Local Government Councils
NNDSS National Notifiable Diseases Surveillance System
NHVPR National HPV Vaccination Programme Register
WHINURS Women’s HPV Indigenous Non-Indigenous Urban Rural Study
VCS   Victorian Cytology Service
VIP   HPV Vaccine Impact in the Australian Population
VIP-I Vaccine Impact in the Australian Indigenous Population

Chapter 5

ABS    Australian Bureau of Statistics
ASPREN  Australian Sentinel Practices Research Network
CDC    Centers for Disease Control and Prevention
CDI    Communicable Diseases Intelligence
CNDA   Communicable Disease Network Australia
CDA    Communicable Disease Australia
DAS    Data Acquisition system
FluCAN Influenza Complications Alert Network
H     Hemagglutinin
ILI    Influenza-Like-Illness
Department of Health Australian Government Department of Health
N     Neuraminidase
NISC   National Influenza Surveillance Committee
NNDSS National Notifiable Diseases Surveillance System
NSC    National Surveillance Committee
OHP    Office of Health Protection
VPDS   Vaccine Preventable Diseases Surveillance
PHLN   Public Health Laboratory Network
YTD    Year-To-Date

Chapter 6

CDI    Communicable Diseases Intelligence journal
Department of Health Australian Government Department of Health
HEMB   Health Emergency Management Branch
NNDSS National Notifiable Diseases Surveillance System
NFP    National Focal Point
NHVPR National HPV Vaccination Programme Register
NIR    National Incident Room
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<th>Abbreviation</th>
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<tr>
<td>PHAA</td>
<td>Public Health Association of Australia</td>
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<tr>
<td>VPDS</td>
<td>Vaccine Preventable Diseases Surveillance</td>
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<td>Watch Officer</td>
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1.1 Overview
My field placement for the Master of Applied Epidemiology (MAE) commenced on 25 February 2013, in the Vaccine Preventable Diseases Surveillance section (VPDS), Health Emergency and Management Branch (HEMB), Office of Health Protection (OHP), Australian Department of Health (the Department of Health). My field supervisor was the director of VPDS, Ms Rhonda Owen. During this time I worked on diseases managed by this section including influenza, Human Papillomavirus (HPV) and legionellosis. Collaboration and supervision was provided for each project by specialists in their fields including Dr. Julia Brotherton from the Victorian Cytology Service (VCS), Christina Bareja (VPDS), Kate Pennington (VPDS) and Amy Bright (VPDS). As part of my placement I also worked with the Australian Capital Territory Health Protection Service (HPS) to investigate an outbreak of gastroenteritis. I was seconded to HPS for 2 weeks to assist with the investigation.

This chapter briefly describes: (1) my work placement; (2) my MAE core activity requirements; (3) public health impacts of the projects; and (4) the structure of the bound volume.

1.2 Placement -Vaccine Preventable Diseases Surveillance section
The Department of Health vision is for “better health and wellbeing for all Australian’s”. This outcome is reached through a series of ten goals that are integrated across the division, branch and section structure of the Department of Health. The goals of the Office of Health Protection (OHP) are to prevent, detect, and respond to communicable diseases in the Australian population. OHP contributes to the sustainability of the Australian health system by reducing preventable illness and mortality due to communicable diseases. It achieves this by designing and implementing evidence-based and targeted programs through four separate branches: (1) the Health Protection Policy Branch; (2) the Immunisation Branch; (3) the Medical and Scientific Advisory Unit; and (4) the Health Emergency Management Branch.

The Health Emergency Management Branch (HEMB) is responsible for risk assessments and coordination of the national response to public health events occurring naturally or deliberately introduced biological and emerging threats. The Vaccine Preventable Diseases Surveillance Section (VPDS) is responsible for monitoring, analysing and reporting on vaccine preventable disease and some bacterial, blood-borne and sexually-transmissible infections. The section provides advice to inform policy on vaccines and pandemic planning, relevant information on VPDs to national and international
stakeholders, and provides epidemiological advice to Communicable Disease Network Australia (CDNA).

1.3 Summary of core activities
During the MAE, I have undertaken four specific projects that have enabled me to systematically examine a variety of infectious diseases with respect to: (1) distribution and characteristics in regards to person, place and time; (2) the determinants of risk and probability of being a disease causing agent; and (3) the quality and accuracy of national notification data. This placement developed my skills through practical experience and underpinned the key messages of: (1) putting it into context; (2) looking at the big picture; and (3) ask ‘so what’ factor.

The projects and activities I completed in order to satisfy the requirements of the MAE were as follows:

1.3.1 Field investigation of a public health problem (outbreak investigation)
This project investigated a small outbreak of gastroenteritis that occurred in the Australian Capital Territory in May 2013. Working with members of HPS, ACT Health, I was one of the primary investigators for the outbreak. This work is presented in chapter 2.

1.3.2 Analysis of public health data
This project involved the analysis legionellosis notifications to examine the epidemiology of this disease. As part of my work on this project, I was the primary author for the legionellosis sections for the 2012 and 2013 Annual Report of the National Notifiable Diseases Surveillance System (NNDSS). The combination of these projects established the burden of legionellosis in Australia from 2001-2012, and identified specific changes in the epidemiology of legionellosis over time. This work is presented in chapter 3.

1.3.3 Conduct and interpret and epidemiological study
This investigation identified potential barriers that affected the completion of Indigenous status within the National Human papillomavirus Vaccination Program Register (NHVPR). The project was requested by the Victorian Cytological Service (VCS) and is presented in chapter 4.

1.3.4 Evaluating a public health surveillance system
This project undertook an evaluation of laboratory-confirmed influenza in the NNDSS. The project examined the quality, efficiency and usefulness of the data collected using the evaluation framework developed by the Centers of Disease Control and Prevention, Atlanta, US, and is presented in chapter 5.
1.3.5 Critical review of scientific literature
All the projects required a critical review of the literature to ensure context and scope prior to starting the project. At the beginning of each chapter a brief contextual introduction is provided. A focused literature review was conducted for the work reviewing barriers to the completion of Indigenous status for the NHVPR and is presented in chapter 4. All four major projects discuss the results in light of current literature.

1.3.6 Scientific manuscript for a peer-reviewed journal
One project resulted in a scientific manuscript published in the Communicable Diseases Intelligence Journal.

- Timothy S. Sloan-Gardner, Anna-Jane Glynn-Robinson, April Roberts-Witteveen, Radomir Krsteski, Keith Rogers, Andrew Kaye & Cameron Moffatt. An outbreak of gastroenteritis linked to a buffet lunch served at a Canberra restaurant. (Chapter 2 Appendix 10.3)

1.3.7 Reports for a public health publications and scientific audiences
- Legionellosis, Other bacterial infections Chapter, Annual report of the National Notifiable Diseases Surveillance System, 2012 and 2013 (Chapter 3 Appendix 12.3 and 12.4)
- Data analysis of rotavirus notifications within the NNDSS; Rotavirus working group paper (Chapter 6 Appendix 6.3)

1.3.8 Reports on projects for non-scientific audience
- Summary notes of consultations with key jurisdictional stakeholders regarding the collection of Indigenous status for HPV vaccinations (Chapter 5 Appendix 8.3).
- Minute to the Assistant Secretary of the Health Emergency Management Branch Investigating the utility of laboratory data for influenza surveillance activities (Chapter 5 Appendix 9.10)

1.3.9 Presentations conferences and other events
During my placement I undertook a number of oral presentations. These included:

National conference
- Anna Glynn-Robinson, Martyn Kirk, Rhonda Owen and Timothy Dobbins. Who is at risk of Legionella infection in Australia?, PHAA 43rd Annual Conference, 15-17 September 2014 (Chapter 3 Appendix 12.2)
National meetings and other events

- Anna Glynn-Robinson and Timothy Sloan-Gardener. Using EpiInfo 7 to investigate a large outbreak of gastroenteritis at a Mother’s Day Lunch, OzFoodNet Face to Face Meeting, 15-16 October 213 (Chapter 2 Appendix 10.4)
- Anna Glynn-Robinson and Rhonda Owen, National Communicable Disease Surveillance: The National Notifiable Surveillance System, presentation to a delegation from Bangladesh, 4 September 2014 (Chapter 6, Appendix 6.5)

1.3.10 Teaching including lesson from the field
I participated in seven lessons from the field, including preparing one which explored issues of Working with Aboriginal and Torres Strait Islander data (Chapter 6 Appendix 6.1).

I also contributed to and participated in a half-day teaching exercise conducted for first year MAE scholars in March 2014. This teaching session aimed to provide the first years with knowledge and practical experience in four major epidemiological concepts.

My contributions can be found in Chapter 6, and included:

- Developing a 40 minute session that explored the concepts of selection and measurement bias;
- Developing a teaching plan (Chapter 6 Appendix 6.2a);
- Developing and editing session presentation slides (Appendix 6.2b);
- Contributing to the instructor guide (Appendix 6.2c);
- Presenting information about measurement bias;
- Developing a participant feedback form (Chapter 6 Appendix 6.2d); and
- Providing feedback to two fellow MAEs on their presentation, delivery and teaching skills.

1.4 Public health impact of major projects

1.4.1 The problem with buffet meals- investigation into an outbreak of gastroenteritis Canberra, May 2103
This investigation contributes to the discussion about food hygiene, preparation and handling, by emphasizing how breakdowns in these processes can result in disease. In particular, the finding from this investigation demonstrated that inefficient temperature control and poor handling of food resulted in a preventable outbreak of gastroenteritis. A direct result of this investigation was the implementation of food management plans and
training of employees to prevent outbreaks of foodborne disease occurring in the future. The investigation resulted in a manuscript being submitted to the *Communicable Disease Intelligence* journal adding to the knowledge of foodborne outbreaks in Australia.

### 1.4.2 Legionellosis in Australia: a review of notified legionellosis from 2001 to 2012

This project has two main public health impacts. Reporting the burden of Legionellosis, as part of the NNDSS annual reports of 2012 and 2013, provides information of this disease to decision makers in the Australian Government Department of Health, jurisdictional health Departments and the general public.

This data analysis contributes to the discussion about legionellosis in Australia describing the epidemiology and identifying changes in the disease epidemiology over time. The analysis identified there are inconsistencies in the application of the national surveillance case definition, which may have resulted in the potential over-representative of *Legionella longbeachae* notifications during the period. This analysis showed notification rates in Australia were stable for the period during 2001 to 2012, but were high compared to the previous ten year period of 1991 to 2000.

This project resulted in the findings being presented at the Public Health Association Australia (PHAA) 43rd Annual conference, 15-17 September 2013.

### 1.4.3 Evaluation of Human Papillomavirus (HPV) vaccination amongst Indigenous females: A review of current issues impacting upon the accuracy of estimates

This project provides insight into some of the barriers encountered when collecting Indigenous status information, and highlights the complexities in addressing these barriers. The study provides simple and useful recommendations to assist national and jurisdictional health authorities in improving the completion on Indigenous status on HPV vaccine notifications.

Consultations with jurisdictional health departments resulted in three jurisdictions reviewing and updating the Indigenous status question on their HPV vaccine consent forms, complying with the recommended national standards. Additionally, a number of jurisdictions have taken action to address the incompletion of Indigenous status, including regular reviews of data, providing information to vaccine providers about the importance of collecting this information, and designing databases to prompt for the follow-up of missing information.
1.4.4 Evaluation of the NNDSS: a focus on influenza

This study is the first to review the surveillance of laboratory-confirmed influenza collected through the National Notifiable Diseases Surveillance System (NNDSS). Outcomes of this study have provided the Australian Department of Health with recommendations to improve the analysis and use of laboratory-confirmed influenza notifications. Results of the report are to be presented to the National Influenza Surveillance Committee in 2015 and will provide the basis for decisions to improve the data quality, reporting and analysis of laboratory-confirmed influenza in the NNDSS.

1.5 Structure of the bound volume

This bound volume is presented in six chapters, with specific content provided in the appendices found at the end of appropriate chapters. The first chapter provides an overview of my field placement and structure of the bound volume. Chapters two through to five provide the detail of the major projects I undertook in my MAE placement. Chapter six details my teaching experiences (including a lesson from the field) and provides an overview of other public health experiences undertaken as part of my work in the VPDS section of OHP. Each chapter addresses more than one competency required to complete the MAE program and Table 1 summaries how each chapter relates to these competencies.
### Table 1: Relationship between chapters in this bound volume and the required MAE competencies

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Chapter 2

The problem with buffet meals: An investigation into a gastroenteritis outbreak associated with a buffet lunch in Canberra, Australian Capital Territory, 2013
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1. Prologue

1.1. Investigatory Role

My role in this outbreak investigation was to assist the lead epidemiologist at the Communicable Diseases Control (CDC) section, Health Protection Service (HPS), ACT Health, with an investigation into a gastroenteritis outbreak that occurred in Canberra in May of 2013. HPS contacted OzFoodNet on 13 May 2013 seeking assistance and extra resources to investigate concurrent outbreaks that had occurred in Canberra over the same weekend. Fellow MAE, Timothy Sloan-Gardner, and I were asked to assist.

HPS was first alerted to this outbreak after receiving a number of complaints from the public who become ill a few hours after attending a luncheon held in a restaurant in Canberra on Sunday 12 May. During the course of the investigation I conducted hypothesis generating interviews, developed a standard questionnaire, completed interviews with patrons, planned patron call-backs and contract tracing, entered interview data and provided descriptive and analytical information for daily Acute Response Team (ART) meetings and the final ACT health report.

I used Epi Info version 7.14.1 for the descriptive analysis and Stata version 13.1 for the multivariable analysis. An outcome of this investigation was a paper produced for the Communicable Disease Intelligence journal.

1.2. Lessons Learnt

During the investigation, I gained experience in performing an outbreak investigation and learnt a number of valuable lessons, including how to communicate, work in pressurised situations, how to develop case definitions and the importance of study analysis plans. As this investigation was conducted concurrently with a second larger and more serious foodborne outbreak, communication was vital to ensuring this investigation ran smoothly. During this investigation I learnt the importance of working well within a team and acknowledging the contribution each team member makes to the investigation.

Reflecting on this investigation there were a number of aspect that could have been undertaken to improve the outcomes. Firstly, after completing the investigation I realised the case definition we used was too broad and should have been refined during the investigation. Revising the case definition during the outbreak investigation would have further minimising misclassification bias.
Our investigation did not have a clear study plan developed when it was initiated. Whilst we had broadly outlined how the investigation would be conducted, having a written study plan would have guided the investigation and ensured all members of the team were clear on the studies objectives and methodologies.

Finally, this investigation would have been improved if we had been able to collect more environmental and human faecal samples. By gathering more samples conclusions about the cause of the outbreak would have been stronger. Additionally, if we had been able to collect more human faecal samples, we may have been able to definitively confirm the aetiological cause of the outbreak. Improving the collection of samples could have been achieved by better engagement with the environmental health officers and asking all ill respondents for faecal samples during the telephone interviews.

During the data analysis phase of the investigation I encountered a number of issues in using Epi Info. Whilst the system has the ability to quickly produce basic statistics, on a number of occasions I had to re-start the analysis as the canvas would freeze, collapse or develop errors in recoding. After the investigation was compete, I spent a lot of time trying to figure out how to conduct more complex statistical analyses in Epi Info. After much frustration, I ended up conducting complex statistical analysis (logistic regressions) and statistical tests in Stata. From this experience I have learnt how to use two different statistical software systems and be able to judge which systems I should use in varying situations. I believe overall this experience has given me skills to undertake outbreak investigations and provided me the confidence to analyse data in both Epi Info and Stata.

1.3. Public Health Implications

This investigation contributes to the discussion about food hygiene, preparation and handling, by emphasizing how breakdowns in these processes can result in disease. In particular, the findings from this investigation demonstrate inefficient temperature control and poor handling of food resulted in a preventable outbreak of gastroenteritis. A direct result of this investigation was the implementation of food management plans and the training of employees, to prevent foodborne disease occurring in the future. The investigation resulted in a manuscript being submitted to and published in the Communicable Disease Intelligence journal adding to the knowledge of foodborne outbreaks in Australia.
2. Abstract

On 13 May 2013 a complaint of food related illness were received by the ACT Health Protection Service (HPS). The complainant reported becoming unwell after eating a buffet style meal at a restaurant in Canberra. On 13 May 2013, another compliant was received with the complainant reporting similar symptoms after attend the same restaurant on the same day. To identify the likely cause of illness, an outbreak investigation was launched. We conducted a retrospective cohort study using a standard questionnaire developed from the restaurants buffet menu. The restaurant booking list was used to conduct telephone interviews, and a case was defined as someone who ate the buffet lunch served at the restaurant on 12 May 2013 and developed symptoms of gastroenteritis (such a diarrhoea, abdominal pain and nausea) following the consumption of food.

We identified 225 of the 303 known patrons (74%), of which 56% (125/225) reported to be ill. The median incubation period was 13 hours, while the median duration of illness was 19 hours. The most common symptoms reported were diarrhoea (94%, 118/125), abdominal pain (84%, 103/125) and fatigue (32%, 40/125). Of the 118 ill patrons reporting diarrhoea, 93 reported having 3 or more diarrhoeal episodes in a 24 hour period.

Our multivariable analysis illustrated that illness was significantly associated with consuming curried prawns (adjusted RR 18.1, 95%CI 8.4-38.6, \( p < 0.001 \)) and Caesar salad (adjusted OR 3.9, 95% CI 1.9-7.9, \( p <0.001 \)). Enterotoxin-producing Bacillus cereus and staphylococci (S. aureus) were detected in samples of cooked food, but were not present in stool samples provided by patrons. Samples of the curried prawns and Caesar salad were not available for laboratory testing.

The results of our investigation suggested consuming food at the buffet lunch on 12 May 2013 led to patrons becoming ill. Laboratory testing identified S. aureus, B. cereus and their enterotoxins in food samples and epidemiological evidence suggested enterotoxin poisoning. However, due the lack human and buffet food samples we were unable to definitively conclude if these pathogens were responsible for the outbreak. The implication of multiple foods for the multivariable analysis and evidence from the interviews with kitchen staff suggest that failures in cleanliness, temperature control and food handling practices resulted in the contamination of the food. Our investigation highlights how cross-contamination, temperature abuse and/or poor food handling practices increase the risk of foodborne illness occurring. This outbreak may have been prevented if the restaurant had used appropriate temperature controls and food handling practices when preparing and serving the buffet style food.
3. Introduction

3.1. Foodborne Gastroenteritis

Foodborne gastroenteritis is a significant public health problem in Australia. Estimations suggest that approximately 5.4 million cases occur every year, costing around $1.2 billion dollars annually.\(^1\) Characterised by a combination of symptoms such as diarrhoea, vomiting, abdominal pain and cramping, symptoms of gastroenteritis are often mild and self-limiting with illness usually lasting between 3 to 5 days.\(^2,3\) However, in some cases illness can be more serious requiring hospitalisation and can occasionally lead to death.\(^2\) Caused by multiple pathogens, bacteria and viruses, gastroenteritis can be transmitted to humans through contaminated food and water, and by direct and indirect contact with an infected person or animal.\(^2,4\)

The Australian foodborne disease surveillance network, OzFoodNet, monitors the incidence of foodborne related illness and disease in Australia. Between the years 2000 to 2010, OzFoodNet assisted in the investigation of 1,179 outbreaks associated with contaminated food, of which 18,557 people were reported to be affected including 1,745 hospitalisations and 53 deaths.\(^5,6\)

3.2. Outbreak description

On Monday 13 May 2013, the Health Protection Service (HPS) at Act Health was notified of a potential outbreak of foodborne gastroenteritis through a complaint made by a member of the public. The complainant reported that they, and other members of their table had become ill after consuming food served at a Mother’s day buffet lunch at a restaurant in Canberra on 12 May 2013. On Tuesday 14 May 2013 HPS received three more complaints (from separate bookings) of gastroenteritis, from patrons who attended the same event at the restaurant.

A hypothesis generating questionnaire was used to interview the complainants and members of their tables to determine if there were any common risk factors associated with the reported illness. From these interviews one common exposure was identified, the attendance at a Mother’s Day buffet lunch on Sunday 12 May between 12:00 and 15:30 at a venue in Canberra. At the Acute Response Team (ART) meeting held on 13 May 2013 at ACT Health an outbreak investigation was launched to identify the cause of illness and determine what public health measures were required to prevent further disease.

The investigation team consisted of ACT HPS and ACT Government Analytical Laboratory (ACTGAL) staff, ACT Environmental Health Officers (EHO) and Master of Applied Epidemiology Scholars Timothy Sloan-Gardner and me.
Chapter 3
Epidemiology of legionellosis in Australia:
An analysis of notified cases from 2001 to 2012
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1. Prologue

1.1. My Role

I was the lead author and investigator in this review. My role involved extracting data from the National Notifiable Diseases surveillance System (NNDSS) to analyse and describe the epidemiology of legionellosis in Australia from 2001 to 2012, analyses changes in the reporting of confirmed and probable legionellosis from 2004 to 2012 and write a report for the Australian Government Department of Health. Working closely with contacts in each of these departments, I examined the number of outbreaks and clusters that occurred during the surveillance period and acquired legionellosis surveillance case definitions used by each jurisdiction to investigate if differences in legionellosis surveillance case definitions existed between jurisdictions.

1.2. Lessons Learnt

By undertaking this analysis, I learnt how to extract data from the NNDSS Discover database, perform complex analytical analyses using Stata™ and manipulate data in Microsoft Excel™ to provide appropriate tables and graphs. Additionally, this analysis has improved my knowledge of legionellosis epidemiology, biology, illness and diagnostic testing methods. I have learnt the value of national notification data and the limits that are often associated with its use and how difference in case definitions can influence national analyses.

1.3. Public Health Implications

This data analysis contributes to the discussion about legionellosis in Australia by identifying changes in the disease epidemiology over time. The analysis identified there are inconsistencies in the application of the national surveillance case definition across Australia, which may have resulted in the potential over-representation of *Legionella longbeachae* notifications during the period of 2001 to 2012. This analysis shows legionellosis notification rates are at their highest since reporting began in 1991, with the exception of the notifications rates in 2000. The national notifications rates remained above 1.3 per 100,000 population, which is inconsistent with the patterns seen previously in Australia and internationally.

The results of this project were presented at the Public Health Association Australia (PHAA) 43rd Annual conference, 15 to 17 September 2014.
A final outcome of this project was the review of legionellosis notifications in the Australian Capital Territory and Tasmania. Both jurisdictions identified a number of legionellosis notifications that have been misclassified or did not meet the national surveillance case definition. These review resulted in both jurisdiction’s reclassifying and deleting incorrect notifications from there notification database and the NNDSS, improving the quality of legionellosis data in the NNDSS. This particular outcome supports my findings that the use of the national surveillance case definition is inconsistently applied across jurisdictions, impacting the quality of legionellosis data in the NNDSS.
2. Abstract

*Legionella* causes atypical pneumonia after susceptible people inhale the bacteria in soil or water. Two main species cause infection in Australia – *Legionella pneumophila* and *Legionella longbeachae*. In 2002, a review of notified legionellosis from the National Notifiable Diseases Surveillance System (NNDSS) examined the epidemiology of the disease in Australia for the period 1991 to 2000. The review found that notification rates for legionellosis were rising in Australia, with older males most at risk of infection, particularly in the Summer and Autumn months. To determine if these epidemiological trends are still consistent in Australia, I reviewed the epidemiology of legionellosis in Australia from 2001 to 2012 and explored how variations in the applications of national surveillance case definitions affect the reporting of legionellosis Australia.

Notifications of legionellosis were extracted from NNDSS for the period of 2001 to 2012. Descriptive analysis was undertaken to examine the distribution of *Legionella* infection by age, sex, and jurisdiction, and describe the seasonality and rates over time. Negative binomial regression was used to examine Notification Rate Ratios (NRR) of *Legionella pneumophila* and *Legionella longbeachae* by jurisdiction, age, sex, season and year. *L. pneumophila* and *L. longbeachae* notifications were analysed by confirmation status (confirmed or probable case) and laboratory diagnosis method and jurisdictional surveillance case definitions were collected to analyses the change in reporting of legionellosis case over the surveillance period.

From 2001 to 2012 there were 3,862 notifications of legionellosis in Australia. Notification rates remained relatively stable for the period at 1.3 to 1.7 per 100,000 population. The populations at highest risk of legionellosis were males over 50 years of age. Fifty percent of all legionellosis notifications were attributed to infection with *L. longbeachae* and 45% with *L. pneumophila*. The median age of *L. pneumophila* cases was 60 years (range 1 to 97 years), 69% were male and rates were highest in Autumn and in Victoria (NRR 1.64, 95%CI 1.44 -1.86). The median age of *L. longbeachae* cases was 63 years (range 13 to 99 years), 60% were male and rates were highest in Spring (NRR 1.24, 95%CI 1.1-1.4) and in Western Australia (NRR 5.24, 95%CI 5.0-6.5).

From 2001 to 2012 legionellosis notification rates remained stable but were but were higher than the previous 10 years with the exception of 2000. This rise in notification rates, variations in causative species between jurisdictions and its propensity for
*L. pneumophila* to cause outbreaks, demonstrates why legionellosis remains an important disease in Australia. In order to better understand this disease and its impact on the Australian society, enhanced routine national reporting should be undertaken to identify common risk factors and sources of exposure (community, nosocomial and travel), improve information regarding laboratory confirmation methods and promote consistency in the application of the national legionellosis surveillance case definition.
3. Background

Legionellosis is an atypical pneumonia caused by the bacteria *Legionella*, which was first identified in 1977 following an outbreak of severe respiratory disease at an American Legion convention in 1976.\(^{(1)}\) Commonly found in water, *Legionella* are ubiquitous in manmade environments and natural habitats. Humans are infected with *Legionella* via contaminated aerosols, with common sources of infection including cooling towers, hot water systems, swimming pools and spas.\(^{(2)}\)

Legionellosis is characterised by a non-productive cough accompanied by symptoms such as malaise, myalgia, headache, fever, abdominal pain and diarrhoea.\(^{(3)}\) Its incubation period ranges from 2 to 10 days,\(^{(3-5)}\) and common risk factors associated with infection include being male, being older in age, smoking and having chronic conditions such as chronic lung disease, diabetes, immunosuppression and renal failure.\(^{(6-8)}\) Epidemiological studies from Canada and Europe have estimated *Legionella* is responsible for approximately 2% to 9% of all community acquired sporadic pneumonia.\(^{(9, 10)}\) Less than 5% of people exposed to this bacteria will develop legionellosis and the estimated case fatality rate rages between 3% and 15% of people who develop pneumonia.\(^{(3)}\) There are 55 species and 70 distinct subgroups of *Legionella* recognised internationally.\(^{(2)}\) However, only a few species are known to cause illness in humans.

The majority of human cases of legionellosis are caused by infection with either *L. pneumophila*,\(^{(11)}\) but other species such as *L. longbeachae* can also cause infection, particularly in Australia and New Zealand.\(^{(12)}\) *L. pneumophila* is primarily aquatic and the organism is ubiquitous within warm water in manmade and natural environments.\(^{(8)}\) It is transmitted to humans via aerosolised water droplets from poorly maintained manmade water systems such as water cooling towers, spas and hot water systems.\(^{(1, 9, 10, 13)}\) In comparison, infection with *L. longbeachae* is linked to the inhalation of commercial potting soil and other decomposing materials such as bark and sawdust.\(^{(11, 12, 14, 15)}\)

Legionellosis notifications have been collected in Australia since 1991, with all jurisdictions providing data to the Australian Department of Health (the Department of Health) through the National Notifiable Diseases Surveillance System (NNDSS). The national objectives of legionellosis surveillance in Australia are to monitor the epidemiology of the disease, including trends in incidence, and the detection of clusters and outbreaks.
A review of legionellosis surveillance in Australia from 1991 to 2000 found that the majority of notified cases were aged 50 years or over (73%), more likely to be male (ratio 2:1) and commonly notified in the Summer and Autumn months. The review also identified an upward trend in legionellosis notification rates between 1997 and 2000, attributed to two large *L. pneumophila* outbreaks that occurred in Australia. To review the current epidemiology of legionellosis in Australia, I examined national notification data from 2001 to 2012, explored the variations in the application of national surveillance case definitions across jurisdictions and analysed how legionellosis notifications were confirmed through laboratory testing.

4. Methods

4.1. Collection of notifications in the NNDSS

Legionellosis is a notifiable disease in all states and territories across Australia and under the provisions of jurisdictions public health legislation is required by law to be notified to the jurisdictional health departments. All laboratory-confirmed infections of *legionella* are notified by treating doctors, diagnostic laboratories or hospitals to the health department within their jurisdiction. Once these notifications have been processed and uploaded into the jurisdictions notifiable disease surveillance system, de-identified data is provided electronically to the NNDSS on a daily basis.

4.2. Legionellosis surveillance case definition

The current case definition used of the national surveillance for legionellosis includes confirmed and probable legionellosis cases as outlined below.

A confirmed case requires both laboratory definitive evidence AND clinical evidence.

<table>
<thead>
<tr>
<th>Laboratory definitive evidence</th>
<th>Clinical evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolation of <em>Legionella</em></td>
<td>Fever;</td>
</tr>
<tr>
<td>OR</td>
<td>OR</td>
</tr>
<tr>
<td>Presence of Legionella urinary antigen</td>
<td>Cough;</td>
</tr>
<tr>
<td>OR</td>
<td>OR</td>
</tr>
<tr>
<td>Seroconversion or a significant increase in antibody level</td>
<td>Pneumonia</td>
</tr>
<tr>
<td>or a fourfold or greater rise in titre to <em>Legionella</em>.</td>
<td></td>
</tr>
</tbody>
</table>

A probable case requires both laboratory suggestive evidence AND clinical evidence.

<table>
<thead>
<tr>
<th>Laboratory suggestive evidence</th>
<th>Clinical evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single high antibody titre to <em>Legionella</em>;</td>
<td>Fever;</td>
</tr>
<tr>
<td>OR</td>
<td>OR</td>
</tr>
<tr>
<td>Detection of <em>Legionella</em> by nucleic acid testing;</td>
<td>Cough;</td>
</tr>
<tr>
<td>OR</td>
<td>OR</td>
</tr>
<tr>
<td>Detection of <em>Legionella</em> by direct fluorescence assay.</td>
<td>Pneumonia</td>
</tr>
</tbody>
</table>
4.3. Statistical analyses

I extracted legionellosis notifications with a diagnosis date between 1 January 2001 and 31 December 2012 from NNDSS. Diagnosis date is a field derived by the NNDSS from date of onset or where the date of onset is not known, the earliest of the specimen collection date, notification date (date when a health professional signed the notification or the laboratory issued the result), or the notification received date (date the notification was received by jurisdictional health authority). These data were analysed using Stata™ version 13.1 (StataCorp., USA) and Microsoft Excel™.

Annual notification rates were calculated using Australian Bureau of Statistics (ABS) mid-year populations for the years 2001 to 2012 as the denominator. The average notification rates for age, sex and jurisdiction were calculated using an average of ABS mid-year populations for the years 2001 to 2012 as the denominator.

To estimate the impact outbreaks or clusters had on national notification rates, a rate of sporadic infections was calculated by identifying and removing outbreak and cluster-associated cases from the outbreak reference field in NNDSS. As this field is intermittently completed, I reviewed jurisdictional annual reports and communicable disease bulletins from 2001 to 2013, the National Notifiable Diseases Annual Reports from 2001 to 2012 and consulted with jurisdictional health departments to confirm the number of clusters or outbreaks reported during the period.

The Australian Statistical Geography Standards (ASGS) was used to examine the geographical distribution of legionellosis and of L. pneumophila and L. longbeachae. The ASGS consists of five remoteness areas; Major Cities, Inner Regional, Outer Regional, Remote and Very Remote. For the purposes of this report these areas have been grouped into Major Cities, Regional (inner and outer regional combined) and Remote (remote and very remote combined). ASGS was mapped using the ABS ASGS correspondence files and the cases’ residential postcode. If a postcode was mapped to more than one ASGS area, then the postcode was allocated to the area with the highest percentage as per the ABS correspondences. If a residential postcode could not be mapped to an ASGS area (such as post office or business centre) the ASGS of the case was classified as unknown.

Pearson’s Chi-square statistic was used to examine the relationships between the number of notifications and the risk factors of age, sex, season, jurisdiction and year. To examine the seasonal changes, the median number of notifications by season and species was calculated and of onset. Un-paired t-tests were used to compare the mean number of notifications in autumn with all other seasons for legionellosis and L. pneumophila, and spring with all other seasons for L. longbeachae. I used negative
binomial regression to examine the relationship between significant factors identified in the Chi squared tests (age, sex, jurisdiction, season and year) and notifications rates of *L. pneumophila* and *L. longbeachae*.

Confirmation status is the categorisation of legionellosis notifications to either a confirmed or probable case according to the national surveillance case definition as. I examined changes in the proportions of confirmed and probable *L. pneumophila* and *L. longbeachae* notifications by analysing the confirmation status by year, species and jurisdiction.
5. Results

Between 2001 and 2012, 3,862 notifications of legionellosis were reported to the NNDSS. Of these 75% (2,912/3,862) were confirmed cases. Place of acquisition was available for 55% (2,105/3,862) of all notifications. Ninety-six percent of these notifications acquired infection within Australia and 4% overseas. Of those acquired overseas, Indonesia (34%), Italy (9%) and China (9%) were the most common countries reported. Mortality data were available for 57% (2,206/3,862) of all notifications, of which 6% (125/2,206) died as a result of infection with legionellosis. The highest rate of deaths occurred in males aged 75 to 79 years at 1.3 per 100,000 population.

The annual national notification rates for legionellosis were relatively consistent over the surveillance period, ranging between 1.3 to 1.7 per 100,000 population (Figure 1). Rates declined slightly in 2008 to 1.3 per 100,000 population, and increased from 2009 to 1.7 per 100,000 population in 2012.

Figure 1: Annual notification rates per 100,000 population for legionellosis, by year, 2001 to 2012, Australia

The annual notification rates of legionellosis in major cities displayed small variations, ranging between 1.4 per 100,000 population to 1.9 per 100,000 population from 2001 to 2012 (Appendix Figure 1). Notification rates in regional areas displayed a similar trend, with small variations ranging from 1 per 100,000 population to 1.6 per 100,000 population. Due to the small number of notifications in cases residing in remote areas, there were greater variations in notification rates. Over the surveillance period
notification rates in remote areas ranged from 1.2 per 100,000 population in 2007 to 3.9 per 100,000 population in 2005.

The majority (94%) of legionellosis notifications from 2001 to 2012 were classified as sporadic (Figure 1). There were 40 outbreaks and clusters (230 cases) of legionellosis reported to the NNDSS during the surveillance period, of which one was multijurisdictional (Appendix Table 1). The multijurisdictional outbreak associated with travel to Kuta, Bali and consisted of 14 cases; 4 from Victoria and 10 from Western Australia. Whilst the majority of outbreaks and clusters reported during the surveillance period were attributed to *L. pneumophila*, one cluster from South Australia in 2002 was attributed to infection with *L. longbeachae*. The largest outbreak reported during the surveillance period occurred in Sydney, New South Wales in 2011. There were 29 cases associated with this outbreak, but no common source of infection was identified. (NSW Department of Health, personal communication, 18 June 2014)

The most common species notified during the surveillance period were *L. pneumophila* and *L. longbeachae*. *L. longbeachae* was the most common species notified in all but 4 years, with 40% to 60% of all notifications attributed to this species, while 37% to 56% were attributed to for *L pneumophila* (Table 1). Subtyping information was available for 58% (996/1736) of *L pneumophila* notifications of which 94% (939/996) were subtyped to *L. pneumophila* serogroup 1. Subtyping information was available for 6% (124/1931) of *L. longbeachae* notifications, of which all but one were subtyped to *L. longbeachae* serogroup 1.

Table 1: Notifications for Legionella infections, by species and year of notification, 2001 to 2012, Australia

<table>
<thead>
<tr>
<th>Year</th>
<th>L. pneumophila</th>
<th>L. longbeachae</th>
<th>All other species &amp; unspecified</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>2001</td>
<td>173</td>
<td>56.0</td>
<td>123</td>
</tr>
<tr>
<td>2002</td>
<td>144</td>
<td>45.6</td>
<td>161</td>
</tr>
<tr>
<td>2003</td>
<td>133</td>
<td>39.9</td>
<td>191</td>
</tr>
<tr>
<td>2004</td>
<td>156</td>
<td>50.0</td>
<td>145</td>
</tr>
<tr>
<td>2005</td>
<td>154</td>
<td>47.4</td>
<td>154</td>
</tr>
<tr>
<td>2006</td>
<td>156</td>
<td>45.1</td>
<td>179</td>
</tr>
<tr>
<td>2007</td>
<td>140</td>
<td>46.2</td>
<td>136</td>
</tr>
<tr>
<td>2008</td>
<td>101</td>
<td>37.1</td>
<td>163</td>
</tr>
<tr>
<td>2009</td>
<td>113</td>
<td>37.7</td>
<td>172</td>
</tr>
<tr>
<td>2010</td>
<td>135</td>
<td>44.3</td>
<td>144</td>
</tr>
<tr>
<td>2011</td>
<td>169</td>
<td>47.2</td>
<td>175</td>
</tr>
<tr>
<td>2012</td>
<td>164</td>
<td>43.0</td>
<td>188</td>
</tr>
<tr>
<td>Total</td>
<td>1,738</td>
<td>1,931</td>
<td>193</td>
</tr>
</tbody>
</table>
Of the other species notified during the surveillance period 75% were *L. micdadei* (24/32), 19% were *L. bozemanii* (6/32), 3% were *L. cherri* (1/32), and 3% were *L. wadworthii* (1/32). In 4% (161/3862) of notifications the species was unspecified.

The annual national notification rates of *L. longbeachae* remained relatively stable over the surveillance period between 0.7 per 100,000 population and 0.9 per 100,000 population. In comparison, the annual national notifications rates for *L. pneumophila* declined between 2001 and 2008, falling from 0.9 per 100,000 population in 2001 to 0.5 per 100,000 population in 2008. Rates for this species increased between 2009 and 2012, but remained lower than the notification rates of *L. longbeachae*.

**Figure 2:** Annual notification rates for *L. longbeachae* and *L. pneumophila*, by year 2001 to 2012, Australia

Annual notification rates by jurisdiction ranged from 0 per 100,000 population in Tasmania (2002) and the Australian Capital Territory (2005) to 4.4 per 100,000 population in Western Australia (2006). South Australia and Western Australia had the highest average notification rates (2001-2012) at 3.2 and 3.3 per 100,000 population respectively, with the majority of notifications attributed to infection with *L. longbeachae* (Figure 3).
I analysed reported laboratory confirmation method to examine the difference in the notification rate of by *Legionella* species. Data for laboratory confirmation method were available for 77% (2,970/3,862) of all notifications. Of these cases, 50% were identified using serology (1,476/2,970), 26% were identified using antigen detection (762/2,970) and 19% were identified using combinations (more than one test reported) of tests (575/2,970). Other laboratory methods used included 3% for culture (85/2,970) and 3% for Nucleic Acid Amplification (NAAT) (69/2,970).

By species, the most common laboratory method used to confirm infection with *L. pneumophila* was antigen detection (40%) followed by a mixture of tests (30%). For infections of *L. longbeachae* serology was the most common method, with 70% of notifications identified using this form of laboratory testing.

**Table 2:** Counts and proportions for legionellosis notifications by laboratory confirmation method and species, Australia, 2001 to 2012

<table>
<thead>
<tr>
<th>Laboratory confirmation method</th>
<th>Species</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pneumophila</td>
<td>Longbeachae</td>
</tr>
<tr>
<td>Antigen</td>
<td>571</td>
<td>131</td>
</tr>
<tr>
<td>Serology</td>
<td>319</td>
<td>1,105</td>
</tr>
<tr>
<td>Culture</td>
<td>36</td>
<td>43</td>
</tr>
<tr>
<td>Other</td>
<td>26</td>
<td>41</td>
</tr>
<tr>
<td>Mixture of tests*</td>
<td>420</td>
<td>129</td>
</tr>
<tr>
<td>Unknown/missing</td>
<td>366</td>
<td>482</td>
</tr>
<tr>
<td>Total</td>
<td>1,738</td>
<td>1,931</td>
</tr>
</tbody>
</table>

**Note:** "Mixture of tests" comprises of all cases with more than one laboratory confirmation method reported to the
5.1. Legionella longbeachae

There were 1,931 cases of *L. longbeachae* notified in Australia between 2001 and 2012. Of these 1,241 (64%) were reported as confirmed cases of infection. Mortality data were available for 68% (1,318/1,931). The case fatality rate of *L. longbeachae* during the surveillance period was 3.8% (50/1,318), with the highest rates of death in males aged 84 years and over at 0.9 per 100,000 population. The male to female ratio was 1.7:1 and the highest age-specific rates were in males aged 75 to 79 years at 5.6 per 100,000 population.

**Figure 4:** Notification rates for *L. longbeachae*, by age and sex, Australia, 2001 to 2012

Spring was the most common season in which *L. longbeachae* was notified (Figure 5). By jurisdiction, South and Western Australia had the highest notification rates at 2.6 per 100,000 population and 2.9 per 100,000 population respectively (Figure 3).
My multivariable model for *L. longbeachae* included 1,905 notifications and was adjusted for age, sex, year, jurisdiction and season. *L. longbeachae* was significantly higher in older age groups. Compared with the 0 to 49 years age group, notification was 5.8 times higher in the 50 to 59 years age group, 10.1 times higher in the 60 to 69 years age group, 15.6 times higher in the 70-79 years age groups and 13.9 times higher in the 80 years and over age group. All of these results were statistically significant (*p* value <0.05) (Table 3). The NRR for males was 1.8 times higher compared with females (*p* value <0.05).

Notifications of *L. longbeachae* were higher in Spring (NRR 1.24) when compared with Autumn and notification rates for were 5.7 times higher in Western Australia, 4 times higher in South Australia and 2.7 times higher in the Northern Territory when compared with New South Wales (*p* <0.05). Whilst the notification rates in all other jurisdictions were lower compared with New South Wales, this difference was only significantly for Victoria and the Australian Capital Territory. Notification rates of *L. longbeachae* were higher in every year except 2007 and 2010 when compared with 2001, but only reached statistical significance for the year 2003.
Table 3: Risk factors for *L. longbeachae* notification from multivariable model, Australia, 2001 to 2012

<table>
<thead>
<tr>
<th>Sex</th>
<th>Notifications (%)</th>
<th>Notification Rate Ratio (NNR)</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>701 (36.8)</td>
<td>ref</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>1,204 (63.2)</td>
<td>1.9</td>
<td>1.7-2.1</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>Notifications (%)</th>
<th>Notification Rate Ratio (NNR)</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>123 (6.5)</td>
<td>ref</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>161 (8.5)</td>
<td>1.26</td>
<td>1.0 - 1.6</td>
<td>0.07</td>
</tr>
<tr>
<td>2003</td>
<td>191 (10.0)</td>
<td>1.47</td>
<td>1.2 - 1.9</td>
<td>0.00</td>
</tr>
<tr>
<td>2004</td>
<td>145 (7.6)</td>
<td>1.09</td>
<td>0.8 - 1.4</td>
<td>0.52</td>
</tr>
<tr>
<td>2005</td>
<td>153 (8.0)</td>
<td>1.12</td>
<td>0.9 - 1.4</td>
<td>0.37</td>
</tr>
<tr>
<td>2006</td>
<td>179 (9.4)</td>
<td>1.27</td>
<td>1.0 - 1.6</td>
<td>0.06</td>
</tr>
<tr>
<td>2007</td>
<td>136 (7.1)</td>
<td>0.94</td>
<td>0.7 - 1.2</td>
<td>0.62</td>
</tr>
<tr>
<td>2008</td>
<td>163 (8.6)</td>
<td>1.09</td>
<td>0.9 - 1.4</td>
<td>0.50</td>
</tr>
<tr>
<td>2009</td>
<td>171 (8.9)</td>
<td>1.15</td>
<td>0.9 - 1.5</td>
<td>0.26</td>
</tr>
<tr>
<td>2010</td>
<td>125 (6.6)</td>
<td>0.82</td>
<td>0.6 - 1.1</td>
<td>0.15</td>
</tr>
<tr>
<td>2011</td>
<td>173 (9.1)</td>
<td>1.10</td>
<td>0.9 - 1.4</td>
<td>0.46</td>
</tr>
<tr>
<td>2012</td>
<td>185 (9.7)</td>
<td>1.16</td>
<td>0.9 - 1.5</td>
<td>0.25</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age group</th>
<th>Notifications (%)</th>
<th>Notification Rate Ratio (NNR)</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-49 years</td>
<td>357 (18.7)</td>
<td>ref</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59 years</td>
<td>381 (20.0)</td>
<td>5.77</td>
<td>4.9 - 6.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>60-69 years</td>
<td>471 (24.7)</td>
<td>10.31</td>
<td>8.8 - 12.0</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>70-79 years</td>
<td>462 (24.3)</td>
<td>15.69</td>
<td>13.5 - 18.2</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>80 years and over</td>
<td>234 (12.3)</td>
<td>14.07</td>
<td>11.8 - 16.8</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Season</th>
<th>Notifications (%)</th>
<th>Notification Rate Ratio (NNR)</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autumn</td>
<td>447 (23.5)</td>
<td>ref</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Winter</td>
<td>465 (24.4)</td>
<td>1.03</td>
<td>0.9 - 1.2</td>
<td>0.72</td>
</tr>
<tr>
<td>Spring</td>
<td>565 (29.6)</td>
<td>1.24</td>
<td>1.1 - 1.4</td>
<td>0.001</td>
</tr>
<tr>
<td>Summer</td>
<td>428 (22.4)</td>
<td>0.95</td>
<td>0.8 - 1.1</td>
<td>0.41</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>State</th>
<th>Notifications (%)</th>
<th>Notification Rate Ratio (NNR)</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>418 (21.9)</td>
<td>ref</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VIC</td>
<td>159 (8.4)</td>
<td>0.51</td>
<td>0.4 - 0.6</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>QLD</td>
<td>199 (10.5)</td>
<td>0.84</td>
<td>0.7 - 1.0</td>
<td>0.06</td>
</tr>
<tr>
<td>SA</td>
<td>408 (21.4)</td>
<td>4.00</td>
<td>3.5 - 4.6</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>WA</td>
<td>671 (35.2)</td>
<td>5.56</td>
<td>4.9 - 6.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>TAS</td>
<td>19 (1.0)</td>
<td>0.59</td>
<td>0.4 - 0.9</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>NT</td>
<td>24 (1.3)</td>
<td>2.77</td>
<td>1.8 - 4.2</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>ACT</td>
<td>7 (0.4)</td>
<td>0.40</td>
<td>0.2 - 0.9</td>
<td>0.03</td>
</tr>
</tbody>
</table>

Note: One case was dropped from the model as sex was unknown.
5.2. Legionella pneumophila

There were 1,738 notifications of *L. pneumophila* from 2001 to 2012, of which 88% (1,531/1,788) were reported as confirmed cases of infection. Mortality data were available for 44% (789/1738) of notifications and the case fatality rate of was 3.8% (66/789). Males aged 84 years and over had the highest rates of death at 1.2 per 100,000 population. Rates of infection were higher in males compared with females, with a ratio 2.2:1. The highest age-specific notification rate was reported in males aged 80 to 84 years (4.4 per 100,000 population).

**Figure 6:** Notification rates of *L. pneumophila*, by age and sex, Australia, 2001 to 2012

*L. pneumophila* was more likely to be diagnosed in the months of Autumn with the majority notified cases reported in April (13%, 228/1,738) and May (10.5%, 182/1,738) (Figure 7). By jurisdiction, the highest *L. pneumophila* notification rates were in Victoria and South Australia at 1.3 per 100,000 population and 0.8 per 100,000 population respectively (Figure 3).
My multivariable analysis included 1,686 *L. pneumophila* notifications and adjusted for age, sex, season, jurisdiction and year. The analysis showed that the notification rates were significantly higher in older age groups (Table 4). Compared with those in the 0 to 49 years age group, notification was 5.0 times higher in the 50 to 59 years age group, 7.1 times higher in the 60-69 years age group, 9.6 times higher in the 70 to 79 years age group and 9.9 times higher in the 80 years and over age group. When comparing notifications rates by sex, infection was significantly higher in males (NNR 1.8) compared with females.

Comparing notification rates by jurisdiction, I found that rates for *L. pneumophila* were 1.64 times higher in Victoria compared with New South Wales (*p* value <0.05). Rates in Western Australia and the Australian Capital Territory were also found to be significant, but were lower when compared with New South Wales (Table 4). Differences by season were also identified. Notifications of *L. pneumophila* was significantly lower in winter (*p* value <0.001), Spring and Summer when compared with Autumn. When I compared rates of notifications by year, I found that 2001 had the highest rates during surveillance period compared with every other year, reaching statistical significance for the years 2003, and 2007 to 2012.
Table 4: Risk factors for *L. pneumophila* notification from multivariable model, Australia, 2001 to 2012

<table>
<thead>
<tr>
<th></th>
<th>Notifications (%)</th>
<th>Notification Rate Ratio (NNR)</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>524 (31.8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>1,162 (68.9)</td>
<td>2.4</td>
<td>2.2-2.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Year</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>173 (10.3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>143 (8.5)</td>
<td>0.82</td>
<td>0.6-1.1</td>
<td>0.11</td>
</tr>
<tr>
<td>2003</td>
<td>133 (7.9)</td>
<td>0.76</td>
<td>0.6-0.9</td>
<td>0.03</td>
</tr>
<tr>
<td>2004</td>
<td>156 (9.2)</td>
<td>0.86</td>
<td>0.7-1.1</td>
<td>0.21</td>
</tr>
<tr>
<td>2005</td>
<td>153 (9.1)</td>
<td>0.84</td>
<td>0.7-1.1</td>
<td>0.17</td>
</tr>
<tr>
<td>2006</td>
<td>156 (9.2)</td>
<td>0.84</td>
<td>0.7-1.1</td>
<td>0.16</td>
</tr>
<tr>
<td>2007</td>
<td>139 (8.2)</td>
<td>0.73</td>
<td>0.6-0.9</td>
<td>0.01</td>
</tr>
<tr>
<td>2008</td>
<td>99 (5.9)</td>
<td>0.50</td>
<td>0.4-0.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2009</td>
<td>113 (6.7)</td>
<td>0.58</td>
<td>0.4-0.8</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2010</td>
<td>113 (6.7)</td>
<td>0.55</td>
<td>0.4-0.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2011</td>
<td>152 (9.0)</td>
<td>0.72</td>
<td>0.6-0.9</td>
<td>0.01</td>
</tr>
<tr>
<td>2012</td>
<td>156 (9.2)</td>
<td>0.74</td>
<td>0.6-0.9</td>
<td>0.02</td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-49 years</td>
<td>413 (24.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59 years</td>
<td>380 (22.5)</td>
<td>5.0</td>
<td>4.3-5.9</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>60-69 years</td>
<td>372 (22.1)</td>
<td>7.10</td>
<td>6.1-8.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>70-79 years</td>
<td>329 (19.5)</td>
<td>9.55</td>
<td>8.1-11.2</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>80 years and over</td>
<td>192 (11.4)</td>
<td>9.99</td>
<td>8.3-12.0</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Season</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autumn</td>
<td>577 (34.2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Winter</td>
<td>339 (20.1)</td>
<td>0.60</td>
<td>0.5-0.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Spring</td>
<td>344 (19.5)</td>
<td>0.60</td>
<td>0.5-0.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Summer</td>
<td>440 (26.1)</td>
<td>0.77</td>
<td>0.7-0.9</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>State</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSW</td>
<td>552 (32.7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VIC</td>
<td>662 (39.3)</td>
<td>1.62</td>
<td>1.4-1.8</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>QLD</td>
<td>254 (15.1)</td>
<td>0.81</td>
<td>0.7-0.9</td>
<td>0.013</td>
</tr>
<tr>
<td>SA</td>
<td>118 (7.0)</td>
<td>0.89</td>
<td>0.7-1.1</td>
<td>0.303</td>
</tr>
<tr>
<td>WA</td>
<td>69 (4.1)</td>
<td>0.43</td>
<td>0.3-0.6</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>TAS</td>
<td>18 (1.1)</td>
<td>0.44</td>
<td>0.3-0.7</td>
<td>0.001</td>
</tr>
<tr>
<td>NT</td>
<td>8 (0.5)</td>
<td>0.65</td>
<td>0.3-1.3</td>
<td>0.226</td>
</tr>
<tr>
<td>ACT</td>
<td>5 (0.3)</td>
<td>0.21</td>
<td>0.1-0.5</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
6. Analysis of confirmed and probable legionellosis notifications

Confirmation status was analysed to measure if changes had occurred in the reporting of confirmed and probable notifications for *L. longbeachae* and *L. pneumophila* during the period of 2001 to 2012. Prior to 2004, the national surveillance case definition for legionellosis did not differentiate between a confirmed and probable case. In 2004, the Communicable Disease Network Australia Case Definition Working Group amended the surveillance case definition for legionellosis to include criteria for a confirmed or probable case of legionellosis. For this reason I have analysed the confirmation status of *L. pneumophila* and *L. longbeachae* from 2004 to 2012.

Over the period of 2004 to 2012, confirmed *L. pneumophila* notifications increased slowly, rising from 79% of all *L. pneumophila* notifications in 2004 to 90% in 2012 (Figure 8). In comparison, probable *L. pneumophila* notifications displayed the inverse trend, falling from 62% of all *L. pneumophila* notifications in 2004 to 39% in 2012. The notifications of confirmed and probable *L. longbeachae* displayed opposing trends to *L. pneumophila* over the surveillance period. From 2009 probable *L. longbeachae* notifications displayed a rising trend, increasing from 34% of all *L. longbeachae* notifications in 2009 to 61% in 2012, while confirmed *L. longbeachae* notifications displayed the opposite, falling from 66% of all *L. longbeachae* notifications in 2009 to 39% in 2012.

To assess if national trends were reflected in the jurisdictions, I analysed the frequency of confirmed and probable *L. pneumophila* and *L. longbeachae* notifications in each jurisdiction. The majority of notifications for *L. pneumophila* reported by New South Wales, Queensland and Victoria were confirmed. Whilst probable notifications were reported in these jurisdictions, they were considerably lower in comparison (Figure 9). The frequency of confirmed and probable *L. pneumophila* notifications in the five remaining jurisdictions shifted more frequently. For *L. longbeachae* the majority of notifications reported in South Australia, Tasmania and Western Australia were probable (Figure 10). Similar to the trends seen for *L. pneumophila*, the majority notifications for *L. longbeachae* reported by Queensland and Victoria were confirmed.
Figure 8: Proportions of confirmed and probable notifications for *L. longbeachae* and *L. pneumophila*, by year, Australia, 2001 to 2012

Figure 9: Comparison of confirmed and probable notifications for *L. pneumophila*, by jurisdiction and year, Australia, 2004 to 2012
Although the national surveillance case definition for legionellosis is used by all jurisdictions, a number have defined the titre cut-offs for single high antibody results as they are currently not defined by the national surveillance case definition (Table 5).

Five jurisdictions have defined these cut offs. The Northern Territory, Tasmania and Victoria apply a titre cut off $\geq 1:512$ probable \textit{L. pneumophila} and \textit{L. longbeachae} notifications. South Australia applies a titre cut off of $\geq 1:256$ for probable \textit{L. pneumophila} notifications and $\geq 1:256$ for probable \textit{L. longbeachae} notifications. Western Australia only applies a titre cut off of $\geq 1:512$ to probable \textit{L. longbeachae} notifications. The remaining three jurisdictions, the Australian Capital Territory, New South Wales and Queensland do not specify titre cut offs for probable notifications for either \textit{L. pneumophila} or \textit{L. longbeachae}.

My consultations with the Australian Capital Territory and Tasmania lead to the review of legionellosis notifications in their jurisdictions from 2010 to 2012 and 2001 to 2012 respectively. From this review, both jurisdictions identified a number of \textit{L. pneumophila} and \textit{L. longbeachae} notifications that had either been misclassified or did not meet the national surveillance case definition. As a result of this review, these notifications were updated and either reclassified or deleted from the jurisdictional notification system and the NNDSS.
### Table 5: Use of the national legionellosis surveillance case definition and details of additional specifications for confirmed or probable cases of legionellosis, by jurisdiction (as of 18 June 2014)

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Uses National Case definition</th>
<th>Has additional specifications</th>
<th>Detail of specification</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Confirmed Case</td>
<td>Probable Case</td>
<td></td>
</tr>
<tr>
<td>ACT</td>
<td>✓</td>
<td>✓</td>
<td>No jurisdictional specifications. Rely on Laboratories to determine if case should be reported.</td>
</tr>
<tr>
<td>NT</td>
<td>✓</td>
<td>✓</td>
<td>Single high antibody titre ≥ 1:512 for both <em>L. pneumophila</em> and <em>L. longbeachae</em></td>
</tr>
<tr>
<td>NSW</td>
<td>✓</td>
<td>✓</td>
<td>No jurisdictional specifications at public health unit level. Laboratories in NSW (does not include test conducted in laboratories in other jurisdictions) thought to use titre ≥ 1:128 for both <em>L. pneumophila</em> and <em>L. longbeachae</em>.</td>
</tr>
<tr>
<td>QLD</td>
<td>✓</td>
<td>✓</td>
<td>No jurisdictional specifications. Rely on Laboratories to determine if case should be reported.</td>
</tr>
</tbody>
</table>
| SA           | ✓                  | ✓                | Single high antibody titre for: *L. pneumophila* ≥ 1:256  
* L. longbeachae ≥ 1:1024 |
| TAS          | ✓                  | ✓                | Single high antibody titre of ≥ 1:512 for both *L. pneumophila* and *L. longbeachae* |
| VIC          | ✓                  | ✓                | Antibody titre of ≥ 1:512 for both *L. pneumophila* and *L. longbeachae* |
| WA           | ✓                  | ✓                | Antibody titre ≥ 1:512 for *L. longbeachae*, unless there is good clinical or radiographic evidence of pneumonia. |
7. Discussion

This analysis of legionellosis notification data shows that there have been two changes in the epidemiology of legionellosis in Australia from 2001 to 2012 – high, but stable notifications rates and a shift in the principal species notified. From 2001 to 2012 notifications rates of legionellosis in Australia have remained constant at around 1.6 per 100,000 population, much higher than the rates seen in the previous 10 years. This is inconsistent with earlier epidemiological studies in Australia, \(^{(5)}\) the United States, \(^{(16, 17)}\) Italy \(^{(2)}\) and France \(^{(18-20)}\) in which rates have displayed a rising trend over time.

There are two factors that may have contributed to the high stable rates since 2001. The first is the introduction and use of Urinary Antigen Test (UAT) for \(L.\ pneumophila\). Since the mid 1990's, UATs have become the most widely used test for initial laboratory notifications of \(L.\ pneumophila\). The rise in legionellosis notifications from 1991 to 2000 was partly attributed to increases in the use of UAT, \(^{(10, 21)}\) which became favoured as a test for \(L.\ pneumophila\) during this period as it is easier to perform and results were received on average 5 days earlier compared to other \(Legionella\) testing methods. \(^{(22)}\) Over this surveillance period, 2001 to 2012, 40% of all \(L.\ pneumophila\) cases were detected using UAT, suggesting the use of this testing method is now standard for \(L.\ pneumophila\) and has contributed to steadier levels of reporting.

The second is the rise in public and clinical awareness and understanding of legionellosis from increasing media attention and the recent growth in epidemiological knowledge about the disease. The 2000 legionellosis outbreak at Melbourne aquarium in Victoria, \(^{(23)}\) Australia's largest recorded outbreak, received significant publicity, \(^{(24-26)}\) bringing legionellosis in the conscious mind of the general public and clinicians. This growing awareness of legionellosis has likely resulted in more frequent testing being undertaken by clinicians, which in turn has potentially resulted in more cases being identified and regularly reported.

From 1996 to 2000, \(L.\ pneumophila\) was the most common species to be to be notified in Australia accounting for 51% of all notifications.\(^{(5)}\) However, I found that between 2001 and 2012 the proportion of legionellosis notifications attributed to \(L.\ pneumophila\) declined to 45%, while notifications of \(L. longbeachae\) increased from 42% in 1996-2000 \(^{(5)}\) to 50% in 2001 to 2012. This rise in \(L. longbeachae\) notifications can be attributed to the rise in the notification of probable cases.

The national surveillance case definition for legionellosis includes single serum serology for the notification of probable legionellosis cases. My analysis identified 70% of probable \(L. longbeachae\) were confirmed using single serum samples. Whilst
serology based testing for Legionella is considered confirmatory when both acute and convalescent-phase serum samples are tested in parallel, results from single serum samples need to be interpreted with caution.\(^{(24)}\) Considering the potential for cross-reactions with other legionellae and other organisms, are common in serology based testing, \(^{(24, 25)}\) the observed rise in L. longbeachae probable notifications may be a result of false positives occurring due to the use of single serum serology.

The observed rise in L. longbeachae notifications may also be a result of the changing laboratory criteria used to report probable cases. Changes in the surveillance case definition in 2004 seemed to have a greater effect on the reporting of L. longbeachae than L. pneumophila. It is possible that the use of a single high titre as a confirmation method for probable cases has increased the likelihood of L. longbeachae notifications being reported. Additionally, differences in the surveillance case definition applied by jurisdictions may have also affected this reporting, as there is currently no consistency in the cut offs for single high titre results. Although the Public Health Laboratory Network of Australia has recommended that a single high titre of 1:512 both L. pneumophila and L. longbeachae as a sensitive indicator of infection, they acknowledge that the actual cut-off titre may vary by laboratory, based on local evaluation of the tests.\(^{(25)}\)

Despite these changes, the age, sex and seasonal distribution of legionellosis did not change over time. For the period 2001 to 2012, the male to female was 2:1 and less than 3% of all notifications were reported in people under the age of 30 years. These findings are consistent with the recognised epidemiology of the disease,\(^{(2, 18-20)}\) and are similar to the age and sex distribution identified in the 1991 to 2000 review.\(^{(5)}\) Males and the elderly are considered to be greater risk of Legionella infection for a number of reasons. It is commonly thought males are more prone to infection with Legionella, as they are more likely to be heavy smokers, and as a result may have poorer respiratory and overall general health.\(^{(27)}\) People of older age are thought to be at greater risk, as advancing age sees the deterioration of general health, increasing the prevalence of co-morbid conditions and use of immunosuppressive treatments, which make these populations more vulnerable to infection when exposed to Legionellae in the environment.

Seasonally, the majority of legionellosis notifications were reported in the months of Autumn. When I analysed season by species, I found that L. pneumophila infections were significantly more likely to be diagnosed in the Autumn months and L. longbeachae infections were more common in the months of Spring. This difference in seasonality is attributed to the likely source of infection. L. longbeachae infection is
commonly associated with the use of potting mixture while for *L. pneumophila* sources of infection are commonly associated with air conditioning cooling towers, spa baths and hot water tanks.\(^{12,14}\) As the transmission of this *L. longbeachae* is closely associated with gardening activities it is not surprising notifications of this species are more common in Spring when this activity is more predominant. \(^{14, 15, 31-33}\)

Previous epidemiological studies have identified the rise in the prevalence of sporadic and outbreak related cases of *L. pneumophila* coincide with late Summer and Autumn. \(^{34,35}\) Colonisation of *Legionella* within cooling towers occurs in seasonal patterns. Two Australian studies examined *Legionella* colonisation in cooling towers. The first reviewed cooling tower water samples from New South Wales, Queensland and the Northern Territory and identified seasonal trends in *L. pneumophila* colonisation with peaks occurring in the Summer and Autumn. \(^{36}\) The second study involved testing 30 cooling towers around Adelaide, and investigators found 80% of these towers were colonised with *Legionella* in the Summer months. \(^{37}\)

There were 40 outbreaks and clusters that occurred during the surveillance period resulting in 230 notified cases of legionellosis. Although the vast majority of notifications were sporadic, the large number of outbreaks and clusters highlights the outbreak potential of this disease remains relatively high in Australia, particularly for infections with *L. pneumophila*.

There are number of limitation with this analysis. Whilst legionellosis is a notifiable disease in all jurisdictions, information provided to the NNDSS only represents a proportion (the ‘notified fraction’) of the total cases occurring in the community. Both probable and confirmed legionellosis notifications require laboratory evidence. Testing is at the discretion of the attending medical practitioner and they may preferentially test people they consider to be at more risk of infection. These assumptions may bias notification data towards sub-populations who are perceived to be at greater risk of infection, such as the elderly, and under-represent other populations groups such as children or young adults. Whilst I was aware of this bias associated with the NNDSS data, I was unable to quantify the degree of under-representation.

The analysis of legionellosis notifications by ASGS was mapped using residential postcode and not by postcode of exposure. As an environmentally acquired bacteria cases may be exposed to *legionella* outside of the locality in which they reside. Analysing notifications by postcode of residence may attribute risk of infection to areas in which the bacteria is not present.
The study was unable to account for all notifications associated with outbreaks and clusters. Whilst we endeavoured to confirm all cases associated with an outbreak or clusters, some cases may have been missed due to changes to notification systems, fluctuations in staff and limited resources. However, by cross checking outbreak or cluster cases identified with the NNDSS outbreak reference field with jurisdictional health departments and public health publications, I believe this limitation has been minimised.

Although data from the NNDSS can be used to monitor of incidence of legionellosis and provide long-term epidemiological analyses, data on risk factors are not routinely collected and could not be analysed. Studies conducted in Europe, (9) United Kingdom, (38, 39) and the United States, (40) indicate the ecology of legionellosis varies by type of infection (communities, nosocomial, outbreak and travel related). Australia’s inability to differentiate between sources of infection limits the practicality of understanding how this disease is acquired in Australia. Additionally the lack of risk factor information such as smoking status, presence of co-morbid conditions and immunosuppression, further restricts epidemiological analyses.

European studies have found that travel-associated legionellosis represents a significant cause of travel-associated respiratory tract infections, and impacts disproportionately on otherwise healthy individuals as a consequence of their travel abroad or within their own country. (41) Although place of acquisition was reported in 55% all notifications in the NNDSS, improving its completion provides opportunities to assess the impact of travel-associated legionellosis in Australia and develop, design and implement of prevention strategies to reduce its burden.

A final limitation with this study was in inability to examine the affect testing practices have had on notifications. Although 77% of all notifications were reported as confirmed cases the information provided was counterintuitive, with a number of L. longbeachae notifications confirmed only using antigen detection methods. There is currently no urinary antigen detection for L. longbeachae, and whilst Direct Fluorescent Antigen (DFA) can be used it is generally only used in outbreak situations. (20) Consultations with jurisdictions suggested they were likely to be a result of errors made at the data entry stage or the wrong fields being transferred to the NNDSS.

8. Conclusion
From 2001 to 2013 notification rates remained stable but were the highest recorded, expect for 2000, since reporting began in 1991. This rise in notification rate in the past 10 years, variations between jurisdictions in causative species and its propensity for L
pneumophila to cause outbreaks highlight legionellosis remains an important disease in Australia. To enhance national reporting and provide a more accurate picture of legionellosis in Australia, NNDSS surveillance should include the routine collection of risk factors and sources of exposure (community, nosocomial and travel), as well as improving information regarding laboratory confirmation methods and promoting consistency in the application of the national surveillance case definition.
9. Recommendations

Based on my analysis of NNDSS legionellosis notifications from 2001 to 2012, I recommend the following:

1. Review of the national surveillance case definition for legionellosis: I recommend the case definition for legionellosis be reviewed by the Case Definitions Working Group (CDWG) of CDNA to consider either the removal of single high titre laboratory results for probable legionellosis cases or the inclusion of titre cut-offs that are agreed and applied by all jurisdictions.

2. The Australia Government Department of Health should work with jurisdictions to improve the information reported in the outbreak reference field.

3. The Australia Government Department of Health should consider collecting enhanced data on travel related cases and risk factors such as smoking history, presence of chronic conditions such as lung disease, diabetes and immunosuppression for legionellosis. This should be done in consultation with jurisdictions as it could add a significant burden to the jurisdiction’s in collecting the information.

4. The jurisdictions and the Australian Government Department of Health to consider collecting routine data on source of infection to differentiate between community, nosocomial and travel acquired cases in NNDSS.

5. Jurisdictions to investigate the potential to collect molecular strain characterization of *Legionella* to help identify multi-jurisdictional cases of infection.
10. Acknowledgments

I would like to acknowledge the following people for their assistance with the analysis: Ms. Christina Bareja and Ms. Cindy Toms, Vaccine Preventable Diseases Surveillance, Office of Health Protection, the Australian Government Department of Health; Dr. Timothy Dobbins, the Australian National University; Ms. Carolien Giele, Department of Health Western Australia; Mr. David Colman, Department of Health and Human Services, Tasmania; Ms. Ellen Donnan, Queensland Health; Ms. Jacqueline Stephens and Ms. Ingrid Tribe, South Australia Health; Ms. Lucinda Franklin and Ms. Zoe Cutcher, Department of Health, Victoria; Dr. Peter Markey, Department of Health, Northern Territory; Ms. Paula Spokes and Ms. Robin Gilmour, Department of Health New South Wales; Ms. Rebecca Hundy, ACT Health; and my supervisors Assoc Prof. Martyn Kirk, the Australian National University and Ms. Rhonda Owen, Vaccine Preventable Diseases Surveillance, Office of Health Protection, the Australian Government Department of Health.
11. References


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12. Appendix

Appendix 12.1 – Additional Figures and tables

Appendix Figure 1: Crude rates of Legionellosis per 100,000 population, by ASGS and year, Australia, 2001-2012
## Appendix 12.2 – Known outbreaks and clusters of Legionellosis, by jurisdiction and year, Australia, 2001-2012

<table>
<thead>
<tr>
<th>No.</th>
<th>Year</th>
<th>Month</th>
<th>Season</th>
<th>Case no.</th>
<th>Place</th>
<th>Area of acquisition</th>
<th>Likely source</th>
<th>Species</th>
<th>Ref.</th>
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<td>May</td>
<td>Autumn</td>
<td>8</td>
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<td>Species</td>
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</tr>
<tr>
<td>40</td>
<td>2012</td>
<td>Dec 2011 - Jan 2012</td>
<td>Summer</td>
<td>2</td>
<td>South East QLD</td>
<td>Retirement village</td>
<td>Unknown</td>
<td><em>L. pneumophila</em></td>
<td>(67)</td>
</tr>
</tbody>
</table>
Who is at risk of Legionella infection in Australia?

Ms. Anna Glynn-Robinson*, Dr. Martyn Kirk, Ms. Rhonda Owen and Dr. Timothy Dobbins
*Masters of Philosophy in Applied Epidemiology Scholar
Australian National University

What is legionellosis?

• Environmentally acquired pneumonia
• Caused by bacteria Legionella spp.
• Infection - inhalation of contaminated aerosols
• Symptoms: non-productive cough, headache, fever & abdominal pain
• Common risk factors
  – Elderly
  – Male
  – Chronic conditions
  – Smoking

Legionella

• Ubiquitous in manmade and natural environments
• Common in water and potting mixture
• 55 known species and 70 known serogroups
• Common species in Australia
  – L. pneumophila - air conditioning cooling towers
  – L. longbeachae - commercial potting mixture

Aim

Describe the epidemiology of notified legionella infection 2001-2012

Methods

• Data from NNDSS
• Stata 13.1 & Excel™
• Descriptive analysis
• Negative binomial regression
• Case definition
  • Confirmed – definitive laboratory and clinical
  • Probable – suggestive laboratory and clinical
Legionellosis 2001-2012

- 3,362 notifications
- Majority male (65%)
- Highest age-specific rates 75-79 years
- 4% resulted in death
- 40 clusters/outbreaks identified
  - majority *L. pneumophila*

*L. longbeachae*

- 1,932 notifications
- Rates 1.9 higher in males
- Notifications highest in Spring
- Compared to NSW:
  - 5.5 times higher in WA
  - 4.0 times higher in SA
  - 2.8 times higher in NT

*L. pneumophila*

- 1,731 notifications
- Males 2.4 times higher than females
- Notifications highest in Autumn
- Compared to NSW
  - 1.6 times higher in VIC
Discussion

- Older males highest at risk
- Notifications
  - L. longbeachae in Spring
  - L. pneumophila in Autumn
- Geographical differences
  - L. pneumophila predominate in east
  - L. longbeachae predominate in west

Acknowledgements

- Australian Department of Health
- National Centre of Epidemiology & Population Health, ANU
- Jurisdictional Health Departments
- Public and Private Laboratories

Questions

Survveillance case definition

<table>
<thead>
<tr>
<th>Confirmed Case</th>
<th>Probable Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laboratory evidence</td>
<td>Clinical evidence</td>
</tr>
<tr>
<td>Isolation of organisms OR Presence of Legionella urinary antigen OR Seroconversion on a significant increase in antibody level or a fourfold or greater rise in titre to Legionella.</td>
<td>Fever OR Cough OR Pneumonia</td>
</tr>
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## Multivariable analysis

<table>
<thead>
<tr>
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<th>NRR</th>
<th>95% CI</th>
<th>Compared to</th>
<th>Variable</th>
<th>NRR</th>
<th>95% CI</th>
</tr>
</thead>
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<tr>
<td>Males</td>
<td>1.0</td>
<td>1.0 - 2.0</td>
<td>Females</td>
<td>Values</td>
<td>2.4</td>
<td>2.2 - 2.7</td>
</tr>
<tr>
<td>20-29 years</td>
<td>5.8</td>
<td>4.0 - 8.7</td>
<td>20-29 years</td>
<td>5.2</td>
<td>4.4 - 6.0</td>
<td></td>
</tr>
<tr>
<td>30-39 years</td>
<td>10.2</td>
<td>8.5 - 11.9</td>
<td>30-39 years</td>
<td>7.1</td>
<td>6.1 - 8.3</td>
<td></td>
</tr>
<tr>
<td>40-49 years</td>
<td>15.7</td>
<td>13.2 - 18.2</td>
<td>40-49 years</td>
<td>9.5</td>
<td>8.1 - 11.1</td>
<td></td>
</tr>
<tr>
<td>50-59 years</td>
<td>14.1</td>
<td>11.9 - 16.3</td>
<td>50-59 years</td>
<td>9.9</td>
<td>8.2 - 11.9</td>
<td></td>
</tr>
<tr>
<td>Winter</td>
<td>1.0</td>
<td>0.8 - 1.2</td>
<td>Autumn</td>
<td>Winter</td>
<td>0.6</td>
<td>0.5 - 0.7</td>
</tr>
<tr>
<td>Spring</td>
<td>1.2</td>
<td>1.1 - 1.4</td>
<td>Spring</td>
<td>Spring</td>
<td>0.6</td>
<td>0.5 - 0.7</td>
</tr>
<tr>
<td>Summer</td>
<td>0.65</td>
<td>0.8 - 1.1</td>
<td>Summer</td>
<td>Summer</td>
<td>0.7</td>
<td>0.7 - 0.8</td>
</tr>
<tr>
<td>WA</td>
<td>0.5</td>
<td>0.3 - 0.9</td>
<td>WA</td>
<td>WA</td>
<td>0.4</td>
<td>0.3 - 0.6</td>
</tr>
<tr>
<td>NT</td>
<td>2.5</td>
<td>1.6 - 4.2</td>
<td>NT</td>
<td>NT</td>
<td>0.4</td>
<td>0.3 - 0.7</td>
</tr>
<tr>
<td>QLD</td>
<td>0.8</td>
<td>0.7 - 0.9</td>
<td>QLD</td>
<td>QLD</td>
<td>0.4</td>
<td>0.3 - 0.7</td>
</tr>
<tr>
<td>TAS</td>
<td>0.6</td>
<td>0.4 - 0.8</td>
<td>TAS</td>
<td>TAS</td>
<td>0.4</td>
<td>0.3 - 0.7</td>
</tr>
<tr>
<td>ACT</td>
<td>0.4</td>
<td>0.2 - 0.8</td>
<td>ACT</td>
<td>ACT</td>
<td>0.2</td>
<td>0.1 - 0.5</td>
</tr>
</tbody>
</table>

### Comparison of confirmed and probable notifications of *L. longbeachae* and *L. pneumophila* by year of diagnosis, Australia, 2001-2012

![Graph comparing confirmations and probable notifications of *L. longbeachae* and *L. pneumophila* by year of diagnosis, Australia, 2001-2012](image)

### Proportion of Legionella notifications by laboratory confirmation test and year of diagnosis, Australia, 2001-2012

![Graph showing proportion of Legionella notifications by laboratory confirmation test and year of diagnosis, Australia, 2001-2012](image)

Legionellosis

- A total of 382 cases of legionellosis were notified in 2012.
- Since 1991, the number of legionellosis notifications has continued to rise.
- *Legionella longbeachae*, traditionally associated with potting mix, was more frequently reported as the causative species in 2012.
- In 2012 there were five clusters and an outbreak of legionellosis reported to the NNDSS.

Legionellosis, caused by the bacterium *Legionella*, can take the form of either Legionnaires’ disease, a severe form of infection of the lungs or Pontiac fever, a milder influenza-like illness. The species that are most commonly associated with human disease in Australia are *Legionella pneumophila* and *Legionella longbeachae*. Legionella bacteria are found naturally in low levels in the environment. In the absence of effective environmental treatment *Legionella* organisms can breed to high numbers in air conditioning cooling towers, hot water systems, showerheads, spa pools, fountains or potting mix.

*Epidemiological situation in 2012*

A total of 382 cases of legionellosis were notified in 2012, representing a rate of 1.7 cases per 100,000. Compared with the previous reporting period the overall number of legionellosis cases increased in 2012 by 7%. This number of annual notifications was the highest since 2007 (Figure 11).
Data on the causative species were available for 93% (n=355) of cases reported in 2012. Of the cases with a reported species, proportionally there were slightly more cases of *L. longbeachae* (54%) than *L. pneumophila* (46%). Single cases of *L. micdadei* and *L. micdadei* or *L. pneumophila* were also reported. The case reported with a species of either *L. micdadei* or *L. pneumophila* was confirmed to be legionellosis but serology was unable to determine which species caused infection. Of the 163 *L. pneumophila* notifications, serogroup data were available on 121 cases (74%); 119 (98%) of those serogrouped were *L. pneumophila* serogroup 1, the remaining were serogroup 2.

Over the period 2007 to 2012, annual notifications of *L. longbeachae* ranged from 136 to 190 cases while annual notifications of *L. pneumophila* ranged from 101 to 169 cases (Figure 11). When compared with 2011, the number of cases of *L. pneumophila* decreased by 4% whilst case numbers of *L. longbeachae* increased by 11%.

Mortality data were available for 66% (n=252) notifications in 2012. There were 11 deaths reported due to legionellosis, a slight increase on the 10 deaths reported in 2011. The majority of deaths were attributed to *L. pneumophila* (82%, n=9) infection (Table 6). However, mortality data should be interpreted with caution given 34% of cases were reported without death data to the NNDSS.

**Geographical distribution**

Jurisdictional-specific rates of legionellosis in 2012 varied from 0.5 per 100,000 in the Australian Capital Territory to 3.5 per 100,000 in Western Australia (Table 6).
The geographical distribution of *L. longbeachae* and *L. pneumophila* across jurisdictions in 2012 mirrored 2011, with the exception of Queensland. In 2012, the majority of notifications in South Australia, Queensland and Western Australia were attributed to *L. longbeachae*, whilst in New South Wales and Victoria *L. pneumophila* was the most common infecting species.

**Table 6: Case of legionellosis, Australia, 2011, by species and state or territory**

<table>
<thead>
<tr>
<th>Species</th>
<th>ACT</th>
<th>NSW</th>
<th>NT</th>
<th>Qld</th>
<th>SA</th>
<th>Tas</th>
<th>Vic</th>
<th>WA</th>
<th>Australia</th>
<th>Deaths due to legionellosis</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>L. longbeachae</em></td>
<td>1</td>
<td>29</td>
<td>3</td>
<td>37</td>
<td>26</td>
<td>5</td>
<td>16</td>
<td>73</td>
<td>190</td>
<td>2</td>
</tr>
<tr>
<td><em>L. pneumophila</em></td>
<td>0</td>
<td>64</td>
<td>0</td>
<td>23</td>
<td>13</td>
<td>6</td>
<td>45</td>
<td>12</td>
<td>163</td>
<td>9</td>
</tr>
<tr>
<td><em>L. micdadei</em></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><em>L. micdadei OR pneumophila</em></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Unknown species</td>
<td>1</td>
<td>9</td>
<td>0</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>0</td>
<td>27</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>2</td>
<td>102</td>
<td>3</td>
<td>70</td>
<td>39</td>
<td>12</td>
<td>69</td>
<td>85</td>
<td>382</td>
<td>11</td>
</tr>
<tr>
<td>Rate (per 100,000 population)</td>
<td>0.5</td>
<td>1.4</td>
<td>1.3</td>
<td>1.5</td>
<td>2.4</td>
<td>2.3</td>
<td>1.2</td>
<td>3.5</td>
<td>1.7</td>
<td></td>
</tr>
</tbody>
</table>

**Age and sex distribution**

In 2012, legionellosis was predominantly seen in older males. Males accounted for the majority (61%) of the notifications resulting in a male to female ratio of 1.6:1. There were no notifications in people under the age of 15 years in 2012. Overall, the age group with the highest notification rate was the 85 years and over (7.5 per 100,000). The highest age and sex specific rates were observed in men aged 85 years and over (10.7 per 100,000, 16 notifications) and women aged 74 to 79 years (5.9 per 100,000, 18 notifications) (Figure 12). The 11 cases that were reported to have died due to legionellosis ranged in age between 38 and 87 years (median 70 years); nine deaths were male and two were female.

An infecting species analysis by age group shows that 93% of *L. longbeachae* notifications were reported in persons 40 years or older and was most predominant in the 70 to 79 year age groups (3.7 per 100,000 for both groups). Similarly 95% of *L. pneumophila* infections notified were in person aged 40 years or older and was most predominant in the 85 years and over age group (3.3 per 100,000).
Seasonality

In 2012, diagnoses of legionellosis were highest in July, with 46 cases notified (Figure 13). *L. pneumophila* occurred most frequently in the summer months, with 51 cases reported over the months January, February and December. *L. longbeachae* cases occurred most frequently in spring with 56 cases reported over the months September to November; however, the highest number of cases reported in any one month occurred in July (n=26) of which half (n=13) were notified in WA. The seasonal pattern of *L. longbeachae* in 2012 was similar to the peaks in notifications experienced in the previous 5 years. However, in 2012 the seasonal peak of *L. pneumophila* differed, with the majority of cases diagnosed in the summer months in 2012 compared with the autumn months of the previous 5 years (Figure 13).
Place of acquisition

Place of acquisition was reported in 73% (n=280) of notified legionellosis cases in 2012. Of these cases 96% (n=267) were reported to be acquired within Australia and 4% (n=13) were reported as overseas acquired. Of these Indonesia (n=3) and Thailand (n=2) were the most commonly reported place of acquisition.

Outbreaks and clusters

In 2012, there were five *L. pneumophila* clusters and one outbreak of *L. pneumophila* notified to NNDSS. Two clusters were reported in New South Wales, one in Queensland, Victoria and South Australia and an outbreak reported by Victoria.

In NSW, 14 legionellosis notifications due to *L. pneumophila* serogroup 1 were reported from February to April in Western Sydney and Nepean Blue Mountains Local Health Districts, approximately twice the number of cases usually seen in this period. The cases were clustered in three time periods; early February, mid-March and late April. Extensive investigations into these clusters were unable to determine any common sources for the infections \(^{154}\). An additional cluster in NSW was identified November and December (four notified cases) but no common source was identified. One cluster and one outbreak were reported in Victoria in 2012, involving a total of seven cases from the Northern and Western Metropolitan region. Both investigations were unable to definitively identify sources of infection \(^{155}\).

The Queensland cluster consisted of two cases diagnosed in January and February of 2012. The cases were identified in residents of a retirement village in South East Queensland. An environmental investigation of the facility was undertaken with water
samples collected from the spa, pool and resident showers. The water samples were negative for *L. pneumophila* and no source of the infection was identified during the investigation.

The cluster in South Australia formed part of an investigation that was conducted from January 2013 to March 2013. In total there were 13 cases identified as the same cluster from South Australia (3 of which were notified in 2012) and 3 cases from Victoria.

**Change in the epidemiology of species from 1991 to 2012**
Since 1991 the number of legionellosis notifications has continued to rise (Figure 14). Before 1998 legionellosis notifications were more likely to be attributed to *L. pneumophila*. However since 1998, the most common infective species has alternated between *L. pneumophila* and *L. longbeachae*.

**Figure 14:** Notified cases of legionellosis, Australia, 1991-2012 by year of diagnosis and species

![Graph showing notified cases of legionellosis, Australia, 1991-2012 by year of diagnosis and species](image)

**Discussion**
Since reporting began in 1991, the number of notifications reported annually for legionellosis has increased by two thirds from 122 notifications in 1991 to 382 notifications in 2012. The increased use of more sensitive diagnostic testing may have contributed to this rise in notifications. The demographic profile of legionellosis since 1991 has remained consistent with the recognised epidemiology of the disease. Less than 7% of notified cases attributed to person under the age of 30 years and over 70% attributed to persons aged 50 years and older. However, since reporting began in 1991 there has been a change in the type of notified species. Whilst *L. pneumophila* was the predominate species notified between the years 1991 and 1997,
since 1998 (with the exception of the 2000 *L. pneumophila* outbreak) the most commonly reported species of legionella has alternated between *L. pneumophila* and *L. longbeachae*. Reasons for the emergence *L. longbeachae* as a most commonly reported species is unclear and will require further investigation.

**References**

### Appendix 12.5 - Legionellosis, Other bacterial infections: Annual report of the National Notifiable Diseases Surveillance System, 2013 – (unpublished)

#### Legionellosis

- A total of 505 cases of legionellosis were notified in 2013.
- Compared with 2012, notifications of legionellosis increased by 32% in 2013.
- *Legionella pneumophila*, commonly associated with man-made water systems, was the most frequently reported causative species in 2013.
- **Five clusters and three outbreaks of legionellosis were reported in 2013**

Legionellosis is an environmentally acquired pneumonia caused by the bacteria *Legionella*. It can take the form of either Legionnaires’ disease, a severe form of infection of the lungs, or Pontiac fever, a milder influenza-like illness. The species most commonly associated with human disease in Australia are *Legionella pneumophila* and *Legionella longbeachae*. *Legionella* bacteria are found naturally in low levels in the environment. In the absence of effective environmental treatments *Legionella* organisms can breed in air conditioning cooling towers, hot water systems, showerheads, spa pools, fountains, commercial potting mix and other decomposing material such as bark and sawdust. *Legionella* is generally transmitted to humans through contaminated water or dust aerosols.

**Epidemiological situation in 2013**

There were 505 notifications of legionellosis in 2013, representing a rate of 2.2 notifications per 100,000. Compared with the previous reporting period notifications of legionellosis increased in 2013 by 32% and were the highest since 2008 (Figure 11). It is likely that at least half of the increase in 2013 can be attributed to the outbreak at the Wesley Hospital in Queensland and the subsequent increase in serological testing during that period. This outbreak received significant media coverage and resulted in Queensland issuing public health alerts to the community.

In 2013, data on the causative species were available for 88% (n=444) of notifications reported. Proportionally, there were slightly more notifications of *L. pneumophila* (51%) than *L. longbeachae* (48%). A single notification of *Legionella anisa* and two notifications of *Legionella micdadei* were also reported (Table 6). Serogroup information was only reported for 70% of *L. pneumophila* notifications and 17% of *L. longbeachae* notifications. Of these, 91% of *L. pneumophila* notifications were typed to *L. pneumophila* serogroup 1 and all *L. longbeachae* notifications were typed to *L. longbeachae* serogroup 1.
Over the period of 2008 to 2013, the notified cases of *L. pneumophila* ranged from 101 to 228, whilst notified cases of *L. longbeachae* ranged from 144 to 213 (Figure 15). When compared with 2012, notifications of *L. pneumophila* increased by 40% and *L. longbeachae* by 13%.

In 2013, mortality data was available for 71% (n=358) of notifications. Of these 3% (n=15) were reported to have died due to legionellosis. This proportion is equivalent to the proportion of notifications reported to have died in 2012 (3%, n=11). The majority of deaths were attributed to infection with *L. pneumophila* (80%, n=12) (Table 6). Over the last five years (2008 to 2013) the mortality data of legionellosis notification has improved with the proportion of cases reported with death information increasing from 49% in 2008 to 71% in 2013.

*Figure 15: Notified cases for legionellosis, by species, Australia, 2008-2013*

**Geographic description**

In 2013, Jurisdictional-specific rates of legionellosis varied from 0.3 per 100,000 in the Australian Capital Territory to 3.8 per 100,000 in South Australia (Table 6).

In 2013, *L. pneumophila* was the most notified infecting species in the Australian Capital Territory, New South Wales, Queensland, South Australia and Victoria, while *L. longbeachae* was more common in the Northern Territory and Western Australian. Tasmania reported and equal number of notifications of both species. The geographic distribution in 2013 differed from 2012 in that *L. pneumophila* was the most commonly
notified species in only New South Wales, Tasmania and Victoria, with *L. longbeachae* being more commonly notified in all other remaining states and territories.

**Table 7:** Notifications, rates and deaths for legionellosis, by species and jurisdiction, Australia, 2013

<table>
<thead>
<tr>
<th>Species</th>
<th>ACT</th>
<th>NSW</th>
<th>NT</th>
<th>Qld</th>
<th>SA</th>
<th>Tas</th>
<th>Vic.</th>
<th>WA</th>
<th>Australia</th>
<th>Deaths due to legionellosis</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>L. longbeachae</em></td>
<td>0</td>
<td>38</td>
<td>4</td>
<td>45</td>
<td>31</td>
<td>3</td>
<td>13</td>
<td>79</td>
<td>213</td>
<td>2</td>
</tr>
<tr>
<td><em>L. pneumophila</em></td>
<td>1</td>
<td>54</td>
<td>1</td>
<td>73</td>
<td>32</td>
<td>3</td>
<td>50</td>
<td>14</td>
<td>228</td>
<td>12</td>
</tr>
<tr>
<td><em>L. anisa</em></td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<td>0</td>
</tr>
<tr>
<td><em>L. micdadei</em></td>
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<td>0</td>
<td>0</td>
<td>0</td>
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<td>0</td>
<td>1</td>
<td>0</td>
<td>61</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>1</td>
<td>105</td>
<td>6</td>
<td>165</td>
<td>63</td>
<td>6</td>
<td>66</td>
<td>93</td>
<td>505</td>
<td>15</td>
</tr>
<tr>
<td>Rate (per 100,000)</td>
<td>0.3</td>
<td>1.4</td>
<td>2.5</td>
<td>3.5</td>
<td>3.8</td>
<td>1.2</td>
<td>1.2</td>
<td>3.7</td>
<td>2.2</td>
<td></td>
</tr>
</tbody>
</table>

* 3 deaths.† 2 deaths.‡ 1 death.

**Age and sex distribution**

In 2013, legionellosis was predominantly seen in older males. Males accounted for the majority (54%) of the notifications resulting in a male to female ratio of 1.2:1. There were no notifications in people under the age of 10 years. The highest age and sex specific rates were observed in men and women aged 75-79 years and over at 8.7 per 100,000 and 8.6 per 100,000, respectively (Figure 12). The ages of the 15 cases reported to have died due to legionellosis in 2013 ranged between 38 and 96 years (median 72 years); 11 deaths were male and 4 were female. In 2013, the demographic profile of legionellosis remained consistent with the recognised epidemiology of the disease. (64-66)

Analysis by infecting species and age group identified that 93% of *L. longbeachae* notifications were reported in persons aged 40 years or older and was the predominant species reported in the 75 to 79 year age groups (4.6 per 100,000). Similarly, 85% of notified *L. pneumophila* infections were in persons aged 40 years or older and was the predominant species in the 85 years and over age group (3.2 per 100,000).
**Seasonality**

In 2013, diagnoses of legionellosis were highest in September, with 60 notified cases (Figure 13). In 2013, the seasonal pattern of *L. pneumophila* and for *L. longbeachae* differed from the seasonal patterns seen in the previous five years. From 2008 to 2012, the diagnosis of *L. pneumophila* commonly occurred in the autumn and summer months, whilst a diagnosis of *L. longbeachae* was more common in the spring months. In 2013, the diagnosis of both species peaked in winter, with 70 *L. pneumophila* cases and 71 *L. longbeachae* cases notified in June, July and August (Figure 13). It is unclear why this change is seasonality occurred, but it may be the result of the increase in legionellosis testing in Queensland between June and September 2013 following the Wesley Hospital Outbreak.
Place of acquisition
In 2013, a place of acquisition was reported in 80% (n=402) of legionellosis notifications. Of these, 94% (n=379) were reported to be acquired within Australia and 6% (n=23) were reported to be acquired overseas. Of the overseas acquired notifications, Thailand (17%, n=4) and Indonesia (13%, n=3) were the most commonly reported places of acquisition.

Outbreaks
In 2013, there were five clusters and three outbreaks of legionellosis notified to the NNDSS. All were attributed to *L. pneumophila* serogroup 1 and occurred in three jurisdictions; Queensland, South Australia and Victoria.

There was one outbreak reported in Queensland. On 5 June 2013, the Wesley Hospital notified Queensland Health of two legionellosis cases, one resulting in death. Environmental investigations identified the most probable source of infection for this outbreak of *L. pneumophila* was contamination of the hospitals heated water systems. In 2013, Victoria reported four clusters and two outbreaks, involving a total of 26 cases, and South Australia reported one cluster involving 12 cases. The sources of infection of these clusters and outbreaks were not determined.

Reference
Chapter 4

Evaluation of Human Papillomavirus (HPV) vaccination amongst Indigenous females: A review of current issues affecting the accuracy of vaccination estimates
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1. Prologue

1.1 My role

As a lead investigator for this project I was responsible for data analysis, collection and interpretation of data from the consultations, undertaking the focused literature review and authoring the report. To undertake this project I submitted and gained ethical approval from the Australian Government Department of Health Human Research Ethics Committee (DEC) and the Australian National University Science and Medical Delegated Ethics Review Committee. I submitted a data request to National Human Papillomavirus Vaccination Programme Register (NHVPR) and used Stata™ version 13.1 (StataCorp, USA) and Microsoft Excel™ to examine incompletion of Indigenous status in the NHVPR.

In collaboration with Dr. Julia Brotherton, I consulted with jurisdictional health departments to explore the barriers to collecting Indigenous status. As part of the consultations I also wrote and distributed a summary of the consultation findings to stakeholders.

1.2 Lessons learned

Undertaking this project has taught me a number of key lessons. By going through the ethical approval process, I learnt how to develop and write ethics documentation, and how to work with Aboriginal and Torres Strait Islander data. In particular, learning about cultural safety has helped me to better understand the complexity involved with collecting Indigenous status and ensure my analysis and interpretation was respectful.

I learnt to be persistent and flexible. There were a number of different processes I had to go through to gain access to data in the NHVPR. Unlike my other projects where access to the data was relatively straightforward, this project required a number of different stages and a high degree of complexity. By undertaking a data request I refined the project aims and objectives and clearly identify how this data related to the overall research question. This enabled me to plan the data analysis component more effectively, and better utilise the data. I also learnt how to analyses large datasets in Stata, gaining expertise in merging data and undertake a complex cleaning processes
1.2 Public health implications

This project provides insight into some of the barriers encountered when collecting Indigenous status information, and highlights the complexities in addressing these barriers. The study provides simple and useful recommendations to assist national and jurisdictional health authorities in improving the completion on Indigenous status for not only HPV vaccinations, but also other disease collections and vaccination programs.

Consultations with jurisdictional health departments resulted in three jurisdictions updating Indigenous status on their HPV vaccine consent forms to align with the national Guidelines. Following the consultations, a number of jurisdictions undertook actions to address the incompletion of Indigenous status within their HPV vaccination collections. These included regularly reviewing the data, informing vaccine providers about the importance of collecting Indigenous status and amending vaccination databases to prompt for the follow up of missing information.
2. Abstract

Genital Human Papillomavirus (HPV) is a viral infection occurring in both males and females. In April 2007 Australia launched the National HPV Vaccination Program (the Program) for females. To monitor the coverage of the Program, the National HPV Vaccination Program Register (NHVPR) was established to collect data on HPV vaccinations administered in Australia.

Although data from the NHVPR is used to estimate HPV vaccination coverage among females, estimates by Indigenous status are difficult to calculate due to the insufficient reporting of these data. Incomplete Indigenous status in Australian healthcare datasets is a common issue. The purpose of this study is to identify the barriers to the collection of Indigenous status for females in the NHVPR and provide recommendations to reduce these barriers and improve Indigenous status identification.

To analyse the completeness of Indigenous status for females in the NHVPR and identify likely barriers to its collection, I undertook a review of the literature; conducted consultations; and reviewed female vaccination records from 2007 to 2012.

The analysis of the NHVPR data identified gaps in the current reporting of Indigenous status by jurisdiction, and highlighted the Northern Territory and Queensland were the only jurisdictions providing sufficient data for Indigenous status. Barriers identified through the literature and consultations included misconceptions about Indigenous status; the presentation of Indigenous status questions on healthcare forms; and variations in data collection methodology and administration of school-based HPV vaccination programs.

Understanding the barriers encountered when collecting Indigenous status for the NHVPR is complex. The findings of my report has identified some of these barriers, but as this is issue is often impacted by a vast range of factors, it has only scratched the surface. Working towards improving statistical information about Indigenous health not only requires national standards to guide information collection but also requires research into issues that prevent the disclosure or the request of Indigenous information. To completely understand the issues relating the completion of Indigenous status in the NHVPR, broader consultations with vaccine providers and consumers and ongoing reviews and evaluations of collection methodologies need to be undertaken.
3. Background

Genital Human Papillomavirus (HPV) is a viral infection occurring in the anogenital region of both males and females. Transmission occurs through close skin to skin or mucosa to mucosa contact and commonly occurs through sexual intercourse. It is estimated that between 50% and 80% of anogenital HPV transmission occurs after a person has engaged in unprotected sexual intercourse.\textsuperscript{(1-3)} Cases of perinatal transmission can also occur, but is relatively infrequent.\textsuperscript{(4)}

There are over 100 HPV genotypes, but only 40 are sexually transmissible.\textsuperscript{(5)} HPV associated anogenital infections are considered to be a normal part of being sexually active. As the majority of infections are asymptomatic, most people will have a HPV infection at some time in their lives and be unaware they have had it. The vast majority (70 to 90%) of HPV infections resolve spontaneously, approximately 12 to 24 months after infection.\textsuperscript{(6)} On occasion, when a HPV infection has not been resolved, there is an increased risk of developing high grade pre-neoplastic abnormalities.\textsuperscript{(7)} A small proportion of persistent HPV infections (around 3% to 10%) may progress to cancers of the anogenital tract.\textsuperscript{(8)}

The four most common HPV genotypes infecting the anogenital areas are HPV 6, 11, 16 and 18. Genotypes 6 and 11 can cause benign or low-grade non-carcinogenic changes in the cervix, anogenital warts and in rare cases recurrent respiratory papillomatosis (RRP). Genotype 16 and 18 are considered to be high-risk, as a small proportion of all infections can progress to cervical, vulvar, vaginal, penile, and anal cancers as well as some oropharyngeal cancers \textsuperscript{(9, 10)} Cervical cancer is the most common HPV-associated cancer in Australia.\textsuperscript{(11)}

The National HPV Vaccination Program (the Program) was introduced for females in April 2007 Australia.\textsuperscript{(12)} The Program initially consisted of two components: an ongoing school-based program for females aged 12 to 13 years and a 2-year catch-up program for females aged 13 to 26 years, which ceased on 31 December 2009. Between 2007 and 2009 around 83% of females aged 12 to 17 years were vaccinated with at least one dose, and 70% completed all three doses.\textsuperscript{(13)} In 2013, the Program was extended to include males, with vaccine made available through school-based programs for males aged 12 to 13 years and a time-limited catch-up program for males aged 14 to 15 years, which concluded at the end of 2014.\textsuperscript{(12)}

There are two HPV vaccines are currently registered in Australia: the bivalent vaccine, Cervarix® and the quadrivalent vaccine, Gardasil®. Cervarix® provides protection against genotypes 16 and 18 and Gardasil® protects against genotypes 16, 18, 11 and 6.\textsuperscript{(12)}

\textsuperscript{4-4}
The current vaccination schedule requires a course of three doses, administered within a 12 month period. The administration of these vaccines is recommended as follows:

- Cervarix – Three doses at 0, 1 and 6 months.
- Gardasil – Three doses at 0, 2 and 6 months.

As HPV infection is not a nationally notifiable disease in Australia, surveillance is conducted as a component of the Program outside of the National Notifiable Disease Surveillance System (NNDSS). The surveillance of HPV is conducted through a number of mechanisms, and aims to monitor the effectiveness of the HPV vaccination on circulating HPV genotypes in the Australian male and female populations.

One of these mechanisms is the National HPV Vaccination Program Register (NHVPR). Established in 2007, the NHVPR is a confidential database that supports the Program by collecting data on HPV vaccinations administered in Australia. Data are provided to the NHVPR by jurisdictional health departments, local government councils (school-based Program), General Practitioners (GP), nurses, Aboriginal health works and other immunisation providers.\(^{14}\) Data on HPV vaccinations are provided to the register under the provisions of the National Health Amendment 2007\(^{15}\) (National HPV Vaccination Program Register).

To determine the baseline prevalence of HPV in the female population, the Women’s HPV Indigenous Non-Indigenous Urban Rural Study (WHINURS) compared the prevalence of genotype-specific HPV among unvaccinated non-Indigenous and Aboriginal and Torres Strait Islander populations in urban and remote areas of Australia.\(^{16}\) Whilst the study found no difference in the rates of HPV genotypes 16 or 18 between Aboriginal and Torres Strait Islander women and non-Indigenous women, it identified risk factors for HPV infection, such as smoking, higher fertility rates and lower participation rates for cervical screening were higher amongst Aboriginal and Torres Strait Islander women.\(^{17}\)

Following WHINURS, the HPV Vaccine Impact in the Australian Population (VIP) study examined the impact the HPV vaccine on the prevalence of HPV genotypes largely in non-Indigenous women following, the roll out of the Program. Initial results from this study showed reductions in vaccine related genotypes of HPV in unvaccinated women.\(^{13}\)

Whilst WHINURS and VIP provide early insight into the potential effectiveness of the HPV vaccines, there is still a need to assess the vaccination coverage within the Aboriginal and Torres Strait Islander female population.\(^{18}\) The burden of cervical cancer is higher in the Aboriginal and Torres Strait Islander women than non-
Indigenous women. \(^{(18)}\) From 2005 to 2009, the incidence rate of cervical cancer among Aboriginal and Torres Strait Islander was 21.4 new cases per 100,000 population and the mortality rate was at 9.0 deaths per 100,000 population.\(^{(18)}\) These rates are significantly higher compared with non-Indigenous woman, at 8.6 new cases per 100,000 population and 1.9 deaths per 100,000 population. \(^{(18,15)}\) As the incidence of cervical cancer and the risk profile is higher amongst Aboriginal and Torres Strait Islander women, it is important to examine and monitor vaccination coverage in these high risk populations.

Although vaccination coverage estimates for Aboriginal and Torres Strait Islander women has been calculated in the past, due to under-reporting of Indigenous status in the NHVPR they have been limited to Queensland and the Northern Territory. \(^{(19)}\) The lack of completeness Indigenous status in Australian healthcare datasets is a common issue. Whilst best practice guidelines have been developed to encourage the systematic and consistent collection of Indigenous status, \(^{(20)}\) underreporting is still prevalent. \(^{(21-27)}\) The purpose of this study is to identify the barriers to the collection of Indigenous status in the NHVPR and provide recommendations to reduce these barriers in the future. As the male HPV vaccination Program did not commence until 2013, male HPV data has not been examined for this study.
4. Methods

4.1 Collection of HPV vaccination records in the NHVPR

HPV vaccination data are collected through the HPV school-based vaccination programs (local councils and jurisdictional health departments) and private providers (GPs, nurses, Aboriginal healthcare workers and other vaccine providers). Data are collected via a number of different mechanisms, including electronic transfers, direct entry to the NHVPR web portal and paper forms which are mailed or faxed to the Victorian Cytology Service (VCS) for data entry.

HPV vaccine consent forms are used to collect data through the school-based vaccination programs and are provided electronically by jurisdictional health departments or Local Government Councils (LCG) (Figure 1).

Data of HPV vaccinations administered through private providers are collected through direct entry into the NHVPR web portal and on vaccine notification forms or GP practice software printouts. Private providers in the Australian Capital Territory, New South Wales, South Australia, Victoria and Western Australia fax or mail notifications forms or software printouts to VCS or directly enter data into the NHVPR web portal through a secure website.\(^{(14)}\)

Private providers in the Northern Territory and Queensland are asked to send HPV vaccination records directly to the jurisdictional health department, where the data are collated with the school-based program collection and electronically transmitted to the NHVPR.

Figure 1: Flow of data inputs into the NHVPR web portal for private and school based vaccinations, Australia
Data elements collected in the register include mandatory and optional fields. Mandatory fields include: date of birth; name; address; state; postcode; vaccine brand; vaccine provider number; vaccine dose number; and date of vaccination. Optional fields include: consumer reference number; middle and given names; previous surname; sex; Indigenous status; Medicare number and reference; country of residence; consent date (on school-based HPV consent forms); name and contact details of consenting parent or guardian (on school-based HPV consent forms); school details (on school-based HPV consent forms); and provider contact details.

Information collected in the NHVPR is used for a range of functions including:

- providing completion of vaccination statements to consumers;
- reminding vaccine consumers of overdue vaccine doses; and
- using de-identified data to monitor and evaluate the participation in the Program to inform policy and research. (14)

Currently, Indigenous status is an optional field in the NHVPR. To accommodate differences in how this information is collected within each jurisdiction the NHVPR accepts:

- A - Aboriginal
- T - Torres Strait Islander
- AT - Aboriginal and Torres Strait Islander
- Y - Aboriginal or Torres Strait Islander
- N - Neither
- U - Unknown or Not Stated
- None (blank)

4.2 Project analysis

To analyse the completeness of Indigenous status in the NHVPR and identify the likely barriers to its collection a mixed methods approach was used. This approach included:

- a review of the literature;
- consultations with jurisdictional health departments; and
- analysis of NHVPR data from 2007 to 2012.

Human Ethical approval was provided by the Australian Government Department of Health Human Research Ethics Committee (DEC) on 21 January 2014 and the Australian National University Science and Medical Delegated Ethics Review Committee (DERC) on 3 March 2014.
4.2.1 Literature review

I searched the literature using Medline and PubMed search engines. Peer-reviewed journal articles and grey literature dated from 1979 to 2013 available in English were included. Letters, editorials, comments and clinical trials were excluded from the analysis.

To ensure relevant articles and grey literature were identified, I conducted two searches (Appendix Figure 1). The first search focussed specifically on articles and reports relating to HPV, while the second expanded used broader terms to identify other relevant literature. The search terms for this review are listed below:

First search terms:

- ‘HPV’ or ‘Human Papillomavirus vaccination’ were used as the Medical Subject Headings (MeSH) with either ‘Indigenous’, ‘Indigenous & Australia’, ‘Indigenous status & healthcare’ as subheadings.

Second search terms:


4.2.2 Consultations

Consultations with key stakeholders were conducted in two stages. The first stage was conducted over 2 weeks in August 2013 and the second between July and August of 2014. This two stage consultation process was used to gain an in-depth understanding of the current processes used to collect and report Indigenous status in each jurisdictions, the barriers they encountered collecting this information and the actions they have been taken to improve Indigenous status completion.

The first stage consultations were un-structured conversations conducted over the phone with immunisation program areas in each jurisdictional health department and an immunisation program co-ordinator based in the Northern Queensland public health unit. These consultations focused on: 1) understanding how jurisdictions collected HPV vaccination data from the schools-based programs; 2) the barriers they believed affected the completion of Indigenous status; and 3) what actions could be taken to improve the collection of Indigenous status.
Second stage consultations were used to follow-up on information and were conducted over the phone using a semi-structured interview. These interviews focused on:

- the collection of school-based HPV vaccination consent forms and GP HPV notification records within each jurisdiction;
- how data from the school-based HPV vaccination consent forms are collated, stored and transmitted to the NHVPR;
- what data are provided to the NHVPR; and
- how missing Indigenous status is managed in each jurisdiction (i.e. are the data followed up, left as missing or imputed).

4.2.3 Statistical analysis

4.2.3.1 NHVPR data extract

I requested de-identified line-listed data of all female vaccination records from 2007 to 2012 in the NHVPR. The data included:

- first implied dose\(^1\) administered between 1 January 2007 and 31 December 2012;
- All subsequent doses (2\(^{nd}\) and 3\(^{rd}\)) to the first implied dose administered between 1 January 2007 and 31 December 2012;
- Implied dose number;
- All non-terminated doses for a consumer;
- Consumer postcode;
- Age at implied dose number;
- Indigenous status;
- State/territory; and
- Date of vaccination

The data excluded terminated doses\(^2\) and information on consumers who opted to be removed from the NHVPR.

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\(^1\) Implied dose number is the number allocated by the NHVPR information system (HVRIS) and is based on dose date and episode status. An implied dose number of zero is allocated if a dose is too close to another dose or if more than three doses have been reported.

\(^2\) A terminated dose is any doses removed from the NHVPR. These can include duplicate records or doses reported in error.
In order to extract and clean the data, the following rules were applied by VCS:

- implied dose number is the number allocated to a dose based on the date and episode status. For records with doses administered too closely together (i.e. 2nd dose was administered within 1 month of the 1st dose) or had more than three vaccination doses reported, the implied dose number of those doses was coded to zero.
- if data for earlier doses was missing, subsequent dose data was used. For example, if a consumer’s doses are recorded as; dose-number-1, dose-number-2 and dose-number-4; the order of these doses was changed to implied-dose-number-1, implied dose-number-2 and implied dose-number-3.

To comply with ethical approval, the following steps were conducted to de-identify the NHVPR data:

- VCS consumer reference number was replaced with a project specific unique identifier. To ensure the unique identifier did not match the VCS consumer reference, vaccination records were randomized by age and the VCS consumer reference number was permanently removed from the dataset; and
- postcode was replaced with an Australian Statistical Geography Standards (ASGS) and postcode information permanently removed from the dataset.

### 4.2.3.2 Australian Statistical Geography Standards (ASGS)

The Australian Statistical Geography Standards (ASGS) was used to examine the geographical distribution of HPV vaccine records. The ASGS consists of five remoteness areas; Major Cities, Inner Regional, Outer Regional, Remote and Very Remote. For the purposes of this report these areas were grouped into Major Cities, Regional (inner and outer regional combined) and Remote (remote and very remote combined). ASGS was mapped using the ABS ASGS correspondence files and the cases’ residential postcodes. If a postcode was mapped to more than one ASGS area, the postcode was allocated to the area with the highest geographical proportion as per the ABS correspondence files. If a residential postcode could not be mapped to an ASGS area (such as post office or business centre) the ASGS of the case was classified as unknown.

### 4.2.3.3 Data analysis

I analysed the data using Stata™ version 13.1 (StataCorp, USA) and Microsoft Excel™. The analysis included all female HPV vaccination records with an implied-dose number 1 administered between 1 January 2007 and 31 December 2013. Vaccination coverage estimates were calculated as the number of valid HPV vaccine
doses by Indigenous status, divided by the 2006 Australian Bureau of Statistics (ABS) single year of age experimental Indigenous population estimates and expressed as a percentage. Age of consumers, is the age they were in 2006, to correspond with the experimental Indigenous population estimates. Indigenous status for the vaccine was defined as:

- Indigenous – records containing the values; ‘A’, ‘T’, ‘AT’ and ‘Y’
- Non-Indigenous – Records containing the values ‘N’
- Unknown or missing – Records containing the values; ‘U’ & ‘None’

I conducted univariable analyses to examine the relationship between unknown Indigenous status and ASGS, age group, jurisdiction and provider. An unknown Indigenous status was defined as records whose Indigenous status values were ‘U’ or ‘None’. A known Indigenous status was defined as records whose Indigenous status values were ‘A’, ‘T’, ‘AT’, ‘Y’ and ‘N’.

Pearson’s Chi-square statistic was used to examine the relationships between the unknown Indigenous status and ASGS, age group, jurisdiction and provider, and the Wilcoxon rank-sum nonparametric test for trend was used to analysis the changes in unknown Indigenous status over time.
5. Results

5.1 Focused literature review

Whilst there is an abundance of literature examining the level of underreporting of Indigenous status in healthcare datasets \(^{(26, 28-30)}\), and how administrative datasets can be used to correct this missing information, \(^{(25, 27, 31-34)}\) there is limited information about the barriers encountered with its collection.

I identified four unique peer-reviewed articles and three grey literature reports which met the parameters of the review. The peer-reviewed articles consisted of two cross-sectional studies, a hospital census and an interviewer-administered survey. The grey literature included reports on the collection of Indigenous status in communicable disease reporting systems, hospital databases and in general practitioners settings.

The information from of each document is summarised in Appendix Table 1 and highlights the varied approach to examining the accuracy of Indigenous status within Australia healthcare datasets.

5.1.1.1 Peer-reviewed literature

The two cross-sectional studies conducted by Adams \(et al\) \(^{(35)}\) and Kohoe and Lovett \(^{(36)}\) investigated what barriers existed to the completion of Indigenous status by staff in medical practices. Both studies surveyed staff attitudes towards asking a person their Indigenous status and found staff were often apprehensive to ask about Indigenous status as they feared offending patients. \(^{(35, 36)}\) Adams \(et al\) (2004) further examined if Breast Screen Victoria (BSV) was complying with the National Best Practice Guidelines for Collecting Indigenous Status in Health Datasets (the Guidelines) developed by the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistic (ABS). \(^{(35)}\) They found that BSV were not compliant, as they did not include a category for ‘Aboriginal and Torres Strait Islander’ or ‘not stated’. They also did not enable women who were born overseas to identify as Aboriginal and/or Torres Strait Islander.

The reluctance of staff in healthcare facilities to ask Indigenous status was echoed in a study conducted in Brisbane. \(^{(37)}\) The study found that some staff in the hospital thought questions regarding Indigenous status were sensitive and felt uncomfortable asking patients. Some staff admitted to guessing or omitting this information on hospital admission forms. Unlike the previously discussed studies, this study included a survey of patients within the hospital complex. This survey was broken into two sections, a five minute survey and a semi-structured interview with patients identifying as Indigenous.

Results from the five minute survey indicated that the majority of patients felt
comfortable with being asked about their Indigenous status, but were unsure why the question was being asked.

Results from the semi-structured interview found Indigenous patients were not offended when asked about their cultural identity, instead stated they were proud to answer questions about their culture and heritage. This study highlighted the juxtaposing attitudes of staff and patients with regards to questions about Indigenous status. The study suggested misconceptions by staff about patient reactions toward these types of questions has led to poor administration processes and underreporting of Indigenous status within the hospital records. Just over half the participants who self-identified as Indigenous had been incorrectly identified in the hospital records.

In 1999, Jackson Pulver et al (2003) interviewed women who had recently given birth at King George V (KGV) hospital in Sydney, to determine if the hospital documentation accurately reflected Indigenous status reported by the patients. The investigation found there was significant under-reporting of Indigenous women in the KGV hospital system. When asked by investigators, two thirds of the study population indicated they were comfortable with staff asking if they identified as an Aboriginal and/or Torres Strait Islander. An interesting finding from this study was the difference in accuracy of Indigenous status between women who self-referred to the hospital compared to those who were transferred from other medical facilities. Women who were transferred were significantly more likely to be correctly identified compared to the women who self-referred. Investigators found hospital staff often relied on clues from transfer documentation to identify the Indigenous status of a woman rather than asking them upon admission.

Whilst these studies identified a number of barriers with the collection of Indigenous status, there were a number of limitations. All surveys and interviews were subject to volunteer and selection bias. In particular the Jackson Pulver (2003) study only sampled women who had delivered live, healthy infants and those who could speak sufficient English. These exclusion criteria may have resulted in the under-representation of Aboriginal and/or Torres Strait Islander women.

Additionally, the generalizability of all these studies limited to medical practice or hospital settings. I was unable to find any studies that considered the collection of Indigenous status outside of healthcare settings, such as school-based vaccination programs. Finally, there are some information gaps in reporting. One study did not provide the sample size of the staff interviewed. By not knowing the number and employment categories of interviewed staff, questions are raised as to whether the
data truly reflects the healthcare provider population, and if it could be generalised to other healthcare settings.

In 2005, Lovett investigated if the attitudes of staff in hospitals in the Australian Capital Territory, at admission and discharge, affected the accuracy of Indigenous status information in hospital data. This study found there were negative attitudes towards the collection and recording of Indigenous status by hospital staff. In particular, staff stated they feared asking a patient if they identified as Aboriginal or Torres Strait Islander due to anecdotal reports of people becoming aggressive when asked. Additionally, the study found a number of staff perceived asking for Indigenous status to be associated with funding and thought the collection of this information was irrelevant, as all patients should be treated equally regardless of their background. However due to the issues in gaining access to staff and the low response rate to interviews, results from the study are limited.

5.1.1.2 Review of grey literature
A review of the collection of Indigenous status in communicable disease reporting systems released in 2004 identified a number of limitations in the collection of this information. These limitations included: the perceived reluctance of Aboriginal and/or Torres Strait Islander people to disclose their Indigenous status; the inconsistent or incorrect use of the standard Indigenous status question; the lack of public awareness regarding the importance of reporting this information; and the limited amount of training available regarding the collection and value of Indigenous information in healthcare datasets. This paper suggested a number of recommendations to improve Indigenous identification including making the collection of Indigenous status mandatory; introducing incentives to improve the quality of information; and including Indigenous status as part of the standard demographic data collection. While the report broadly outlines some of the most common barriers faced in collecting Indigenous in administrative datasets, it main purpose was to provide particular recommendations for communicable disease reporting systems.

In 2012, ABS conducted a number of focus groups to explore attitudes to Indigenous identification in census and survey contexts in urban areas. This study conducted focus groups in Sydney, Melbourne, Brisbane, Perth, Darwin and Hobart, with Aboriginal and/or Torres Strait Islander people were asked about their propensity to provide Indigenous status. These focus groups found participants were unlikely to provide their Indigenous status on survey forms as it:

- could result in negative repercussions to an individual and/or the wider community;
could lead to racism, discrimination or differential treatment;
may offended in certain contexts; or
they did not understand why this information was relevant to the collection

The study found that younger Aboriginal and/or Torres Strait Islander people were more likely to disclose their Indigenous status compared to older participants, and that identifying Indigenous status on behalf of another person is considered to be inappropriate unless the identification is made by an immediate family member. (41)

In evaluating the implementation of the Guidelines, the AIHW conducted a project that examined the identification of Aboriginal and Torres Strait Islander status in General Practice (GP). (22) Undertaken between January 2011 and December 2012, the project investigated what information on Indigenous identification is available in the GP sector, the barriers to identification and the measures taken to improve identification. The project found a number of barriers had been addressed since the implementation of the Guidelines, but GP attitudinal issues contributed to low rates of routine identification and high levels of reporting variability. One of the identified barriers to raising awareness of the importance of Indigenous status within the GP sector was the lack of coordination between agencies involved in general practice setting.

5.2 Consultations
All eight jurisdictional health departments and one immunisation program co-ordinator participated in the consultations. There were three major topics discussed during the consultations: 1) how vaccination data are collected; 2) the barriers encountered in the collection of Indigenous status; and 3) actions taken to improve the reporting of Indigenous status through the school-based programs.

5.2.1 Data collection through the school-based programs
All stakeholders indicated HPV consent forms were collected by vaccine providers and either provided directly to the Local Government Councils (LGC), public and population health units or jurisdictional health departments for data entry and transmission to the NHVPR. However, this flow of data varied considerably by jurisdiction (Table 1). In South Australia, Tasmania, and Victoria, the LGCs are responsible for the data entry and transmission to the NHVPR. Although the jurisdictional health departments receive a copy of all NHVPR transmissions, the frequency and responsibility for the data and its completeness resides with the LGCs.

Data from the Australian Capital Territory, New South Wales, the Northern Territory, Queensland and Western Australia, is collated and transmitted by the jurisdictional health departments at varying frequencies. For New South Wales and Western
Australia data are transmitted to the NHVPR on a yearly basis. During the course of the consultations I asked if the frequency of data transmission to the NHVPR could be increased. Both these jurisdictions indicated this would not be possible as the data are not uploaded into their databases until the all school-based programs have been completed for the year.

Table 1: School-based Program HPV vaccination consent form collection, data entry and data transmission to the NHVPR, by jurisdiction, 2013

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Collected by</th>
<th>Data entered by</th>
<th>Transmission to NHVPR</th>
<th>Transmission frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>Vaccine providers</td>
<td>ACT Health</td>
<td>ACT Health</td>
<td>Weekly</td>
</tr>
<tr>
<td>NSW</td>
<td>Vaccine providers</td>
<td>Scanned in by external contractor for NSW health</td>
<td>NSW Health</td>
<td>Yearly</td>
</tr>
<tr>
<td>NT</td>
<td>Vaccine providers</td>
<td>NT Health</td>
<td>NT health</td>
<td>Monthly</td>
</tr>
<tr>
<td>QLD</td>
<td>Vaccine providers</td>
<td>QLD Health</td>
<td>QLD health</td>
<td>Daily</td>
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<tr>
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<td>Vaccine providers</td>
<td>Local councils</td>
<td>Local councils</td>
<td>Subject to Local council</td>
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<td>Copy of extract provided to SA health</td>
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<tr>
<td>TAS</td>
<td>Vaccine providers</td>
<td>Local councils</td>
<td>Local councils</td>
<td>Subject to Local council</td>
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<td>VIC</td>
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<td>Local councils</td>
<td>Local councils</td>
<td>Subject to Local council</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>VIC health access data via IMPS</td>
<td></td>
</tr>
<tr>
<td>WA</td>
<td>Vaccine providers</td>
<td>Population health units</td>
<td>WA Health.</td>
<td>Yearly</td>
</tr>
</tbody>
</table>
5.2.2 Collection, transmission and management of Indigenous status in the school-based programs

In 2010, the AIHW and the ABS released the Guidelines. This document provides a systematic national approach for collecting and recording accurate information on the Indigenous status in administrative health datasets. The collection of Indigenous status on HPV vaccine consent forms varied between jurisdictions. New South Wales, the Northern Territory, Queensland and Victoria were the only jurisdictions using the Guidelines’ recommended format in 2013 (Table 2).

Stakeholders from the Australian Capital Territory, South Australia and Tasmania stated they were unaware of the Guidelines and suggested that the binary responses and single tick boxes being used on consent forms were a reflection of how these data are currently collected on other jurisdictional healthcare forms. After the first stage consultations, the Australian Capital Territory, South Australia and Tasmania reviewed their HPV consent forms and updated the request for Indigenous status to reflect the Guidelines. Changes to the forms took effect in 2014.

Western Australia stated that the collection of Indigenous status is governed by the Aboriginal Cultural Respect Framework. This framework specifies that:

“Within Western Australia, the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of Western Australia. No disrespect is intended to our Torres Strait Islander colleagues and community.” (42, 43)

Due to this framework, Western Australia is currently unable to change how Indigenous status is collected within their in healthcare data.
Table 2: Question about Indigenous status on HPV vaccine consent forms, by jurisdiction, Australia, 2013 to 2014 schools

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Question asked on form</th>
<th>Changed</th>
<th>Question changed on form to</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>Aboriginal/Torres Strait Islander</td>
<td>Yes, 2014</td>
<td>Is your child of Aboriginal or Torres Strait Islander origin?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes, Aboriginal</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes, Torres Strait Islander</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes, Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>NSW</td>
<td>Indigenous status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes, Aboriginal</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes, Torres Strait Islander</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes, Aboriginal and Torres Strait Islander</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NT</td>
<td>Ethnicity:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Non-Aboriginal</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aboriginal</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Torres Strait Islander</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aboriginal and Torres Strait Islander</td>
<td></td>
<td></td>
</tr>
<tr>
<td>QLD</td>
<td>Aboriginal</td>
<td></td>
<td>Is your child of Aboriginal or Torres Strait Islander origin?</td>
</tr>
<tr>
<td></td>
<td>Aboriginal and Torres Strait Islander (TSI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>TSI</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Not Aboriginal or TSI</td>
<td></td>
<td>Yes, Aboriginal</td>
</tr>
<tr>
<td></td>
<td>Not stated/unknown</td>
<td></td>
<td>Yes, Torres Strait Islander</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes, Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>SA</td>
<td>Aboriginal/Torres Strait Islander</td>
<td>Yes, 2014</td>
<td>Is your child of Aboriginal or Torres Strait Islander origin?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes, Aboriginal</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes, Torres Strait Islander</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes, Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>TAS</td>
<td>Is your child of Aboriginal or Torres Strait Islander origin?</td>
<td>Yes, 2014</td>
<td>Is your child of Aboriginal or Torres Strait Islander origin?</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td>Yes, Aboriginal</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes, Torres Strait Islander</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes, Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>VIC</td>
<td>Is the person of Aboriginal or Torres Strait Islander consent?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aboriginal</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Torres Strait Islander</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aboriginal and Torres Strait Islander</td>
<td></td>
<td></td>
</tr>
<tr>
<td>WA</td>
<td>Aboriginal</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Indigenous status information has been collected on HPV vaccine consent forms in all jurisdictions, except New South Wales since 2007 (Table 3). The transmission of Indigenous status to the NHVPR began in 2007 for all jurisdictions except the Australian Capital Territory, New South Wales and Tasmania, where transmission did not occur until 2012.

**Table 3: The years Indigenous status was first collected on HPV consent forms and provided to the NHVPR, by jurisdiction, Australia 2014**

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Year Indigenous status first collected</th>
<th>Year Indigenous status information first transmitted NHVPR</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>2007</td>
<td>2012</td>
</tr>
<tr>
<td>NSW</td>
<td>2011</td>
<td>2012</td>
</tr>
<tr>
<td>NT</td>
<td>2007</td>
<td>2007</td>
</tr>
<tr>
<td>QLD</td>
<td>2007</td>
<td>2007</td>
</tr>
<tr>
<td>SA</td>
<td>2007</td>
<td>2007</td>
</tr>
<tr>
<td>TAS</td>
<td>2007</td>
<td>2012</td>
</tr>
<tr>
<td>VIC</td>
<td>2007</td>
<td>2007</td>
</tr>
<tr>
<td>WA</td>
<td>2007</td>
<td>2007</td>
</tr>
</tbody>
</table>

The completion of Indigenous status on consent forms is not mandatory in any jurisdiction. Follow-up of missing Indigenous status is completed by the vaccine providers in all jurisdictions. During consultations, five jurisdictions indicated they actively encourage the follow-up of missing Indigenous status. These jurisdictions used workshops and consultations to promote the collection of Indigenous status, identified and highlighted records with missing information and conducted cross checks with other health databases to complete missing information. Table 3 outlines how each jurisdiction manages missing Indigenous status on HPV consent forms.

Victoria was the only jurisdiction that indicated they impute missing Indigenous status. Stakeholders from Victorian Department of Health and Human Services stated that if a HPV vaccine consent form is provided to the LGC without Indigenous status the record should be coded to ‘no’. However, they were unsure if this practice is conducted consistently across all LGCs in Victoria.
Table 4: Follow up and management of missing Indigenous status on HPV vaccine consent forms, by jurisdiction, Australia, 2007-2014

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Mandatory field</th>
<th>Follow up actions</th>
<th>Missing value changed</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>No</td>
<td>None</td>
<td>×</td>
</tr>
<tr>
<td>NSW</td>
<td>No</td>
<td>New South Wales health has been emphasizing the importance of recording of Indigenous status to the Public Health Units. Consent forms scanned into the NSW Register without Indigenous status recorded are being highlighted to enable the capture of this information at the next immunisation visit. The NSW Health school protocol has been amended to require the immuniser to ask the child about their Indigenous status if the information is incomplete on the form.</td>
<td>×</td>
</tr>
<tr>
<td>NT</td>
<td>No</td>
<td>Cross check with the NT whole of life database</td>
<td>×</td>
</tr>
<tr>
<td>QLD</td>
<td>No</td>
<td>The school-based program has no targeted resources to follow up missing Indigenous status. However, QLD health has been promoting the collection of this field for a number of years to health staff.</td>
<td>×</td>
</tr>
<tr>
<td>SA</td>
<td>No</td>
<td>None</td>
<td>×</td>
</tr>
<tr>
<td>TAS</td>
<td>No</td>
<td>Workshops to encourage vaccine providers to collect Indigenous status.</td>
<td>×</td>
</tr>
<tr>
<td>VIC</td>
<td>Yes</td>
<td>New vaccination records cannot be created unless Indigenous status is completed. A new value of ‘To Be Advised (TBA)’ has been created in the vaccine notification system to encourage LGCs to follow up missing Indigenous status data. ✓- Missing data reclassified to ‘No’ for years 2007 to 2013. From 2014- missing reclassified “to be advised”</td>
<td>✓</td>
</tr>
<tr>
<td>WA</td>
<td>No</td>
<td>None</td>
<td>×</td>
</tr>
</tbody>
</table>

5.2.3 Barriers to collecting Indigenous status

During the consultations I asked jurisdictions about the barriers they believed impacted the completion of Indigenous status in school-based programs and for private providers.

5.2.3.1 School-based Program

All stakeholders thought Indigenous status was acceptable field on the HPV consent forms, as they had not received complaints from parents or schools about the question. The main barriers identified by stakeholders for the school-based programs were classified into two groups: 1) social and knowledge; and 2) consent form format.

There were three main barriers identified through consultations that were classified as social and knowledge: 1) awareness of the use of Indigenous status; 2) self-identification of the parent or guardian; and 3) literacy capabilities.
Seven stakeholders thought the most common barrier to collecting Indigenous status was misconceptions about why the question is being asked. They suggested parents/guardians may not see Indigenous status as relevant to vaccinations and may neglect to answers the question. Two stakeholders stated the completion of Indigenous status is dependent on which parent/guardian completes the consent form. They suggested if one parent/guardian identifies as Aboriginal and/or Torres Strait Islander and the other does not, whoever fills in the form may complete the question based on their own self-identity.

Three stakeholders suggested a potential barrier may lie with literacy capabilities of the parent/guardian. If a parent/guardian is illiterate or English is not their primary language they may not understand how to answer the question. These stakeholders suggested consent forms should be available in different languages (as required) or vaccination providers should engage with local communities and verbally explain the form. This would of course need to be addressed at a local level and would rely heavily on resources available.

There were three main barriers identified with the consent form format: 1) the layout; 2) number of questions; and 3) how Indigenous status is requested.

Five stakeholders suggested the layout of the form, such as the font size and positioning of questions may be confusing, while three stakeholders suggested the number of questions on consent forms may be overwhelming. Both barriers could result in the question about Indigenous status being overlooked, misunderstood or ignored by the parent/guardian.

The last barrier identified in this category related to how Indigenous status is requested. Four of the nine stakeholders suggested single tick responses (for example Aboriginal/Torres Strait Islander) or the use of binary responses (such as ‘are you Aboriginal or Torres Strait Islander’ YES/NO) inadvertently excludes a person who identifies as Aboriginal or Torres Strait Islander or both. Not being able to identify with the population groups listed the parent/guardian may skip or ignore the question.

5.2.3.2 Completion of Indigenous status by General Practitioners

Consultations revealed stakeholders thought barriers in private settings were a result of the perceptions and attitudes of healthcare providers. All stakeholders thought of GPs and practice staff may be reluctant to ask a person’s Indigenous status as they either perceive the question to be of little relevance, feared it could be considered racist or would invoke an aggressive response from the patient.
Five stakeholders suggested that GPs and practice staff may also assume the Indigenous status of a person based on their appearance or previously formed assumptions. These predetermined opinions may have led to the misclassification of a person’s Indigenous status as it had been determined without consulting with the patient.

5.2.3.3 **Actions taken to address Indigenous status underreporting**

During the follow up consultations I asked stakeholders if they had taken any actions to improve Indigenous status since the first stage consultations. All jurisdictions indicated they were working towards improving the collection of Indigenous status within the school-based programs and have undertaken actions including linking data from other databases, active follow up of missing information and changes to vaccination database collection tools. The actions undertaken by each jurisdiction are outlined in Appendix 11.3.

5.3 **Data analysis**

Due to the potential of the force cleaning of Indigenous status by Victoria, which may have led to misclassification of Indigenous status of NHVPR records from this jurisdiction. For this reason, data from Victoria was not been included in the below analysis.

There were 1,448,388 female HPV vaccination records provided to the NHVPR from 2007 to 2012 from all states and territories excluding Victoria. Of these 3% were of Aboriginal and/or Torres Strait Islander origin, 44% were non-Indigenous and 53% did not have a valid Indigenous status reported. By age the largest number of records were from the 12 to 13 years age group (31%, 447,989/1,448,388) followed by 14 to 15 years (16%, 231,506/1,448,388) and 16 to 17 years (10%, 151,202/1,448,388) (Table 5), consistent with the target age groups of the Program. The median age was 16, with a range of 0 to 112 years.

Fifty-nine percent (858,072/1,448,388) of HPV vaccination records were provided to HPV consumers through school-based programs. Most of which were provided to females aged 0 to 17 years. Geographically, 59% (991,822/1,448,388) of HPV vaccines were provided to females who resided in major cities, 29% (413,000/1,448,388) to females who resided in regional areas and 3% (42,305/1,448,388) to females who resided in remote areas. By jurisdiction, 41% of HPV consumers resided in New South Wales, 29% in Queensland, 13% in Western Australia, 10% in South Australia, 3% in Tasmania, 2% in the Australia Capital Territory and 2% in the Northern Territory.
Table 5: Details of female HPV vaccine records in the NHVPR as of 14 March 2014, 2007 to 2012, Australia

<table>
<thead>
<tr>
<th>Indigenous status</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Known</td>
<td>683,948</td>
<td>47.22</td>
</tr>
<tr>
<td>Unknown or missing</td>
<td>764,440</td>
<td>52.78</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age group</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-11 years</td>
<td>57,257</td>
<td>3.95</td>
</tr>
<tr>
<td>12-13 years</td>
<td>447,898</td>
<td>30.92</td>
</tr>
<tr>
<td>14-15 years</td>
<td>231,506</td>
<td>15.98</td>
</tr>
<tr>
<td>16-17 years</td>
<td>151,202</td>
<td>10.44</td>
</tr>
<tr>
<td>18-19 years</td>
<td>109,692</td>
<td>7.57</td>
</tr>
<tr>
<td>20-26 years</td>
<td>439,889</td>
<td>30.37</td>
</tr>
<tr>
<td>27 years and over</td>
<td>10,944</td>
<td>0.76</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Provider</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schools program</td>
<td>858,072</td>
<td>59.24</td>
</tr>
<tr>
<td>Non-schools program</td>
<td>590,316</td>
<td>40.76</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ASGS</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major Cities</td>
<td>991,822</td>
<td>68.48</td>
</tr>
<tr>
<td>Regional</td>
<td>413,000</td>
<td>28.51</td>
</tr>
<tr>
<td>Remote</td>
<td>42,305</td>
<td>2.92</td>
</tr>
<tr>
<td>Unknown or missing</td>
<td>1261</td>
<td>0.09</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>34,415</td>
<td>2.38</td>
</tr>
<tr>
<td>NSW</td>
<td>602,360</td>
<td>41.59</td>
</tr>
<tr>
<td>NT</td>
<td>24,051</td>
<td>1.66</td>
</tr>
<tr>
<td>QLD</td>
<td>417,329</td>
<td>28.81</td>
</tr>
<tr>
<td>SA</td>
<td>137,080</td>
<td>9.46</td>
</tr>
<tr>
<td>TAS</td>
<td>43,485</td>
<td>3</td>
</tr>
<tr>
<td>WA</td>
<td>189,503</td>
<td>13.08</td>
</tr>
<tr>
<td>Unknown or overseas</td>
<td>165</td>
<td>0.01</td>
</tr>
</tbody>
</table>

Note: Data from Victoria is not included.
5.3.1 Completion of Indigenous status

Fifty-three percent (764,440/1,448,388) of female HPV vaccinations records were reported with unknown Indigenous status between the years 2007 and 2012 (Table 5). While there were small declines the proportion of unknown Indigenous status from 2008 to 2011, the most notable changes occurred in 2012, with the proportion of unknown Indigenous status dropping from 54% in 2011 to 25% in 2012 (Figure 2). This drop was the result of the Australian Capital Territory, New South Wales and Tasmanian school-based programs providing Indigenous status data to the NHVPR for the first time.

Figure 2: Proportion of female vaccination records in the NHVPR with and without Indigenous status records, by year, 2007 to 2012, Australia

Note: Excludes data from Victoria

5.3.1.1 Age distribution

The proportion of unknown Indigenous status by age was highest in the 0 to 11 years age group at 69%, followed by the 14 to 15 years age group at 62% and the 16 to 17 year age group at 60% (Figure 3). The 18 to 19 years age group and the 26 to 26 years age group had the lowest proportions of unknown Indigenous status, at 43% and 45% respectively.

When I examined the proportion of unknown Indigenous status by age group over time, I found from 2009 to 2012 the proportions of unknown Indigenous status declined in the
0 to 11, 12 to 13, 14 to 15 and 16 to 17 years age groups. For all other age groups small variations occurred over the period, with no distinct trend.

**Figure 3:** Proportions of female HPV vaccine records in the NHVPR, by vaccination age group and stated Indigenous status, 2007 to 2012, Australia

![Proportions of female HPV vaccine records in the NHVPR, by vaccination age group and stated Indigenous status, 2007 to 2012, Australia](image)

**Note:** Excludes data from Victoria

### 5.3.1.2 Jurisdiction

The proportion of HPV vaccination records with unknown Indigenous status varied by jurisdiction (Figure 4). Overall, the Northern Territory had the lowest proportion with only 4% of records reported without Indigenous status. For Queensland, this proportion was less than a third, while for South Australia it was almost half (49%) and for WA is was 63%. As the school-based programs for the Australian Capital Territory, New South Wales and Tasmania did not provide Indigenous status until 2012, they have not been included in Figure 4.
**Figure 4:** Proportion of female HPV vaccination records, by jurisdiction and Indigenous status, 2007-2012, Australia

**Note:**
1. Excludes data from ACT, NSW and TAS as Indigenous status information was not provided to the NHVPR until 2012.
2. Excludes data from Victoria

### 5.3.1.3 School-based Program

For the vaccinations provided as part of the school-based programs consumers residing in Western Australia displayed the highest proportion of unknown Indigenous status (Table 6). Peaking at 91.6% of all female records in 2008, this proportion declined from 2009 to 13.2% in 2012. The Northern Territory and South Australia displayed similar trends, but the magnitude was substantially smaller. South Australia was the only jurisdiction in which these changes over time were significant.

Queensland was the only jurisdiction that showed considerably increases in the proportion of unknown Indigenous status during the period. Queensland displayed an upward trend in the proportion of unknown Indigenous status, rising from 13.3% in 2010 to 49.5% in 2012. However, the displayed rise in unknown Indigenous status in Queensland is thought to be a result of a change from manual to automated data reporting. This change in reporting began in 2012 and resulted in difficulties with the transfer of Indigenous status to Queensland Health’s HPV vaccination database.
Table 6: Proportion of female HPV vaccine records from school-based vaccination programs without Indigenous status, by year and jurisdiction, 2007 to 2012, Australia

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT*</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>97%</td>
<td>-</td>
</tr>
<tr>
<td>NSW*</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>11.2%</td>
<td>-</td>
</tr>
<tr>
<td>NT</td>
<td>2.6%</td>
<td>4.5%</td>
<td>3.2%</td>
<td>3.9%</td>
<td>1.6%</td>
<td>2.5%</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>QLD</td>
<td>13.5%</td>
<td>12.7%</td>
<td>16.8%</td>
<td>13.3%</td>
<td>21.2%</td>
<td>49.5%</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>SA</td>
<td>21.9%</td>
<td>23.0%</td>
<td>14.9%</td>
<td>10.6%</td>
<td>9.8%</td>
<td>9.6%</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>TAS*</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>47.5%</td>
<td>-</td>
</tr>
<tr>
<td>WA</td>
<td>81.1%</td>
<td>91.6%</td>
<td>82.2%</td>
<td>49.9%</td>
<td>26.1%</td>
<td>13.2%</td>
<td>&gt;0.05</td>
</tr>
</tbody>
</table>

Notes:
1. * Indigenous status information was not provided to the NHVPR until 2012.
2. Excludes data from Victoria

5.3.1.4 Private providers

The proportion of unknown Indigenous status reported by private providers declined from 2010 in all jurisdictions except in the Australian Capital Territory and Tasmania. The proportion of unknown indigenous status reported by private providers in Tasmania increased to 85% in 2011 before declining in 2012 to 74%, while for the Australian Capital Territory changes were more varied, with increases the proportion of unknown indigenous status occurring in 2008, 2009, 2010 and 2012. Consistent with the findings for the school-based programs, the changes over time were only significant for South Australia.

However, changes in the proportions of unknown Indigenous status for private providers from 2010 onwards should be interpreted with caution. The number of vaccinations provided privately declined substantially in 2010 coinciding with the cessation of the HPV vaccine incentives for GPs. In 2010, 2011 and 2012 the number of HPV vaccinations administered by private providers each year was less than 5,300 nationally.

Table 7: Proportion of female vaccination records from private providers without Indigenous status, by year and jurisdiction, 2007 to 2012, Australia

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>53.7%</td>
<td>48.3%</td>
<td>50.3%</td>
<td>60.7%</td>
<td>43.8%</td>
<td>69.2%</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>NSW</td>
<td>46.1%</td>
<td>44.2%</td>
<td>41.7%</td>
<td>52.9%</td>
<td>27.1%</td>
<td>18.9%</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>NT</td>
<td>7.1%</td>
<td>11.6%</td>
<td>13.6%</td>
<td>0.0%</td>
<td>4.3%</td>
<td>2.5%</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>QLD</td>
<td>24.8%</td>
<td>26.6%</td>
<td>29.0%</td>
<td>31.5%</td>
<td>25.0%</td>
<td>27.0%</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>SA</td>
<td>95.8%</td>
<td>93.7%</td>
<td>92.6%</td>
<td>83.5%</td>
<td>51.4%</td>
<td>26.9%</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>TAS</td>
<td>40.0%</td>
<td>43.2%</td>
<td>47.6%</td>
<td>78.3%</td>
<td>85.0%</td>
<td>74.0%</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>WA</td>
<td>51.5%</td>
<td>58.0%</td>
<td>60.9%</td>
<td>74.3%</td>
<td>48.1%</td>
<td>43.9%</td>
<td>&gt;0.05</td>
</tr>
</tbody>
</table>

Notes:
1. * Indigenous status information was not provided to the NHVPR until 2012.
2. Excludes data from Victoria
5.3.1.5  **Australian Statistical Geographic Standard (ASGS)**

Major cities had the highest proportion of unknown Indigenous status (55%), followed by regional areas (49%) and remote areas (29%). From 2007 and 2011 each ASGS area displayed steady declines in the proportion of unknown Indigenous status. In 2012, the proportion of HPV vaccination records with unknown Indigenous status in each ASGS area declined markedly, falling to 24% in major cities, 26% in regional areas and 11% in remote areas (Figure 5).

**Figure 5**: Proportion of unknown Indigenous status female HPV vaccine records by ASGS and year, 2007 to 2012, Australia
6. Discussion

Accurate vaccination coverage estimates are considered essential in assessing the effectiveness of the HPV vaccine in the population. To calculate these estimates, high-quality and complete data are required. Although my analysis found some improvement over time in the collection of Indigenous status in NHVPR data, overall the collection of remains poor in the NHVPR. From 2007 to 2012 just under half of female HPV vaccine records were reported to the NHVPR without a valid Indigenous status.

The insufficient reporting of Indigenous status is ubiquitous in many Australian healthcare datasets (21-23, 25-27) and is not unique the NHVPR. This project sought to identify the barriers which impede the collection of Indigenous status for females in the NHVPR and provide recommendations to reduce the effect of these barriers and improve Indigenous status identification.

In analysing, data by jurisdiction, I identified that the Northern Territory and Queensland were the only jurisdictions in which there has been sufficient reporting of Indigenous status to calculate vaccine coverage estimates. This is consistent with previous review of the data. (19) The insufficient reporting of Indigenous status data by jurisdiction makes it difficult to estimate, with any level of accuracy, the HPV vaccination coverage by Indigenous status nationally. This is a concern given the importance of maintaining high HPV coverage rates in Aboriginal and/or Torres Strait Islander women. (16, 18) Although my stratification by age, ASGS and provider identified gaps in the completion of Indigenous status, it was unclear from this analysis why these gaps are occurring.

A review of the literature and the results of the consultations identified there are potentially a number of barriers affecting the collection of Indigenous status in the NHVPR. The three main barriers identified were: misconceptions about Indigenous status; the layout and presentation of Indigenous status questions on consent forms; and variations in data collection methodology and administration of school-based HPV vaccination programmes.

Misconceptions about the purpose and implications of Indigenous status reporting were found to be the principle barrier to data collection. At the consumer level, underreporting of Indigenous status may arise when a parent/guardian is disinclined to disclose the Indigenous status of their child as they do not understand the relevance of the question. It has been suggested that a person’s propensity to disclose Indigenous status is associated with previous experiences of racism, the belief healthcare will be provided differently if disclosed, or not knowing why this information is relevant to
healthcare. Providing information about the importance and use of Indigenous status to parents/guardians may counter these misconceptions.

Misunderstandings at the healthcare provider level about the collection and use of Indigenous status data also appears to be contributing to the underreporting. The literature and consultations suggested healthcare providers actively avoid asking a patient’s Indigenous status as they perceive it is either irrelevant to providing healthcare, may provoke an aggressive response or is only being asked to regulate funding. These perceptions are thought to have developed due to the lack of information and training provided to healthcare providers about the relevance and use of Indigenous status in healthcare data.

In addition to these misconceptions, specific barriers to data collection through the school-based programmes were identified, including poor or confusing layouts of the HPV consent forms, the way in which Indigenous status is requested, and variations in data collection methodology and administration.

Upon reviewing each of the jurisdictions’ HPV consent forms, I found the layout, number of questions and the positioning of the Indigenous status question varied considerably. It is possible that the differing structure of HPV consent forms has contributed to the variations in the completion of Indigenous status identified in the data. This concept was supported by the consultations, with stakeholders suggesting that parents/guardians may overlook, ignore or misunderstand what they are being asked, as the consent forms are overcrowded, hard to read and/or difficult to interpret.

Another barrier relating to the layout of the forms was the varying terminology used to collect Aboriginal and/or Torres Strait Islander data between jurisdictions. I found that in 2013 four jurisdictions were not collecting Indigenous status as recommended in the Guidelines. The need for national consistency regarding the inclusion and wording of Indigenous status on school-based vaccination program consent forms has been identified previously. Inconsistencies in terminology used to define Aboriginal and/or Torres Strait Islander people could partially explain why some jurisdictions had a higher numbers of records with missing Indigenous status compared to others.

As a result of my consultations, in 2014 three jurisdictions updated the Indigenous status question on HPV consent forms to align with the Guidelines. I was unable to find evidence to suggest that changing the way in which Indigenous status is requested improves its reporting. As these three jurisdictions have changed the way in which they request Indigenous status, there is an opportunity to examine if standardising Indigenous status on healthcare forms improves the likelihood of the data being
completed. Future analyses of data from these three states should include provision to analyse the impact this change has had on completion rates of Indigenous status.

Finally, inconstancies in way the data are collected and managed for school-based programs could also explain the differences in the Indigenous status completion. Although a number of jurisdictions have undertaken actions to improve the collection of Indigenous status, follow up of missing information is at the discretion of the vaccine provider. At the time of writing this report it is not clear to what extent these actions have had on the completion of Indigenous status.

There are a number of activities that could be undertaken to minimise the impact of the barriers discussed in this report. Firstly providing information explaining why Indigenous status is collected, its uses and benefits through improved vaccination policies for the Aboriginal and/or Torres Strait Islander communities should be included on vaccine consent forms or provided on an information sheet. Currently, none of the jurisdictional school-based consent forms provided information to consumers or healthcare providers explaining why Indigenous status is collected. Adding a short explanation about the collection of Indigenous status promotes cultural safety and ensures the healthcare being provided is respectful of person’s culture and beliefs, and free from discrimination.\(^{(39,45)}\)

Secondly, there is a need to provide education promoting better awareness of Indigenous status collection amongst vaccination providers (both schools and private). Whilst some jurisdictions have already undertaken these steps, it needs to be considered in all jurisdictions and potentially standardised at a national level.

Finally, there is a need to gather information and evaluate the collection methodologies of HPV vaccination data in each jurisdiction. Having a better understanding of how the data are collected and managed within each jurisdiction will enable actions to be targeted towards specific barriers affecting the completion of Indigenous status at the source of collection.

A major limitation with this study was the exclusion of vaccine providers, general practitioners, parents/guardians and Aboriginal and/or Torres Strait Islander people from the consultation process. Limiting consultations to jurisdictional health departments is likely to result in confirmation bias, seeking or interpreting evidence that are partial to an individuals or institutions existing beliefs.\(^{(46)}\) Undertaking broader consultations would have provided support for the barriers identified in the literature and/or identified other barriers that have not been considered in the analysis.
Limitations also lie with errors in data provided to the NHVPR. From the consultations it became apparent that some local areas and/or jurisdictions may have been imputing Indigenous status on records with missing information. The extent of this imputation was not able to be determined as part of this study, leading to the possibility that the data presented in the analysis may have under-represented the degree of missing Indigenous status in the NHVPR.

7. Conclusion

Understanding the barriers encountered when collecting Indigenous status for the NHVPR is complex. The findings of my report has identified some of the barriers affecting Indigenous status reporting to the NHVPR, but as this is issue is often impacted by a vast range of factors, it has only scratched the surface. Working towards improving statistical information about Indigenous health not only requires national standards to guide information collection but also requires research into issues that prevent the disclosure or request of Indigenous information. To completely understand the issues relating the completion of Indigenous status in the NHVPR, broader consultations with vaccine providers and consumers and ongoing review and evaluation of collection methodologies needs to be undertaken.
8. Recommendations

Based on the analysis outlined above, I recommend the Department of Health and the Victorian Cytological Service consider the following recommendations:

- Develop, in consultation with jurisdictions, standard wording that can be used to explain the purpose of the collection of Indigenous status for HPV vaccine administration and how the data are used in healthcare statistics.
- Develop a national dataset that could be used for other immunisation databases. To ensure standardisation in the collection of data across Australia, this should include a data dictionary which defines what the terms ‘Yes’, ‘No’, ‘Unknown’ and ‘blank’ mean for Indigenous status.
- Liaise with the General Practitioners (GP) Round Table to identify ways to promote/remind GPs to report HPV vaccine and Indigenous status to the NHVPR.
- Undertake qualitative studies to gather better information about the propensity to disclose or not disclose Indigenous status information from the parent/guardians, general practitioners and other private providers and Aboriginal and/or Torres Strait Islander people.
- In line with the recommendations of the Guidelines, and in consultation with the jurisdictions, consider making Indigenous status a mandatory field for HPV and other immunisation data collections.
- Implement and conduct annual reviews of Indigenous status completion for both female and male HPV vaccination records held in the NHVPR. These analyses should be stratified by jurisdiction and provider, to assess the changes in completeness over time, identify gaps and improvements in reporting, and develop, in consultation with jurisdictions, strategies to maintain adequate reporting levels.
- Evaluate if making changes to the way Indigenous status is requested in the Australian Capital Territory, South Australia and Tasmania have had any effect on the completion of Indigenous status in these jurisdictions.
- Review the results of the pilot study conducted in Victoria to improve the completion of Indigenous status by Local Government Councils.
- Work with New South Wales and Western Australia to increase frequency of transmission of school-based program data to the NHVPR.
9. Acknowledgments

I would like to acknowledge the following people for their assistance with the analysis: Dr. Julia Brotherton, Karen Winch and Genevieve Chappell, Victorian Cytology Service; Ms. Amy Bright, Vaccine Preventable Diseases Surveillance, Office of Health Protection, the Australian Government Department of Health; Dr. Stephanie Davis, the Australian National University; Ms Carolyn Banks, ACT Health; Ms. Carmel Bannon, Townsville Public Health Unit, Queensland Health, Dr. Donna Mak, Department of Health, Western Australia; Ms. Karen Peterson and Ms. Vicki Bryant, Queensland Health; Ms. Kerry Nettle, Department of Health and Human Services, Tasmania; Ms. Maureen Watson, South Australia Health; Ms. Catherine McNamara and Mr. Michael Batchelor, Department of Health, Victoria; Ms. Rosalind Webby and Mr. Charles Strebor, Department of Health, Northern Territory; Sue Campbell-Lloyd, Department of Health New South Wales; and my supervisors A/Prof. Martyn Kirk, the Australian National University and Ms. Rhonda Owen, Vaccine Preventable Diseases Surveillance, Office of Health Protection, the Australian Government Department of Health.
10. References

43. Office of Aboriginal Health. WA Health Aboriginal cultural respect-implementation framework. Western Australia Department of Health; 2005.
11. Appendices

Appendix 10.1 – Details of the literature search

Appendix Figure 1: Flow chart depicting the search criteria, review process and final document number, by search tier

**PubMed**
Primary search HPV or human papillomavirus vaccination (MeSH heading) AND [Indigenous OR Indigenous & Australia OR Indigenous status & healthcare (subheadings)]
Secondary search Indigenous status (MeSH heading) AND [healthcare collections OR health system OR recording OR recording & Australia OR recording & HPV OR recording & improving OR Human papillomavirus OR vaccinations OR missing (subheadings)]

<table>
<thead>
<tr>
<th></th>
<th>44 articles</th>
<th>19 articles</th>
<th>5 articles</th>
</tr>
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<tbody>
<tr>
<td><strong>Scanned titles &amp; abstracts</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Removal of duplicates</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>LIMITS</strong></td>
<td>Humans</td>
<td>English Articles</td>
<td>Primary studies</td>
</tr>
<tr>
<td></td>
<td>No reviews/ letters/ comments/ clinical trials</td>
<td></td>
<td></td>
</tr>
<tr>
<td>207 articles</td>
<td>78 articles</td>
<td>12 articles</td>
<td></td>
</tr>
<tr>
<td>28 articles</td>
<td>20 articles</td>
<td>5 articles</td>
<td></td>
</tr>
<tr>
<td>71 articles</td>
<td>31 articles</td>
<td>8 articles</td>
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12 unique documents

**Medline**
Primary search HPV or human papillomavirus vaccination (MeSH heading) AND [Indigenous OR Indigenous & Australia OR Indigenous status & healthcare (subheadings)]
Secondary search Indigenous status (MeSH heading) AND vaccination OR healthcare collections OR [health system OR recording OR recording & Australia OR recording & HPV OR recording & improving OR Human papillomavirus OR vaccinations OR missing (subheadings)]
## Appendix Table 1: Summaries of the eight unique documents reviewed

<table>
<thead>
<tr>
<th>Author, year (Ref)</th>
<th>Study design</th>
<th>Setting</th>
<th>Population</th>
<th>Data source(s) &amp; measurement</th>
<th>Study size</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adams, Kavanagh &amp; Guthie, 2004 (35)</td>
<td>Cross-Sectional Hybrid</td>
<td>Victoria</td>
<td>BreastScreen (BS) Victoria Staff in eight regional areas. Survey completed by staff members assisting clients with completion of BS1 forms before screening. Audit of Indigenous status at first and last visit by a client at the 8 regional BS centres. Self-administered structured questionnaire returned via mail. Fishers exact was used to compare difference in employment categories of BS staff and regions. <strong>Audit</strong> Random sample- records with Indigenous on their last visit. Discrepancies were identified by comparing Indigenous status at first visit and last visit. <strong>Best practice</strong> AIHW and ABS guidelines.</td>
<td>Response rate 92% (n=122) Audit 200 records</td>
<td>Staff survey • 34% not following best practice guidelines. • 45% felt something prevented them asking Indigenous status. Statistical significance p=0.001 between 8 regions. • 16% left Indigenous status blank. • 7% received informal and formal training to seek Indigenous status. <strong>Audit</strong> • 25% Indigenous status not recorded at first visit. • 4% recorded as unknown. • 29% discrepancies from first to last visit. <strong>Review of best practice guidelines</strong> • not meeting the best practice recommendations. • unable to record Aboriginal and Torres Strait Islander. • born overseas could not identify as Indigenous. • No not stated category.</td>
<td></td>
</tr>
<tr>
<td>Australian Bureau of Statistics, 2012 (41)</td>
<td>Focus Groups</td>
<td>All Australian Capital Cities except Canberra and Adelaide in 2012</td>
<td>Aboriginal and Torres Strait Islander people located in Sydney, Melbourne, Brisbane, Perth, Darwin and Hobart</td>
<td>Focus groups were conducted in 2012 explored the concepts of • Reasons for identifying and not identifying as Aboriginal or Torres Strait Islander or both; • Impact of collection mode; • Identifying in behalf of a third party (or the experience of having ones identity disclosed by a third party); • Changes in identification behaviours overtime.</td>
<td>203 Aboriginal and Torres Strait Islander people 18 focus group sessions</td>
<td><strong>Factors which encouraged</strong> identifying as of being Aboriginal or Torres Strait Islander included: • A sense of pride and confidence in their identity; • The perception disclosing the identity leads to benefits for Aboriginal and Torres Strait Islander people; and • The perception disclosing the identity promotes recognition for issues relating to Aboriginal and Torres Strait Islander people. <strong>Factors which discouraged</strong> identifying as of being Aboriginal or Torres Strait Islander included: • The belief and experience that identifying: • may lead to negative consequences for an individual or they wider community; and • May lead the racism, discrimination or differential treatment. • Learned behaviour as a result of past experiences • Being offended at being asked the identity questions in some contexts; • Needing more information about the reason why identity is being asked; and • Concerns about privacy and confidentiality of information; and • Young Aboriginal people not raised in a community setting less likely to identify.</td>
</tr>
<tr>
<td>Author, year (Ref)</td>
<td>Study design</td>
<td>Setting</td>
<td>Population</td>
<td>Data source(s) &amp; measurement</td>
<td>Study size</td>
<td>Results</td>
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| Australian Institute of Health and Welfare, 2013 (22) | Self-administered survey | Australia December 2003 to January 2004, Randomly stratified sample of General Practitioners nationally | Two part questionnaire was mailed to GPs. Part 1: all GPs asked recommendations for vaccinations, the NPII program, promotional activities, methods of Identifying Aboriginal and Torres Strait Islander people; how many patients were of Aboriginal and Torres Strait Islander origin Part 2: GPs who immunised Aboriginal and Torres Strait Islander adults – asked how many vaccinations episodes by age and type; ease of access to vaccines; models of immunisation; collaboration with other sectors And methods of patient data collection | 1,653 (701 responded, response rate 43%) | • Other factors that discouraged disclosure of identity included:  
  - Who was conducting the survey;  
  - The content, purpose and relevance;  
  - Perceived relevance of the identity question;  
  - Access to information being collected; and  
  - Practical considerations such as timing, durations and setting.  
• Other notable findings included:  
  - Propensity to identify was the same regardless of how a survey is enumerated;  
  - Younger participants were more likely to disclose identity then older participants;  
  - It is unacceptable to provide another person identity unless the person was an immediate family member (for example child).  
  - Identification can promote issues relating to Aboriginal and Torres Strait Islander people;  
  - Need for more accurate statistics for Aboriginal and Torres Strait Islander people;  
  - Asking a patients Indigenous status:  
    - 32% of GPs thought Indigenous status routine for every patient;  
    - Of the remaining 68% - 56% of GPs asked only if they thought the patient was Aboriginal and Torres Strait Islander; 42% did not routinely asked; 33% rely on patients to self-identify;  
  - Reasons for not asking for Indigenous status:  
    - Of the 42% of GPs who did not routinely ask for Indigenous status; 19% indicated it was too difficult to ask and 64% stated Aboriginal and Torres Strait Islander patients rarely attend they practice.  
  - Barriers to immunisations of Aboriginal and Torres Strait Islander people  
    - 60% were unsure if they were the sole health care providers;  
    - 8% indicated difficulty in accessing vaccine supplies |
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<thead>
<tr>
<th>Author, year (Ref)</th>
<th>Study design</th>
<th>Setting</th>
<th>Population</th>
<th>Data source(s) &amp; measurement</th>
<th>Study size</th>
<th>Results</th>
</tr>
</thead>
</table>
| Brough, Shannon & Haswell-Elkins, 2001 (37) | Hospital Census | Brisbane, QLD Mid 1996 | Patients and staff at the Royal Brisbane, Women’s and Children’s Hospital (Major Brisbane public hospital complex) | Mid 1996 wards in the hospital complex randomly selected for patients. Interviewer conducted structured questionnaire with patients in 2 parts- Part 1 all patients; part 2 semi-structured questionnaire only for patients that identified as Indigenous patients Interviewer conducted structured questionnaire with staff | 451 patients Royal children’s and Brisbane hospitals Number staff interviewed not provided | **Staff interviews:**
- Nursing and clerical staff indicated difficulties in asking indigenous status of patients.
- Ethnicity question was sensitive as patients as they don’t see this question relevant to their treatment.
- Ambiguity surrounding ethnicity question irritated patients.

**Patient interviews:**
- 5.5% identified as Indigenous.
- 59.2% recalled filling in admission form.
- 44% of identified as Indigenous on admission forms.
- Discrepancies in hospital records.
- 6.4% in study compared to 3.6 in hospital records @ children’s hospital.
- 2.7% in study compared to 0.96% in hospital records @ royal Brisbane.
- 36.6% all participants asked about ethnicity.
- Of Indigenous patients 32% asked about ethnicity.
- 50.8% all participants knew why ethnicity was asked. |

| Jackson Pulver, Bush & Ward, 2003 (38) | Interviewer-administered survey. | Sydney, May to July 1999. | Consecutive sample of women who delivered live, well infants | Interviewer-administered survey was divided into two parts. Part one included all participants. Part two asked questions only of women who identified as Aboriginal and/or Torres Strait Islander asked an additional 6 questions | 536 women | **29 (5%) self-disclosed as being Aboriginal or Torres Strait Islander;**
- Only 10 identified as Aboriginal or Torres Strait Islander in hospital records.
- Aboriginal and Torres Strait Islander women referred by another organisation significantly more likely than those who self-referred to KVG Hospital to be correctly identified.
- Nine of the 29 Aboriginal and Torres Strait Islander women recalled being asked either by a staff member.
- 1% of non-Aboriginal women indicated they would have objected to being asked if they were Aboriginal or Torres Strait Islander by staff.
- Two thirds of the Aboriginal and Torres Strait Islander women in the study stated they would feel more comfortable if there were more Aboriginal and Torres Strait Islander staff working at the hospital. |

| Lovett, 2006 (39) | Interviewer-administered survey. | Calvary Hospital, Canberra, 2005 | Hospital staff based in Public Hospitals in Canberra, the Australian Capital Territory | Presentation to staff at the admissions and discharge office. Information sheet and Self-administered survey provided after presentation. Follow up visits to collect questionnaire | 17 of 40 staff (response rate 43%) 7 responding staff were ward clerks and 9 were administrative officers | **Limited understanding as to why Indigenous status is collected.**
- Staff feared asking people accessing hospital about their Indigenous status as they anticipated they would receive an aggressive response from both non-Indigenous and Aboriginal and Torres Strait Islander people.
- May staff though the purpose of asking was related to funding.
- Most staff were aware of and used the ABS standards question for Indigenous status.
- Staff justified not collecting Indigenous status as they believed that we are all Australians and should be treated equally, implying they |
<table>
<thead>
<tr>
<th>Author, year (Ref)</th>
<th>Study design</th>
<th>Setting</th>
<th>Population</th>
<th>Data source(s) &amp; measurement</th>
<th>Study size</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Health Information Development unit, University of Adelaide, 2004 (40)</td>
<td>Data analysis review</td>
<td>Data collected through communicable disease surveillance systems across Australia.</td>
<td></td>
<td>Survey of relevant literature from 1997 Consultations with jurisdictional health departments Interviews and surveys with identified key stakeholders</td>
<td></td>
<td>believed ethnic groups within Australian received preferentially treatment. There appeared to be relationship between education levels of staff and their attitudes towards collection Indigenous status, with those with education levels higher than year 12 more likely to think collecting the information was important. Completion of Indigenous status in the jurisdiction communicable disease notification system in 2002: 26% NSW, 44% IN Vic, 26% QLD, 55% WA , 72% SA, and 92% in NT; TAS results were not available; ACT had very few notifications with Indigenous status completed. The review found the limitations with current Indigenous status information included: Differences in jurisdiction in legislation, notification and reporting systems; Regional reporting structures; Core business viewpoints; Concerns about data sharing; Limited capacity to engage with Aboriginal and Torres Strait Islander populations; Deficiencies in systems such a pathology and services, and resources; Deficiencies in primary data collection and baseline information (population numbers); Data not being transferred specially for pathology based services; National information of on-communicable disease not readily available; Data is incomplete and of dubious quality; Not collected at the national standard; Data collections lack quality assurance and do not account for population mobility or cross-border issues; Lack of training to collect and value the information; Lack of public health awareness; and Information is not non-integrated.</td>
</tr>
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</table>
Appendix 10.2- List of activities being taken to improve Indigenous status data in the NHVPR by jurisdictional health departments

1. Tasmania, South Australia and the Australian Capital Territory have updated their HPV consent forms to reflect the national standards provided by AIHW on how to ask Indigenous status in health collections. These changes took effect in 2014.

2. New South Wales health has been emphasizing the importance of recording of Indigenous status to the Public Health Units. The NSW Health school protocol has been amended to require the immuniser to ask the child about their Indigenous status if the information is incomplete. Consent forms scanned into the NSW Register without Indigenous status recorded are being highlighted to enable the capture of this information at the next immunisation visit. The recording of Indigenous status has improved significantly in the last year.

3. Northern Territory encourages all school based vaccine providers to ask Indigenous status at the time of vaccination if it is incomplete on the consent form.

4. Queensland Health has been encouraging their staff to follow up missing Indigenous status information since the vaccine program was introduced. However this is not consistent across the state as not all school vaccines are administered by Queensland Health staff.

5. Tasmania has been holding consultations with vaccination providers and GPs. These consultations have been used to educate and encourage vaccine providers and GPs about the need to complete the Indigenous status field. These consultations have also been used to inform GPs about providing HPV notification forms to the NHVPR.

6. Victoria is running a pilot study to improve the completion of Indigenous status by Local Government Councils (LGC). In selected LGCs they are trialling the use of a new function in the jurisdictional database. New vaccination records cannot be created unless Indigenous status is completed. A new value of ‘To Be Advised (TBA)’ has been created to allow the record to be entered but encourage the follow up of missing Indigenous status information. Victoria is hoping to have this new function rolled out across the state in 2015.

7. In 2013, Victoria changed its HPV vaccination legislation to enable schools to provide personal information about students to LGCs.

8. Western Australia has been monitoring the completion of Indigenous status on HPV vaccination forms. It has seen a marked improvement in the completion of this field since the program began in 2007.
Appendix 10.3 - Summary of consultations with key jurisdictional stakeholders

Summary of consultations with key jurisdictional stakeholders regarding the collection of Indigenous status for HPV vaccinations

Project background
In conjunction with the Victorian Cytology Service, the Department of Health (Health) is investigating the completion of Aboriginal and Torres Strait Islander (Indigenous) status in the National HPV Vaccination Program Register (NHVPR). Using data from the NHVPR and information collected via consultations with jurisdictional health departments, the aims of the project are to identify if Indigenous status of females is underreported in the NHVPR and what barriers exist that could be impeding its collection.

As part of the project, consultations were conducted with all jurisdictions from August 2013 to July 2014 and focused on two areas: 1) what barriers they believed impede the collection of Indigenous status; and 2) what actions could be taken to improve the collection of this variable.

Results of consultations

Below are the aggregated responses from the consultations. They have been divided into two topics; 1) barriers to collecting Indigenous status and 2) actions already taken by jurisdictions to improve Indigenous status collection.

1. Barriers to collecting Indigenous status

The consultations asked jurisdictions about the barriers they believed impacted the completion of Indigenous status. The most common barriers identified by the jurisdictions include:

School based program:
These barriers relate to collection of Indigenous status through the HPV vaccination consent forms provided through the school-based National HPV Vaccination Program.

1.1. Parents, guardians and students may not understand why the question is being asked: This particular barrier was identified by all jurisdictions and was considered to be the most common reason as to why Indigenous status was not provided. Some jurisdictions suggested that providing information to explain why the question is asked may help improve Indigenous status completion. This information could be provided on the consent forms or as a separate information sheet.

1.2. The completion of the Indigenous status depends on who fills out the HPV vaccine consent form: This barrier was identified by two jurisdictions. Completion of Indigenous status on the consent forms may vary depending on whether the student
or the parent has completed the consent form. Some jurisdictions suggested providing information about the importance of collecting Indigenous status, as outlined above, may help reduce this barrier. However it would be difficult to determine whether this is occurring and if the provision of information has any impact.

1.3. **Indigenous is status not thought to be a high priority in the provision of healthcare.** All jurisdictions identified this as a barrier to collection Indigenous status. They indicated that the question may be accidently or internally missed as it is not considered to be as relevant to the healthcare being provided. This barrier leads back to 1.1, in which there is a misunderstanding as to the importance of collection of this information in healthcare settings.

1.4. **The parent(s) of the child may not want the school to known their ethnicity.** One jurisdiction identified this as a barrier and is considering conducting a pilot study to assess if this barrier exists. As part of the study, a reply-paid envelope will be provided with each vaccination consent form to enable parents to send forms back to the vaccine providers without going through the school.

### General Practitioners:

The barriers outlined below relate to the completion of Indigenous status on the HPV notifications forms, which are provided to GPs by jurisdictional health departments when they request a HPV vaccine dose.

1.5. **General Practitioners and practice staff are reluctant to ask Indigenous status as they feel it is either not relevant to healthcare or considered asking the question to be racist.** This was the most common barrier identified by jurisdictions as to why Indigenous status may be incomplete on the HPV notification forms. Whilst all jurisdictions identified this barrier, some indicated they believe this issue is declining within their jurisdiction.

1.6. **General Practitioners and practice staff may assume the Indigenous status of a person based on appearance.** Six jurisdictions identified this barrier and highlighted it is likely to result in Indigenous status being incorrectly completed on notification forms. Jurisdictions were unsure how this barrier could be addressed.
Other barriers:

The barriers outlined below were identified by a number of jurisdictions, but relate to the construction of the HPV consent and notification forms and social issues.

1.7. **Structure of how Indigenous status is asked on the consent or notification forms.**

Four jurisdictions thought that the way in which Indigenous status is asked on consent forms may result in its incompletion. If the form uses the below responses, Indigenous status may be incomplete as it does not enable individuals who identify as only an Aboriginal or as a Torres Strait Islander or both to choose a relevant category.

- **Single tick box**
  - Aboriginal/Torres Strait Islander

- **Binary response**
  - “Is your child of Aboriginal or Torres Strait Islander origin?” YES/NO

1.8. **The placement of the question on consent forms.** Three jurisdictions noted that if the placement of the Indigenous status question is not prominent on the form it could be overlooked.

1.9. **Too many questions on the notification or consent forms.** One jurisdiction suggested if there is a large amount of information requested in the form, than Indigenous status may be overlooked. To address this issue the jurisdiction suggested either reducing the number of questions on the form or moving Indigenous status to a more prominent position.

1.10. **Literacy issues –** This barrier was identified by one jurisdiction and relates to parents who may be functionally or medically illiterate or for whom English is not their primary language. This Jurisdiction suggested that providing forms in a number of different languages and/or have vaccination providers engage local communities and verbally explain the vaccination form may reduce this issue. However, this would need to be addressed at a local level and would rely heavily on available resources.
2. Actions already taken by jurisdictions to address Indigenous status reporting

2.1. Tasmania, South Australia and the Australian Capital Territory have updated their HPV consent forms to reflect the national standards provided by AIHW on how to ask Indigenous status in health collections. These changes took effect in 2014.

2.2. New South Wales health has been emphasizing the importance of recording of Indigenous status to the Public Health Units. The NSW Health school protocol has been amended to require the immuniser to ask the child about their Indigenous status if the information is incomplete. Consent forms scanned into the NSW Register without Indigenous status recorded are being highlighted to enable the capture of this information at the next immunisation visit. The recording of Indigenous status has improved significantly in the last year.

2.3. Northern Territory encourages all school based vaccine providers to ask Indigenous status at the time of vaccination if it is incomplete on the consent form.

2.4. Queensland Health has been encouraging their staff to follow up missing Indigenous status information since the vaccine program was introduced. However this is not consistent across the state as not all school vaccines are administered by Queensland Health staff.

2.5. Tasmania has been holding consultations with vaccination providers and GPs. These consultations have been used to educate and encourage vaccine providers and GPs about the need to complete the Indigenous status field. These consultations have also been used to inform GPs about providing HPV notification forms to the NHVPR.

2.6. Victoria is running a pilot study to improve the completion of Indigenous status by Local Government Councils (LGC). In selected LGCs they are trialling the use of a new function in the jurisdictional database. New vaccination records cannot be created unless Indigenous status is completed. A new value of ‘To Be Advised (TBA)’ has been created to allow the record to be entered but encourage the follow up of missing Indigenous status information. Victoria is hoping to have this new function rolled out across the state in 2015.

2.7. In 2013, Victoria changed its HPV vaccination legislation to enable schools to provide personal information about students to LGCs.

2.8. Western Australia has been monitoring the completion of Indigenous status on HPV vaccination forms. It has seen a marked improvement in the completion of this field since the program began in 2007.
Chapter 5
Evaluation of laboratory-confirmed influenza notifications in the National Notifiable Disease Surveillance System (NNDSS)
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5-iii
1. Prologue

1.1. Role

I was the lead author investigator in this evaluation. I formulated and developed the survey instruments used to undertake consultations with four key stakeholder groups: two via telephone interviews and two completed electronically by stakeholder. I extracted, cleaned and analysed laboratory-confirmed influenza notifications from the National Notifiable Diseases Surveillance System (NNDSS), influenza-like-illness general practice presentations from the Australian Sentinel Practices Research Network (ASPREN) and influenza hospitalisations from the Influenza Complications Alert Network (FluCAN) to evaluate key attributes of the NNDSS as an influenza surveillance system. I also developed a project proposal and requested laboratory testing data to investigate if influenza testing data could be utilised for national reporting activities.

1.2. Lessons learnt

By completing this evaluation I have learnt about the structure, purpose and objectives of the NNDSS and how it relates to communicable disease surveillance in Australia. I have learnt how to use and interpret laboratory-confirmed influenza notifications from the NNDSS and understand the limitations of using notification data for this disease. From my review of the literature and consultations with the influenza epidemiologists I have expanded my understanding of influenza biology, epidemiology, illness and its impact internationally and within Australia. I have also gained a comprehensive knowledge of the systems used to in the surveillance of influenza nationally and how the NNDSS fits into this structure.

A key lesson I learnt in undertaking this evaluation, is to always go back to the basics and plan, plan, plan. During the course of this evaluation I had underestimated the need to plan the data analysis component. Assuming the statistical analyses for this evaluation were pretty straight forward, I inadvertently overlooked some key steps. This evaluation has taught me that no matter how small the analysis or how organised you think you are, you should always have a written plan of attack.
1.3. Public health implications

This evaluation is the first to review the surveillance of laboratory-confirmed influenza collected through the NNDSS. Outcomes of this study have provided the Department of Health with recommendations to improve the analysis and use of laboratory-confirmed influenza surveillance in Australia. Results of this evaluation are to be presented to the National Influenza Surveillance Committee in 2015 and will provide the basis for decisions to improve the data quality, reporting and analysis of laboratory-confirmed influenza from the NNDSS.
2. Abstract

The Australian National Influenza Surveillance Scheme combines reporting of influenza activity from sentinel general practice consultations for influenza-like illness (ILI), consultations rates for ILI presentations at hospital emergency departments, influenza hospitalisations, laboratory-confirmed influenza notifications, community based data collections and mortality data. These data are used to guide the appropriate public health responses to influenza, including the development of guidelines on vaccination, antiviral treatments and the assessments of additional medical resources. The National Notifiable Diseases Surveillance System (NNDSS) is one of the primary influenza surveillance systems used in Australia. Collecting data for all laboratory-confirmed influenza, it provides information on circulating viruses, demographic details and characterises the Australian seasonal and inter-seasonal periods.

The Australian Government Department of Health initiated this evaluation of laboratory-confirmed influenza notifications in the NNDSS to assess the utility of notifications in meeting the national influenza surveillance objectives. This evaluation was conducted using the Updated Guidelines for Evaluating a Public Health Surveillance Systems developed by the Centers for Disease Control and Prevention (CDC), Atlanta. These guidelines provided the framework to described and evaluate the attributes of the system. To understand the usefulness of laboratory-confirmed influenza in the NNDSS four primary stakeholder groups were surveyed: (a) the National Influenza Surveillance Committee, (b) jurisdictional health department data managers, (c) the Department of Health influenza epidemiologists, and (d) NNDSS data managers.

The evaluation revealed the NNDSS is an acceptable, simple and useable system, providing high quality data for the national surveillance of laboratory-confirmed influenza in Australia. The system is perceived by stakeholders to be highly valuable and was found to contribute to four of the six national objectives for influenza surveillance in Australia.
3. The public health importance of influenza in Australia

Influenza is an acute viral disease that is highly contagious and can affect large numbers of people in a limited space of time.\(^1\) Clinical symptoms of influenza include fever (38-39°C), myalgia, cough, sore throat, headaches, coryza, vomiting, nausea, diarrhoea and prostration.\(^2\) Symptoms normally onset suddenly, and infection is communicable for 3 to 5 days in adults, and 7 to 10 days in children. Disease severity of influenza ranges from asymptomatic to mild-upper respiratory tract illness and severe complications including pneumonia.\(^4\) This severity is determined by features intrinsic to the virus, including its similarity to previous circulating strains, vaccine strains, and host factors such as the presence of chronic conditions, pregnancy and smoking.\(^5\) Influenza is predominantly transmitted via large droplets (other modes of transmission include nuclei and contact transmission) and its incubation period is estimated to be on average 2 days.\(^2\)\(^6\)

There are three types of the influenza virus: influenza A, influenza B and influenza C. Influenza viruses A and B are the most common virus seen in humans and are the cause of significant morbidity and mortality worldwide.\(^7\) While infections with influenza C viruses occur in humans, they are less common and often associated with a milder disease.\(^6\)

Influenza A is divided into subtypes based on two proteins on the virus's surface: the haemagglutinin (H) and the neuraminidase (N). There are 18 different H subtypes and 11 different N subtypes. The subtypes of influenza A viruses currently circulating widely amongst humans include A (H1N1) and A (H3N2).\(^2\) The primary reservoir of influenza A viruses is aquatic birds, but these viruses can also circulate in other animals including pigs, horses and seals.\(^2\) Influenza A viruses are the most likely to develop into pandemic based strains, and have been responsible for four pandemics in the 20th century: 1918 “Spanish influenza”; 1957 “Asian Flu”;1968 “Hong Kong” H3N2 virus; and 2009 H1N1 “Swine Flu”.\(^7\)\(^-\)\(^9\) Influenza B is not divided into subtypes, but assigned two antigenically distinct lineages that have been in circulation worldwide since 1983; B/Yamagata and B/Victoria.\(^10\) Humans are the primary reservoir for influenza B viruses.

Both influenza viruses A and B cause annually reoccurring seasonal outbreaks in temperate regions, with activity peaking during the winter months; November to April for the northern hemisphere and May to October for the southern hemisphere.\(^9\) The circulating strains identified during the northern hemisphere influenza season are often mirrored in the subsequent southern hemisphere season.\(^1\)\(^7\)
Depending on the strains circulating during the annual influenza season, attack rates can range anywhere between 2% to 10% in the general community, and to more than 50% in closed population groups, such as nursing homes and schools.\(^{(2, 3, 11)}\) Global estimates suggest influenza results in three to five million cases of severe illness and between 250,000 to 500,000 deaths each year.\(^{(3, 9)}\) In 2013, influenza was the underlying cause of death in 80 deaths in Australia, representing a rate of 0.1 per 100,000 population.\(^{(12)}\) However, this rate is thought to be an underestimation of the influenza mortality as relatively few deaths are specifically coded as influenza. A study conducted in 2008 \(^{(13)}\) found that the annual excess mortality attributed to influenza was 6.4 per 100,000 populations in those aged 50 to 64 years and 116.4 per 100,000 population in those aged 65 years and over, suggesting the mortality burden of influenza is much higher in Australia than current statistical data indicates.

The severity of influenza is unpredictable and whilst the majority of cases recover approximately one week after symptom onset, some people are either hospitalised or develop life threatening complications such as pneumonia.\(^{(3)}\) In 2013, it was estimated that 5,400 hospital admissions were due to infection with influenza in Australia.\(^{(14)}\) Of these, 68% were in persons under 65 years of age.

Influenza infections result in an extensive socio-economic burden.\(^{(15, 16)}\) Estimations from the United States suggest that the total annual cost of influenza is $US87 billion, of which $US10 billion accounts for all direct medical costs, such as medical consultations and hospital fees.\(^{(3, 17)}\) In France and Germany, it is estimated that annually influenza costs from $US10 to $US15 billion,\(^{(11)}\) and in Guangdong province China, the annual medical cost for influenza-like-illness (ILI) is estimated to be $US115 million.\(^{(15)}\)

In Australia, the indirect costs associated with influenza, such as loss in working time and productivity, are considered to have the highest economic burden.\(^{(11, 18, 19)}\) Per influenza episode, on average 3 to 5 days of work are lost, resulting in substantial losses in productivity and economic growth.\(^{(11, 17)}\) The cost of influenza to the Australian health care system is considerable. Between April 2000 and March 2006, influenza and ILI was attributed to 310,000 General Practitioner (GP) consultations and 18,400 hospitalisations, with a combined estimated cost to the Australian health care system of $AUD115 million.\(^{(17)}\)

In order to allocate health care resources, determine public health interventions and develop cost effective programs, surveillance of influenza needs to be conducted.
frequently and over time. In Australia, the surveillance of influenza is conducted using information from community, primary and tertiary health care and laboratory based settings. This report details an evaluation of the laboratory confirmed influenza surveillance through the National Notifiable Diseases Surveillance System (NNDSS).

4. Evaluation Framework

4.1. Aims and objectives of the evaluation
To evaluate surveillance of laboratory-confirmed influenza in Australia by:

- systematically and objectively evaluate laboratory-confirmed influenza surveillance against the objectives of national influenza surveillance; and
- providing recommendations to improve the collection and analysis of laboratory-confirmed influenza notifications in the NNDSS.

This evaluation was conducted using the Updated Guidelines for Evaluating a Public Health Surveillance Systems developed by the Centers for Disease Control and Prevention (CDC), Atlanta. These guidelines provided the framework in which I will describe and evaluate the surveillance of laboratory-confirmed influenza in the NNDSS.

4.2. System Description
To describe the NNDSS I collected information from the Australia Government Department of Health (the Department of Health) website, the NNDSS annual reports and face-to-face consultations with the Vaccine Preventable Diseases Surveillance (VPDS) epidemiologist responsible for influenza and NNDSS data managers in the Office of Health Protection (OHP) at the Department of Health.

4.3. Evaluation of the attributes and usefulness
Attributes of the NNDSS for influenza surveillance were defined and evaluated as follows:

- Acceptability – the willingness of persons and organisations to provide to and use laboratory-confirmed influenza data from the NNDSS.
- Data quality – the completeness and accuracy of laboratory-confirmed influenza notifications in the NNDSS. This was measured by examining the completeness and accuracy of the National Surveillance Committee (NSC) priority data fields for influenza. These include:
  - sex;
  - age at onset;

5-6
- date of birth;
- true onset date;
- specimen date;
- Indigenous status;
- influenza subtype;
- death; and
- laboratory diagnosis method.

- Flexibility – the NNDSS ability to adapt to the changing information needs or operating conditions for the surveillance of laboratory-confirmed influenza.
- Positive predictive value – the proportion of notifications that truly have influenza infection.
- Stability – the reliability (ability to collect, manage and provide data without error) and availability (ability to be operational when it is needed) of laboratory-confirmed influenza notifications in the NNDSS.
- Sensitivity – the ability for the NNDSS to capture laboratory-confirmed influenza in the community, measured by the NNDSS’s ability to:
  - detect and report the proportion of influenza occurring in the community by analysing the inter-seasonal laboratory-confirmed notifications numbers from 2008 to 2013; and
  - detect outbreaks of influenza.
- Simplicity – the structure of the NNDSS and the ease in extracting notifications for surveillance activities.
- Representativeness – the representativeness of laboratory-confirmed influenza in the NNDSS, measured by comparing the age distribution of NNDSS laboratory-confirmed influenza notifications with:
  - the age distribution of aggregated Australian Sentinel Practices Research Network (ASPREN) ILI presentations; and
  - the age distribution of laboratory-confirmed cases reported the Influenza Complications Alert Network (FluCAN), a sentinel Hospital surveillance system.
- Timeliness – the ability of the NNDSS to receive laboratory-confirmed influenza notifications to produce timely accurate results and reports, measured by calculating the median number of days for laboratory-confirmed influenza notifications to be confirmed by a laboratory, sent to a jurisdictional health department and provided to the NNDSS.
- Usefulness – the extent laboratory-confirmed influenza NNDSS notifications contribute to the understanding of the influenza picture in Australia.
4.4. Engagement with key stakeholders

The key stakeholders for the surveillance of influenza in Australia were identified with the assistance of the Department of Health (Appendix 12.1). I conducted consultations with members of the National Influenza Surveillance Committee (NISC) (Appendix 12.2a), the Department of Health influenza epidemiologists (Appendix 12.2b), jurisdictional data managers (Appendix 12.2c) and NNDSS data managers (Appendix 12.2d).

4.4.1. National Influenza Surveillance Committee (NISC)

NISC is a sub-committee of the Communicable Disease Network Australia (CDNA). Membership comprises of the Department of Health influenza epidemiologists, jurisdictional surveillance officers and epidemiologists and other influenza surveillance systems (ASPREN, FluCAN, FluTracking) coordinators and managers. Members of this committee frequently use NNDSS data to assess influenza activity in Australia. NISC members, except the Department of Health epidemiologist, were contacted by email to partake in the consultations and semi-structured interviews were conducted by phone from April to August of 2014.

4.4.2. Jurisdictional data managers

Each jurisdiction has one or more data managers or surveillance officers that are responsible for the transmission of notification data from the jurisdiction’s database to the NNDSS. The role data managers and surveillance officers varies between the jurisdictions, with some performing all tasks relating to the storage, maintenance and transference of notification data, while others oversee the process conducted by a dedicated data team. Data managers and surveillance officers were contacted by email to partake in the consultations and semi-structured interviews were conducted by phone in May of 2014.

4.4.3. Department of Health influenza epidemiologist and NNDSS data managers

There are two influenza epidemiologist and two NNDSS data managers placed within VPDS in the OHP at the Department of Health. The roles of the epidemiologist are to monitor and report on influenza activity in Australia, co-ordinate national influenza surveillance and manage contracts for sentinel influenza surveillance systems. The roles of the NNDSS data managers are to monitor and maintain the NNDSS, run system diagnostics, conduct quality assurance checks and assist jurisdictions with the transmission of notification data to NNDSS. Consultations with the Department of
Health influenza epidemiologist and NNDSS data managers were conducted using a self-administered electronic survey developed in Survey Monkey™. Each participant was emailed a web link and asked to complete the survey over a 2 week period in May and June of 2014.

4.4.4. Scope of consultations
Consultations with NISC members and the Department of Health influenza epidemiologist focused on the usefulness, acceptability, flexibility, sensitivity and stability (Table 1). The consultations with the jurisdictional and NNDSS data managers focused on the practicalities of sending and receiving data, the flexibility of communicable disease notification systems and NNDSS data specifications. Information collected during the consultations were recorded, stored and analysed using Survey Monkey™.

Table 1: List of attributes evaluated in stakeholder consultations, by stakeholder group and method of consultation

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Stakeholder</th>
<th>Consultation method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptability</td>
<td>NISC member</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>Department of Health epidemiologist</td>
<td>Electronic survey</td>
</tr>
<tr>
<td>Data quality</td>
<td>NISC member</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>Department of Health epidemiologist</td>
<td>Electronic survey</td>
</tr>
<tr>
<td></td>
<td>Jurisdictional data manager</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>NNDSS data manger</td>
<td>Electronic survey</td>
</tr>
<tr>
<td>Flexibility</td>
<td>Jurisdictional data manager</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>NNDSS data manger</td>
<td>Electronic survey</td>
</tr>
<tr>
<td>Stability</td>
<td>NISC member</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>Department of Health epidemiologist</td>
<td>Electronic survey</td>
</tr>
<tr>
<td></td>
<td>Jurisdictional data manager</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>NNDSS data manger</td>
<td>Electronic survey</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>NISC member</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>Department of Health epidemiologist</td>
<td>Electronic survey</td>
</tr>
<tr>
<td>Simplicity</td>
<td>NISC member</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>Department of Health epidemiologist</td>
<td>Electronic survey</td>
</tr>
<tr>
<td></td>
<td>Jurisdictional data manager</td>
<td>Phone consultation</td>
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<td></td>
<td>NNDSS data manger</td>
<td>Electronic survey</td>
</tr>
<tr>
<td>Representativeness</td>
<td>NISC member</td>
<td>Phone consultation</td>
</tr>
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<td></td>
<td>Department of Health epidemiologist</td>
<td>Electronic survey</td>
</tr>
<tr>
<td>Timeliness</td>
<td>NISC member</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>Department of Health epidemiologist</td>
<td>Electronic survey</td>
</tr>
<tr>
<td>Usefulness</td>
<td>NISC member</td>
<td>Phone consultation</td>
</tr>
<tr>
<td></td>
<td>Department of Health epidemiologist</td>
<td>Electronic survey</td>
</tr>
</tbody>
</table>
4.5. Data analysis

Notifications of laboratory-confirmed influenza with a diagnosis date between 1 January 2008 and 31 December 2013 were extracted from the NNDSS on 18 August 2014 and analysed using Stata version 13™ and Microsoft Excel 2012™. Diagnosis date is a field derived by the NNDSS from date of onset, or where the date of onset is not known, the earliest of the specimen collection date, notification date (date when health professional signed notification or the laboratory issued results), or the notification received date (date the notification was received by jurisdictional health authority). Age-specific notification rates were calculated using Australian Bureau of Statistics (ABS) mid-year populations from 2008 to 2013.

5. Analysis of laboratory-confirmed influenza notifications in the NNDSS, 2008-2013

There were 198,617 notifications from 2008 to 2013. Over this period, the seasonal pattern and timing of influenza notification activity remained relatively consistent, however each season’s and inter-seasonal duration and magnitude varied (Figure 1). The lowest notification numbers occurred in 2008 (n=9,175) and, as a result of the 2009 influenza A (H1N1) pandemic, the highest number of notifications occurred in 2009 (n=59,028).

Although the number of laboratory-confirmed influenza notifications declined substantially following the 2009 pandemic, notifications reported to the NNDSS increased from 13,468 in 2010 to 44,570 in 2012, before declining to 28,333 in 2013.

Since the 2009 pandemic, annual influenza notifications have been substantially higher compared with previous seasons (2007 and 2008), which were considered at the time to be severe. (21, 22) While the increase in notifications since 2009 may imply that the 2010 to 2013 seasons were severe, evidence suggest that since 2007, and particularly after 2009, there has been a steady increase in and more widespread testing of influenza in Australia. Increases in notifications from 2010 are more likely to be a reflection of a rise in testing being undertaken than an actual increase in disease or severity of illness. (24)

Of the notifications reported over the surveillance period females accounted for 52.2% (n=103,622). Rates of notification were higher amongst females in most age groups, except for those aged less than 15 years, and those aged 84 years and over. The median age of notifications during this reporting period was 30 years, with a range of 0
to 113 years. The highest number of notifications occurred in the 0 to 4 years age group, which accounted for 13% of all notifications (Figure 2).

**Variations in rates of influenza by age group and time** reflect the circulating influenza viruses. The 2009, 2010, 2011 and 2013 influenza seasons were dominated by the pandemic influenza A(H1N1)pdm09 virus. This particular strain is more likely to affect younger age groups and display a downward trend with increasing age. In comparison, the 2012 season was dominated by influenza A(H3N2), which commonly affects those aged under 10 years and those aged 70 years and over.

The NNDSS is one system used for the surveillance of influenza in Australia. Developed in 1990 under the auspices of the Communicable Disease Network Australia (CDNA), the NNDSS is used to collate information for 69 communicable diseases that have been agreed to be nationally reported. However, whilst these diseases are listed in the National Notifiable Disease List (NNDL), not all have been made a notifiable in each jurisdiction.

The NNDSS collects a core dataset which includes five mandatory data fields: unique record reference number, notifying jurisdiction, disease code, date of notification to the jurisdictional health department and confirmation status (confirmed or probable case). Non-mandatory core data fields, collected as part of the national dataset, include age, sex, Indigenous status, postcode of residence, date of disease onset, death, and outbreak reference.

If relevant, additional information is collected on species, serogroups/subtypes and phage types of organisms, and vaccination status of the case. The NNDSS also collects enhanced surveillance information for newly acquired hepatitis B and hepatitis C, invasive pneumococcal disease, donovanosis, gonococcal infection, syphilis infection less than 2 years duration and tuberculosis. Enhanced data fields
include but are not limited to country of birth, residency status, site of infection and risk factors for infection.

The National Health Security Act 2007 provides the legislative basis for, and authorises the exchange of health information, including personal information, between jurisdictional health departments and the Australian Government.\textsuperscript{(26,27)} The Act provides a legislative instrument to establish the National Notifiable Diseases List, which specifies the diseases for which personal information can be exchanged.\textsuperscript{(27)} In order for data to be provided under the Act, the National Health Security Agreement 2008 was developed and provides the operational arrangements to formalise and enhance existing surveillance and reporting systems.\textsuperscript{(28)}

6.1. National surveillance of influenza in Australia

There are six objectives of national influenza surveillance. They are to:

- provide an early alert for the onset of influenza epidemics;
- facilitate the characterisation of an epidemic;
- evaluate the impact of clinical, laboratory and public health measures;
- isolate and characterise circulating viruses;
- assess the impact of influenza (health service demand, health impact, economic and social impacts); and
- ensure accurate information is available in a timely manner.\textsuperscript{(29)}

The National Influenza Surveillance Scheme (the Scheme) combines the influenza activity reporting from community based data, sentinel general practice consultations for ILI, consultations rates for ILI presentations at hospital emergency departments, influenza hospitalisations, mortality data, laboratory-confirmed influenza notifications and virological surveillance. These data are used to guide the appropriate public health responses to influenza, including the development of recommendations on vaccination and antiviral treatments and the assessments of additional medical resources. Figure 3 outlines the surveillance systems used to monitor influenza in Australia.

The National Surveillance Committee (NSC) ensures the data quality and consistency of data collected in the NNDSS. NSC has prioritised the completion of the following data fields for surveillance of laboratory-confirmed influenza: subtype, date of birth, laboratory diagnosis method, Indigenous status, specimen date and death.

6.2. Purpose of influenza surveillance using the NNDSS

The NNDSS collects data on all laboratory-confirmed influenza notifications in Australia. This collection is directed by a nationally agreed case definition and national
core data specifications. Influenza notifications have been collected in the NNDSS since January 2001 and these data are used to provide information on circulating influenza viruses, demographic details and characterise the seasonal and inter-seasonal periods. Whist the majority of jurisdictions have provided influenza notifications to the NNDSS since 2001, it wasn’t until 2008 that all jurisdictions were able to provide laboratory-confirmed influenza notifications to the NNDSS. (30, 31)

Figure 3: Levels of influenza surveillance operating in Australia, 2014

6.3. National Surveillance Case definition for influenza

The national surveillance case definition for influenza includes confirmed cases only. A confirmed case requires laboratory definitive evidence of either:

- isolation of influenza virus by culture from appropriate respiratory tract specimen;
  OR
- detection of influenza virus by nucleic acid testing from appropriate respiratory tract specimen;
  OR
- laboratory detection of influenza virus antigen from appropriate respiratory tract specimen;
  OR

- NNDSS
- Sentinel Laboratory Surveillance
- WHO Collaborating Centre for Reference & Research on Influenza (WHO CC)

- NNDSS
- Births, Deaths and Marriages from NSW

- Influenza Complications Alert Network (FluCAN)
- Queensland Public Hospital Admissions (EpiLog)
- Paediatric Severe Complications of Influenza

- NSW, NT and WA Emergency Departments

- Australian Sentinel Practices Research Network (ASPREN)

- Flu Tracking
- National Health Call Centre Network (NHCCN)
- IgG seroconversion or a significant increase in antibody level or a fourfold or greater rise in titre to influenza virus;  
  OR
- single high titre by CFT or HAI to influenza virus.

6.4. Population under surveillance
As a national system, the NNDSS provides surveillance data for laboratory-confirmed influenza notifications in the entire Australian population.

6.5. Data sources
Treating doctors, diagnostic laboratories and hospitals report notifiable communicable diseases to jurisdictional health departments under the provisions of the jurisdictions public health legislation. Under the National Health Agreement 2008, jurisdictional health departments forward de-identified notification data electronically to the NNDSS on a daily basis. This flow and use of notification data is depicted in Figure 4.

NNDSS influenza notifications are analysed by the Department of Health influenza epidemiologists and provided fortnightly to the CDNA. These data are also provided through the Department of Health’s website and through the Communicable Diseases Intelligence journal (CDI). NISC and CDNA provide the forums in which influenza notifications are discussed by the jurisdictions and the Department of Health, along with other institutions, sentinel surveillance system managers and key stakeholders.

NISC jurisdictional members have indicated that the majority of influenza notifications are provided by diagnostic laboratories. However, in some jurisdictions notifications are also provided by treating clinicians (57%, 4/7) and hospitals (30%, 2/7). To calculate influenza notification rates, ABS mid-year population data are used and updated regularly within the NNDSS.

6.6. Transference and management
Jurisdictional health departments transmit data for laboratory-confirmed influenza notifications through the Department of Health Data Acquisition system (DAS). Since 2008 all jurisdictions have provided notification data using this system. Each jurisdiction has its own purpose built database that stores and manages notification data. The platforms used for these systems include Oracle™, Microsoft Access™ and MAVEN™. The NNDSS is operated on an Oracle™ platform.

Six jurisdictions automatically transmit data to the NNDSS and two generate (require users to manually send the data) a notification extract. Transmissions to the NNDSS occur daily, and in some jurisdictions hourly. All jurisdictional data managers stated
their notification systems were highly reliable and all transmission to the NNDSS is run routinely without failure. Data managers indicated interruptions to transmission would only occur if there was catastrophic failure in an external server or DAS collapsed.

**Figure 4:** Data flow of laboratory-confirmed influenza notifications into the NNDSS

1. **Patient presents to clinician or hospital with ILI symptoms**
   - **Specimen for influenza taken**
     - **Positive test result**
       - **Clinician or hospital**
         - **Notified to the Jurisdictional Health Department**
           - **Notified to the NNDSS**
             - **Analysed by Health**
               - **The NNDSS Annual Report**
               - **National Influenza Surveillance Scheme Annual Report**
               - **Australian National Influenza Surveillance Report**
               - **NNDS summary tables on CDA website**
               - **CDNA fortnightly reports**
   - **No specimen taken**
   - **Negative test result reported to clinician or hospital**
For data to be accepted in the NNDSS, the Department of Health’s DAS runs a number of business rules and data checks. Table 2 details the business rules used for all disease notifications to be accepted by the NNDSS. Data quality checks are not conducted on free text fields such as subgroup or the multiple entry fields such as laboratory diagnosis method. There are currently no logical data checks (i.e notification date occurs before specimen date) conducted by DAS. However, at the time of writing of this evaluation, work was being undertaken to identify where these logical rules are needed and how they can be implemented in the future.

Table 2: Data rules relating to the all notified disease including laboratory-confirmed influenza uploaded into the NNDSS

<table>
<thead>
<tr>
<th>Data rule</th>
<th>Data fields applied to</th>
<th>Manual entry available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion of mandatory field with accepted value for the disease as outlined in the NNDSS data specifications</td>
<td>• Confirmation status &lt;br&gt;• State code &lt;br&gt;• Disease code &lt;br&gt;• Notification received date &lt;br&gt;• Notification ID</td>
<td></td>
</tr>
<tr>
<td>Meets the values as specified by the NNDSS data specifications</td>
<td>• Indigenous Status &lt;br&gt;• Sex &lt;br&gt;• Death &lt;br&gt;• Age onset (0&gt; &amp; &lt;103)</td>
<td></td>
</tr>
<tr>
<td>Date is not in the future (i.e notification for 2017 when year is 2014)</td>
<td>All date fields (birth, specimen, notification, notification received, &amp; true onset)</td>
<td></td>
</tr>
<tr>
<td>Date not before 1901</td>
<td>Date of birth</td>
<td>Yes, on a case by case basis. Completed by NNDSS data managers</td>
</tr>
<tr>
<td>Date not before 1960</td>
<td>Vaccination date</td>
<td></td>
</tr>
<tr>
<td>Date not before 1991</td>
<td>• True onset date &lt;br&gt;• Notifications date &lt;br&gt;• Specimen date &lt;br&gt;• Notification received date</td>
<td>Yes, for chronic conditions – hepatitis B &amp; C, tuberculosis, syphilis unspecified, leprosy</td>
</tr>
</tbody>
</table>

The Department of Health provides the NNDSS data specifications to all jurisdictional health departments. These specifications describe each of the data fields in the NNDSS providing the name, alias, description, type of field (i.e numeric, alpha and alpha numeric), accepted data values (if applicable) and if it is a compulsory field.

All jurisdictional data managers indicated they had access to the NNDSS data specifications and found them to be useful. However, five suggested some fields, such as vaccination status, were confusing and required further clarification. One data manager suggested the history of changes to the specifications should be provided to enable jurisdictions to review their systems and ensure they meet the data requirements of the NNDSS.
6.7. Data analysis, reporting procedures and dissemination

NNDSS influenza notifications are analysed for a variety of purposes. These include fortnightly summary tables and reports, annual reports, media and data requests. Influenza notifications received in the NNDSS are analysed by the Department of Health influenza epidemiologists every fortnight and provided to CDNA in a fortnightly summary table. This table provides the number of notifications received in the last fortnight and year-to-date (YTD) for each jurisdiction and nationally. To ascertain if any action is required, national YTD notifications are compared against the YTD five-year rolling mean plus or minus two standard deviations. The summary table is published fortnightly on the Department of Health’s website.

NNDSS laboratory-confirmed influenza notifications are analysed to determine when the start and peak of the annual Australian influenza season occurs. During the annual influenza season, NNDSS laboratory-confirmed influenza notifications are analysed fortnightly in conjunction with other influenza surveillance systems and reported in the Australian National Influenza Surveillance Report. This report provides an update on influenza activity and is published fortnightly on the Department of Health’s website.

The most comprehensive analyses of NNDSS laboratory-confirmed influenza notifications are: (1) the Australia's Notifiable Diseases Status: Annual report of the NNDSS (NNDSS annual report), (2) the National Influenza Surveillance Scheme Annual Report and (3) the quarterly NNDSS summaries. The NNDSS annual report compares the historical trends of influenza with the current year’s data and provides information on the age and sex distribution of cases, number of notifications by jurisdiction, the seasonality of influenza infections and circulating strains. The Annual National Influenza Surveillance Scheme report is similar to the NNDSS annual report, but provides a more in-depth analysis of influenza in Australia using data from the NNDSS and other influenza surveillance systems. The quarterly NNDSS summaries provide the number of notifications reported by jurisdictions in the preceding quarter. All three reports are published in CDI.

Finally, data are analysed to provide responses to data and media requests. Data requests are processed by the Department of Health influenza epidemiologists, and depending on their complexity, sensitivity and detail, may be reviewed by CDNA. Basic aggregated data, data caveats and in some cases de-identified line-listed data are provided. Data for media requests are completed by the Department of Health epidemiologist and require the clearance of OHP executives.
There are three problems that currently exist with the analysis of influenza notifications by the Department of Health. Firstly, there are often small discrepancies between NNDSS influenza numbers and the jurisdictional numbers. Although laboratory-confirmed influenza notifications are transferred daily from jurisdictional databases, delays in receiving the information may also occur when DAS rejects notifications that do not comply with the NNDSS business or data rules (Table 2). Rejected notifications may not be addressed by the jurisdictions for some time, causing discrepancies between the numbers in the NNDSS and jurisdictional databases.

The second is the insufficient subtype information provided for the majority of influenza notifications. Forty-eight percent of influenza A notifications received by the NNDSS between the years 2008 to 2013 had incomplete or missing sub-typing information (Table 5). This issue was raised by NISC members and was considered to be one of the biggest weaknesses with NNDSS. These stakeholders considered sub-typing vital to understanding the current epidemiology of influenza, as it characterises circulating viruses. One NISC member stated:

‘Laboratories should be encouraged by the Department of Health to complete sub-typing of all positive influenza A results.’

Finally, the dissemination of influenza notification data from the NNDSS data in reports is slow. Whilst the Department of Health is working towards improving this issue, at the time of writing this report, 2008 was the latest Annual National Influenza Surveillance Scheme Report and 2011 was the latest NNDSS annual report. To ensure the objectives of influenza surveillance are continued to be met, the Department of Health needs to work towards a more timely analysis and reporting of laboratory-confirmed influenza data.

6.8. Accessing laboratory-confirmed influenza data in the NNDSS

Summary data are available from the Communicable Disease Australia (CDA) website and reports for laboratory-confirmed influenza notifications are available on the Department of Health website. These provide the numbers or rates of influenza notifications by jurisdiction, month, year, age group and sex. Summary data outputs are also available through the reports previously described and noted in Figure 4. Results of the stakeholder consultations indicated that the majority of NISC members accessed NNDSS laboratory-confirmed influenza data through the Australian Influenza Surveillance Report, online summary data and CDNA fortnightly reports (Table 3).

Accessing NNDSS influenza notification data was considered to be relatively easy. Eighty-three percent of NISC members stated data is accessible and readily available.
However, 75% of NISC members stated that data publically available is too broad. These members suggested extending data available on the CDA website to either provide counts and rates as weekly aggregates or de-identified line-listed data.

One member indicated they found it hard to access the data they required, suggesting the Department of Health should:

'Provide de-identified line listed data, weekly aggregates rather than monthly, data on sub-typing and develop a list of trusted data users who can readily access data when required.'

The Department of Health epidemiologists were more divided on the ease of accessing data. The primary system used within the Department of Health to access laboratory-confirmed influenza notifications is a web interface called “Discoverer”. One epidemiologist thought using “Discoverer” was difficult, as there are no training tools available and limited information about its functions and usability. In contrast, the other epidemiologist thought “Discoverer” enabled easy access to influenza notifications.

Table 3: Current use of NNDSS influenza notifications by NISC members and the resource they use to access the data

<table>
<thead>
<tr>
<th>Accesses national influenza data through</th>
<th>NISC jurisdictional member (n=8)</th>
<th>NISC non-jurisdictional member (n=5)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online summary data on the CDA website</td>
<td>5 (63%)</td>
<td>5 (100%)</td>
<td>10</td>
</tr>
<tr>
<td>Australian Influenza Surveillance Report and activity update reports</td>
<td>7 (88%)</td>
<td>5 (100%)</td>
<td>12</td>
</tr>
<tr>
<td>CDNA fortnightly report</td>
<td>5 (63%)</td>
<td>3 (60%)</td>
<td>8</td>
</tr>
<tr>
<td>NNDSS and Influenza Surveillance Scheme Annual Reports (in CDI)</td>
<td>3 (38%)</td>
<td>4 (80%)</td>
<td>7</td>
</tr>
<tr>
<td>Data requests</td>
<td>0</td>
<td>2 (40%)</td>
<td>2</td>
</tr>
</tbody>
</table>

6.9. Resources and cost required to operate the system

Two personnel are assigned full-time to the operation of the NNDSS and the management of all disease notifications: a data manager (Executive Level 1) and an assistant data manager (Australian Public Service (APS) level 6). Both are based within the VPDS section of the OHP and are responsible for the day to day operation of the NNDSS, assisting the jurisdictional data managers with transmission and performing data quality checks.

There are two main costs associated with the NNDSS; costs associated with the management and maintenance of the NNDSS IT servers and costs associated with the technical support requested from the Technology Group (TG).
Technical support and maintenance are provided by the TG located within the Department of Health. On request from the NNDSS data managers, this group performs updates to the NNDSS websites and make changes NNDSS system coding (such as data business rules). There is no annual cost associated with these services. Charges are applied after a request is made by data managers. For the 2013 to 2014 financial year requests to TG cost $35,825.

IBM is contracted by the Department of Health to manage and maintain all of the Department of Health’s IT platforms and servers. The services provided by IBM include: the physical housing, security and maintenance of the Department of Health IT server and maintenance and support the Department of Health’s IT platforms which include the NNDSS. The cost associated with these services for the NNDSS were not provided for this evaluation.

7. Surveillance objectives of the NNDSS for laboratory-confirmed influenza

There were some difference in opinion between NISC members and the Department of Health epidemiologists on which influenza surveillance objectives were met by the NNDSS. Most stakeholders agreed the NNDSS enables the long-term epidemiological analysis of influenza, identifies trends and patterns of influenza infection and facilitates the characterisation of an influenza epidemic (Table 4). However, there was strong difference in opinions about the remaining objectives. Eight (67%) NISC members thought the NNDSS was not a useful system to provide influenza sub-typing information or identify the onset of an influenza epidemic. In comparison, both the Department of Health epidemiologists thought the NNDSS met all the objectives, with information enhanced by data collected in supporting sentinel surveillance systems.
Table 4: Surveillance objectives of laboratory confirmed influenza collected through the NNDSS, by stakeholder groups, Australia 2014

<table>
<thead>
<tr>
<th>Objectives</th>
<th>NISC members (n=12)</th>
<th>Department of Health epidemiologists (n=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilitates the ability to identify patterns and trends of influenza</td>
<td>9 (75%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Enables long-term epidemiological analyses</td>
<td>9 (75%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Provides data for early alerts reading the onset of influenza epidemics</td>
<td>4 (33%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Facilitates the characterisation of an epidemic</td>
<td>8 (67%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Provides information on the subtype of the circulating influenza viruses</td>
<td>4 (33%)</td>
<td>2 (100%)</td>
</tr>
</tbody>
</table>

8. Use of NNDSS laboratory-confirmed influenza notification data

Influenza notifications are currently used for a number of different activities, which varied between stakeholders (Figure 5). Sixty-seven percent (8/12) of the NISC members indicated that they used the data to monitor national influenza trends and provide comparisons with other systems or across jurisdictions. Forty-two percent of members (5/12) indicated they used the data for influenza reporting in their jurisdictions, 25% (3/12) for policy development, and 17% (2/12) for research and to inform influenza program management. One member indicated they used the data to evaluate influenza public health interventions.

Both of the Department of Health epidemiologists stated they used NNDSS influenza data to monitor national trends, provide comparisons, develop influenza policy, inform project management and analyse the impact of influenza in each jurisdiction. One of these epidemiologists stated the data can also be used to conduct research and evaluate influenza public health interventions. Although both respondents stated the NNDSS is a useful indicator of influenza activity, both highlighted factors such as: testing practices, notification practices, over-representation of certain at-risk populations (children and the elderly) and the health-care seeking behaviours of individuals, need to be considered when interpreting laboratory-confirmed influenza notifications from the NNDSS.
9. System performance

9.1. Acceptability

I found a major strength of the NNDSS is its high level of acceptability. As a notifiable disease in each jurisdiction, it is a legal requirement that all cases of laboratory-confirmed influenza are reported to jurisdictional health departments. All NISC members, the Department of Health epidemiologists and data managers (NNDSS and jurisdictional) thought it is acceptable to provide laboratory-confirmed influenza notifications to the NNDSS. The NNDSS is considered by all stakeholders to be a primary surveillance system for influenza in Australia, complimented by other smaller sentinel systems. NNDSS laboratory-confirmed influenza data is published regularly on the internet, in government reports and commonly cited in research articles and other publications.

9.2. Data quality

Data quality was assessed by examining how many laboratory-confirmed influenza notifications were provided to the NNDSS with a valid field entry according to the data specifications of the NNDSS. Notifications reported with an "unknown status" were considered to be complete in this analysis as they meet the criteria outlined in the NNDSS data specifications.
Overall, I found the NNDSS provides good quality data for the NSC priority influenza data fields (Table 5). From 2008 and 2013 the completeness of these fields was high, with 60% (6/10) of fields completed in over 90% of laboratory-confirmed influenza notifications. Of the incomplete fields, 47.7% of notifications were reported without subtype information for influenza A, 40.3% reported without true onset date, 25% without death and 19.3% without Indigenous status. Whilst the NSC has prioritised fields for Indigenous status and death, improving completeness of these variables is difficult. At present, laboratory request forms do not provide the opportunity to collect information for Indigenous status or recorded in the case died. Information on these variables, if provided to the NNDSS, is provided through a notification by the treating doctor or hospital.

It is difficult to evaluate the accuracy of influenza notifications in the NNDSS. Designed to be a repository of information provided by eight individual notification systems, the accuracy of data in the NNDSS is heavily dependent on the business rules and data quality checks conducted by the jurisdictional health departments. Whilst I enquired about the data checks and assurance being conducted in the jurisdictions, there was not enough detail provided during the consultations to ascertain the accuracy of NNDSS influenza notifications.

9.2.1. Perceptions of data quality

NISC members, the Department of Health epidemiologists and data managers (NNDSS and jurisdictional) thought the majority of laboratory-confirmed influenza notifications in the NNDSS were complete. However, stakeholders suggested the completeness of Indigenous status and sub-typing information could be improved.

Table 5: Number and proportions of completion for core data fields for influenza notifications in NNDSS, 2008 to 2013, Australia

<table>
<thead>
<tr>
<th>NSC priority field</th>
<th>Number of notifications</th>
<th>Number missing data</th>
<th>Proportion missing data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtype for influenza A</td>
<td>161,356</td>
<td>76,952</td>
<td>47.7%</td>
</tr>
<tr>
<td>True onset date*</td>
<td>198,617</td>
<td>80,005</td>
<td>40.3%</td>
</tr>
<tr>
<td>Indigenous status</td>
<td>198,617</td>
<td>38,433</td>
<td>19.3%</td>
</tr>
<tr>
<td>Death</td>
<td>198,617</td>
<td>49,593</td>
<td>25%</td>
</tr>
<tr>
<td>Laboratory diagnosis method</td>
<td>198,617</td>
<td>6,587</td>
<td>3.3%</td>
</tr>
<tr>
<td>Specimen date</td>
<td>198,617</td>
<td>3,289</td>
<td>1.8%</td>
</tr>
<tr>
<td>Date of Birth</td>
<td>198,617</td>
<td>222</td>
<td>0.1%</td>
</tr>
<tr>
<td>Age of onset</td>
<td>198,617</td>
<td>208</td>
<td>0.1%</td>
</tr>
<tr>
<td>Residential postcode</td>
<td>198,617</td>
<td>57</td>
<td>0.03%</td>
</tr>
<tr>
<td>Sex</td>
<td>198,617</td>
<td>12</td>
<td>0.01%</td>
</tr>
</tbody>
</table>

*True onset date refers to the earliest date the case reported exhibiting symptoms to the treating doctor or was observed by the treating doctor. This date is provided by the doctor, laboratory or hospital as part of the notification made to the jurisdictional health department.
9.3. Flexibility
The NNDSS is not considered to be a flexible surveillance system. Seventy-five percent (6/8) of jurisdictional and both NNDSS data managers thought flexibility was the NNDSS weakest attribute as adding, removing and modifying data fields is difficult to undertake. Adding, changing or removing data fields from the NNDSS requires agreement from CDNA, an analysis of the system performance needs, user acceptance testing and new data specifications. The NNDSS data manager indicated that these processes can take months to complete and are dependent on available resources and funding.

Additionally, as data collected by the NNDSS is provided by eight individual surveillance systems, any modifications made to the NNDSS will have a flow on effect to the jurisdictional systems. Data managers in six jurisdictions stated it is very difficult to add, remove or modify data fields to their own notification systems. To make changes to these systems they would need to engage the original system developer, which is costly and can take months or years to complete. The remaining two jurisdictions did not think it would be difficult to add, remove or modify data fields to their systems, but also stated making changes would be time consuming and costly.

9.4. Positive Predictive Value
As the NNDSS only accepts laboratory confirmed cases of influenza, false positives would be notified, suggesting the positive predictive value of the influenza notifications in the NNDSS is relatively high. All NISC members and both Department of Health epidemiologists stated they thought the notifications in the NNDSS for influenza represent only true cases of influenza infection.

While influenza notifications in the NNDSS are only reported if they are confirmed by laboratory testing, the inclusion of single high titre by CFT or HAI to influenza virus in the national case definition has raised concerns about “true” influenza incidence against the number laboratory-confirmed influenza notifications provided to the NNDSS. Notifications based on single high titre can represent high quality evidence of probable recent infection when they are combined with clinically compatible influenza like symptoms and periods of high influenza activity. If all these conditions are not met, single samples with a high titre are considered to be unreliable. The examination of this issue is outside the scope of this evaluation, but should be considered in any future evaluation of influenza surveillance systems.
9.5. Stability
The NNDSS is perceived to be a stable surveillance system. Data held within the NNDSS are able to be integrated easily and regularly to produce fortnightly, quarterly and annual surveillance reports. NNDSS data managers and the Department of Health epidemiologists indicated they use this system daily and thought it was reliable with had minimal down-time in operation. Stakeholders indicated the main weakness associated with the stability of the NNDSS are the lack of staff to enter data at the jurisdictions, staff turnover, loss of corporate knowledge, the reliance on external system developers, and costs in updating or changing the NNDSS.

9.6. Simplicity
The reporting of influenza notifications to the NNDSS is relatively simple, with both jurisdictional and NNDSS data managers stating the upload of notifications were a simple process. Positive laboratory results are provided by public and private laboratories in all jurisdictions, by general practitioners and clinicians in four jurisdictions and by hospitals in two jurisdictions. The majority of results in Queensland, South Australia, Western Australia and New South Wales are electronically transferred. In Tasmania, the Northern Territory, the Australian Capital Territory and Victoria, results are provided by fax or secure printers and manually entered. At the time of writing this evaluation, Victoria was in the process of implementing an electronic system for laboratory notifications.

9.7. Representativeness
Opinions regarding the representativeness of laboratory-confirmed influenza notifications in the NNDSS were divided between stakeholders. Eighty-three percent (10/12) of NISC members and both of the Department of Health epidemiologists thought the laboratory-confirmed influenza notifications in the NNDSS did not represent the true occurrence of influenza throughout the community. As influenza notifications are reliant on laboratory confirmation, stakeholders suggested inherent biases in testing practices, health seeking behaviours and notification practices by jurisdictional health departments, limited the representativeness of laboratory-confirmed influenza notifications in the NNDSS. One of the Department of Health epidemiologists stated:

‘Our ability to improve representativeness is difficult. As data received in the NNDSS is dependent on health seeking behaviours of individuals, notification data is essentially opportunistic.’
I examined the representativeness of influenza notifications in the NNDSS by comparing the age distribution of these notifications with ILI presentations from ASPREN and confirmed influenza hospitalisations from FluCAN.

9.7.1. Comparing ASPREN and the NNDSS

ASPREN is a network of sentinel general practices run through the Royal Australian College of General Practitioners and the University of Adelaide. This system collects de-identified information on ILI and other conditions seen in general practice. Established in 1991, it aims to provide an indicator of the burden of disease in the primary health care setting and to act as an early warning indicator in the event of an influenza pandemic. There are no age restrictions to data collected in this system.

Overall the NNDSS and ASPREN display similar trends in age, suggesting the representativeness of laboratory-confirmed influenza corresponds with ILI presentations in general practice settings. In both systems the proportion of notifications increased from the 0 to 4 years age group, peaking in the 20 to 49 years age group. This trend was consistent from 2010 to 2013. There were small variations in proportions between the two systems. The NNDSS proportions were slightly higher in the younger age groups compared to ASPREN, while in ASPREN proportions were higher in the 50 to 64 years age group compared to the NNDSS. This analysis suggests influenza notifications in the NNDSS are representative of ILI presentations in primary health care, but perhaps reflect a tendency to test younger children.
9.7.2. Comparing FluCAN and the NNDSS

FluCAN is a real time hospital sentinel system that was established in 2009. It is designed to fill the gap in reliable, comprehensive, consistent and rapidly available data on adult influenza hospitalisations, including ICU admissions. Data are collected from April to November each year. Patients are selected to participate if they are diagnosed with influenza using nucleic-acid detection on respiratory samples. From 2010 to 2013 the majority of FluCAN notifications were for adults. To increase the representativeness by age in the surveillance system, FluCAN began collecting data of influenza hospitalizations from paediatric hospitals in 2014.

There were marked differences in the age groups represented in the NNDSS influenza notifications and FluCAN hospitalisations (Figure 7). From 2010 to 2012, the proportions of influenza notifications captured in FluCAN for the 0 to 4 years and 5 to 19 years age groups was lower compared to the NNDSS. However, this difference is most likely due to the low representation people aged 0 to 19 years in FluCAN from 2010 and 2012 (Appendix Table 1).
In 2010, 2011 and 2013 both systems displayed a peak in notifications for the 20-49 years age group, before displaying a decline in proportions for those aged 50 years and over. In comparison, the age distribution in 2012 was more varied, with FluCAN displaying higher proportions of confirmed influenza from those aged 50 years and over compared with the NNDSS. However, these variations can be explained by examining the dominating influenza viruses in each season. The 2010, 2011 and 2013 influenza seasons were dominated by the pandemic influenza A(H1N1)pdm09 virus, which is more likely to affect younger age groups. In comparison, the 2012 season was dominated by influenza A(H3N2), which particularly affects preschool-age children and older adults. Influenza A (H3N2) is known to be more severe especially in the older populations, which may resulted in higher numbers of hospitalisations identified in the FluCAN system. Whilst both surveillance systems only collect data for laboratory-confirmed influenza, as FluCAN only collects data on patients who were hospitalized, the population under surveillance in this system are likely to be older and with more severe disease, and thus FluCAN would be expected to display higher proportions of influenza hospitalizations in the older age groups compared with the NNDSS.
9.8. Sensitivity

The sensitivity of the NNDSS as a surveillance system for influenza is considered to be low, as data only represents a proportion (the ‘notified fraction’) of the total cases occurring in the community. However, I found that over time the sensitivity of laboratory-confirmed influenza notifications in the NNDSS appears to have improved. Since 2008 the number of inter-seasonal\(^1\) influenza notifications received by the NNDSS has increased (Figure 8). The duration of the inter-seasonal period before and after the annual influenza season were similar from 2008 to 2013, expect for the inter-seasonal period following the 2009 H1N1 pandemic, which was markedly shorter. Inter-seasonal notifications rose markedly from November 2010, suggesting influenza awareness and testing has increased, enabling the NNDSS to capture more notifications and potentially increase the NNDSS sensitivity.

Whilst I have suggested that the NNDSS sensitivity may be improving, it is difficult to judge without taking into context the number of tests requested during the period of surveillance. Using only positive influenza notification data ignores the potential influence of testing patterns has on apparent influenza activity.

9.8.1. Outbreak detection

Just over half of NISC members (58%, 7/12) thought the NNDSS would not be able to detect geographically localised influenza outbreaks. Members indicated these health events are more likely to be detected using jurisdictional notification systems as notifications are processed by jurisdictional health departments before they are analysed in the NNDSS. Additionally, as NNDSS notifications are analysed fortnightly, the likelihood the Department of Health would detect an influenza outbreak before the jurisdictions would be low. Forty-two percent (5/12) NICS members thought the NNDSS would only be able to detect a multi-jurisdictional outbreak.

\(^1\)The inter-seasonal period is defined as the period in which influenza activity has returned to baseline. Baseline is the usual or average level of influenza activity that occurs during a typical year and remains consistent for a period of time. The inter-seasonal periods defined in this evaluation reflect those report used by the Australian Government Department of Health which are based on the evaluation of influenza activity in the NNDSS and other supporting surveillance systems for each reporting year. These dates associated with the inter-seasonal periods for the evaluation report are described on the y-axis in Figure 8.
9.9. Timeliness

Notifications of influenza to the NNDSS play a role in describing the current epidemiology of the influenza season. Timeliness is essential to this surveillance system to ensure the start and end of the influenza season are detected quickly. To assess timeliness, I examined the median and inter-quartile ranges of four time intervals. These intervals are described in Table 6.
Table 6: Description of the date fields used for analysis of the attribute timeliness, evaluation of the laboratory-confirmed influenza in the NNDSS, 2009 to 2013

<table>
<thead>
<tr>
<th>Time interval</th>
<th>Description</th>
<th>Date description</th>
<th>Calculation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Onset to Loaded</td>
<td>The median number of days between a person exhibiting symptoms and the notification being received by the NNDSS</td>
<td>First loaded date - date the notification was first received by the NNDSS</td>
<td>First loaded date - true onset date</td>
</tr>
<tr>
<td></td>
<td></td>
<td>True onset date - the earliest data person reported or exhibited symptoms</td>
<td></td>
</tr>
<tr>
<td>Notification received to Loaded</td>
<td>The median number of days between the jurisdictional health department receiving a laboratory-confirmed influenza notification and providing this notification to the NNDSS</td>
<td>First loaded date - date the notification was first received by the NNDSS</td>
<td>First loaded date - notification received date</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Notification received date - date the notification of diseases was received by the communicable disease section of the jurisdictional Health authority</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Notification date - date when health professional signed the notification form or the laboratory issued the results</td>
<td>Notification received date – notification date</td>
</tr>
<tr>
<td>Notification to Notification received</td>
<td>Median number of days between the confirmation of influenza infection and the jurisdictional health departments receiving the notification</td>
<td>Notification received date - date the notification of diseases was received by the communicable disease section of the jurisdictional Health authority</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Notification date - date when health professional signed the notification form or the laboratory issued the results</td>
<td></td>
</tr>
<tr>
<td>Specimen to Notification</td>
<td>Median number of days between a specimen being provided and laboratory confirming influenza infection</td>
<td>Notification date - date when health professional signed the notification form or the laboratory issued the results</td>
<td>Notification date- specimen date</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Specimen date - Date when first laboratory specimen was taken.</td>
<td></td>
</tr>
<tr>
<td>Onset to Specimen</td>
<td>Median number of days between the person exhibiting symptoms and a specimen being taken by a treating doctor or hospital</td>
<td>Specimen date - Date when first laboratory specimen was taken.</td>
<td>Specimen date – true onset date</td>
</tr>
<tr>
<td></td>
<td></td>
<td>True onset date - the earliest data person reported or exhibited symptoms</td>
<td></td>
</tr>
</tbody>
</table>

Over the period of 2009 to 2013 the median number of days for an influenza notification to be uploaded into the NNDSS after the onset of influenza symptoms were reported or exhibited was 4 days (IQR 4 days) (Table 7). The median number of days for an influenza infection to be confirmed after a specimen was taken was 2 days (IQR 2 days); for a notification to be reported to the jurisdictional health department after infection was confirmed by the laboratory was 0 days (IQR 1 day); and for a notification
to be uploaded into the NNDSS after it was received by the jurisdictional health department was 1 day (IQR 2 days).

**Table 7**: Median, quartile 1, quartile 3 and inter-quartile range (IQR) in days of laboratory-confirmed influenza notifications in the NNDSS by time interval, Australia 2009 to 2013

<table>
<thead>
<tr>
<th>Time interval</th>
<th>Median</th>
<th>25th percentile</th>
<th>75th percentile</th>
<th>IQR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Onset to Loaded</td>
<td>4 days</td>
<td>2 days</td>
<td>8 days</td>
<td>4 days</td>
</tr>
<tr>
<td>Notification received to Loaded</td>
<td>1 day</td>
<td>0 days</td>
<td>3 days</td>
<td>2 days</td>
</tr>
<tr>
<td>Notification to Notification received</td>
<td>0 days</td>
<td>0 days</td>
<td>1 day</td>
<td>1 day</td>
</tr>
<tr>
<td>Specimen to Notification</td>
<td>2 days</td>
<td>1 day</td>
<td>4 days</td>
<td>2 days</td>
</tr>
<tr>
<td>Onset to Specimen</td>
<td>0 days</td>
<td>0 days</td>
<td>2 days</td>
<td>2 days</td>
</tr>
</tbody>
</table>

From 2008 to 2013 median number of days for each time interval remained relatively consistent (Table 8). The largest medians and IQRs for all time intervals occurred in 2009 and 2010, which were approximately 2 to 4 days longer compared with 2011, 2012 and 2013. These slight delays were a result of the 2009 influenza A (H1N1) pandemic.

During the pandemic period a secondary surveillance system, NetEpi, was used to collect enhanced data. Preferring to report to one surveillance system instead of two, a number of jurisdictions only uploaded laboratory-confirmed influenza notifications into NetEpi during the pandemic period, and New South Wales continued to use NetEpi as its influenza reporting system in 2010. The use of this secondary system resulted in the NNDSS not receiving a large number of laboratory-confirmed influenza notifications from 2009 and 2010 until late 2010, resulting in the large IQR in 2010 (Table 8).

**9.9.1. Perceptions of timeliness**

Two thirds (66%) of the NISC members and both the Department of Health epidemiologists considered timeliness to be a strength of this system. One member stated that:

> ‘*Influenza data is provided to the NNDSS on a timely basis. For this reason I can use the data to take a quick snapshot of what is happening around the country and highlight any areas on concern.*’

5-33
Table 8: Median, quartile 1, quartile 3 and inter-quartile range (IQR) in days of laboratory-confirmed influenza notifications in the NNDSS by time interval and year, Australia 2009 to 2013

<table>
<thead>
<tr>
<th>Year</th>
<th>Time interval</th>
<th>Median</th>
<th>Q1</th>
<th>Q3</th>
<th>IQR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Onset</td>
<td>5</td>
<td>3</td>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>2009</td>
<td>Loaded</td>
<td>3</td>
<td>1</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Notification received</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Notification</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Specimen</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Onset</td>
<td>5</td>
<td>3</td>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>2010</td>
<td>Loaded</td>
<td>3</td>
<td>1</td>
<td>235</td>
<td>234</td>
</tr>
<tr>
<td></td>
<td>Notification received</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Notification</td>
<td>3</td>
<td>1</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Specimen</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Onset</td>
<td>3</td>
<td>2</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>2011</td>
<td>Loaded</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Notification received</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Notification</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Specimen</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Onset</td>
<td>3</td>
<td>1</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>2012</td>
<td>Loaded</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Notification received</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Notification</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Specimen</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Onset</td>
<td>4</td>
<td>2</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>2013</td>
<td>Loaded</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Notification received</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Notification</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Specimen</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>
10. Discussion
The national surveillance of influenza in Australia is complex. To adequately examine the impact infection with influenza has on the Australian community, data from a variety of surveillance systems, including community, primary and tertiary healthcare and laboratories, are required. In this chapter, I have evaluated one aspect of influenza surveillance, laboratory-confirmed infections captured by the NNDSS. Although there are six national objectives for the surveillance of influenza in Australia, it is unclear which of these the NNDSS is required to meet. For this reason I have discussed below the extent to which the NNDSS meets all six objectives.

Objective 1: Provide data for early alerts regarding the onset of influenza epidemics
As a passive surveillance system that relies on data collected through other notification systems, being able to detect early onset of illness is limited by the ability of laboratories, treating doctors, hospitals and jurisdictional health departments to process laboratory-confirmed influenza notifications efficiently. The NNDSS is limited in its ability to monitor rapid changes in disease incidence by the efficiency in which it receives notifications. Although notification data are uploaded daily, this evaluation found the median number of days for an influenza notification to be provided to the NNDSS after symptom onset was 4 days. Whilst this timeframe is appropriate for the routine surveillance of influenza, it is not appropriate to provided early alerts regarding the onset of influenza epidemics.

However, it is not imperative for the NNDSS to meet this objective. Syndromic surveillance systems such as Flutracking and ASPREN, are more suited to this objective. As these systems monitor the ILI activity in the community, they have detected the onset of influenza seasons before increases in the laboratory-confirmed notifications have been identified. (37, 38)

Objective 2: Characterise the nature of the epidemic
As a stable, reliable and simple system that provides high quality data, the NNDSS can be used to characterise the nature of seasonal influenza epidemics in Australia. Universally accepted by stakeholders, notifications are provided routinely, which enables the fortnightly reporting of the trends and patterns in influenza activity across Australia.

However, as noted in a previous generic evaluation of the NNDSS, (39) the system is relatively inflexible, limiting its ability to characterise the nature of epidemics due to novel influenza viruses and pandemics. Due to its design and reliance on data
collected in other communicable disease surveillance systems, it is unable to rapidly adapt to changing information requirements and cannot provide more detailed epidemiological information specific novel influenza viruses or pandemics.

Additionally, using only positive influenza notification data ignores the potential influence of testing on apparent influenza activity. It has been argued that notification data alone cannot provide an accurate picture regarding the incidence of influenza, as the method ignores the influence of testing on apparent influenza activity. A study conducted in Queensland examined the utility of influenza-negative laboratory testing data and found using these types of data account for the regional or temporal differences for the number of tests performed for influenza, providing a more complete picture of influenza during seasonal and pandemic periods and improves our epidemiological knowledge of the disease. (40)

As a result of this evaluation, a pilot project is being undertaken to evaluate if influenza laboratory testing data can be routinely obtained and utilised as seasonal and inter-seasonal denominators for national reporting activities (Appendix 14.3).

**Objective 3: Evaluate the impact of clinical, laboratory and public health measures**
As laboratory-confirmed influenza has been collected in the NNDSS since 2001, it has the capacity to provide longer term epidemiological trends. This enables retrospective analyses to be undertaken to evaluate the impact clinical, laboratory and public health measures had on influenza epidemiology.

**Objective 4: Provide information on the subtype of the circulating influenza viruses**
At present data held within the NNDSS does not provide adequate sub-typing information for influenza A viruses. This evaluation found 48% of influenza A viruses notifications within the NNDSS are currently reported without a subtype. To account for this missing information, subtyping data are collected from four sentinel laboratories located in Western Australia, New South Wales, Victoria and Tasmania. However, as influenza samples sent to these laboratories are from sites across their respective states (on occasion they may process samples from a neighbouring state) results are not nationally representative. As a comprehensive national system for influenza surveillance, collecting a representative sample of sub-typing data from each jurisdiction through the NNDSS would provide a national sample of sub-typing data. This would provide further information on circulating influenza viruses and the relationship between the dominate virus and the annual season severity. (41)
However, as influenza A virus sub-typing is conducted at the discretion of the laboratory, to improve the quality of these data in the NNDSS, laboratories would need to commit to carrying out sub-typing for a proportion of positive influenza test results. This would be difficult to achieve, as testing practices of laboratories are determined based on their own resources, capacity and ability to complete this aspect of the testing. The Department of Health and NISC should consider engaging with the Public Health Laboratory Network (PHLN) of Australia to facilitate a representative sample of sub-typing being conducted in laboratories across Australia.

**Objective 5: Assess the burden of diseases (health service demand, health impact, economic and social impacts) related to influenza;**

Assessing the burden of disease associated with influenza is multifaceted and requires the aggregation of data collected through multiple surveillance systems. The NNDSS meets this objective by describing the epidemiology of influenza, detailing the broad geographical spread and the age and sex distribution, as well as providing comparisons over time, between influenza seasons and by jurisdiction. Used in conjunction with other surveillance system data, laboratory-confirmed influenza notifications in the NNDSS assist with health system planning and inform the development of longer term policy.

**Objective 6: Ensure accurate information is available to the appropriate people in a timely manner**

The simple electronic transmission of influenza notifications enables data sharing across jurisdictions and provides the ability to conduct national epidemiological analyses. Fortnightly reporting to CDNA ensures all jurisdictions are aware of the changes occurring in influenza nationally, allowing them to adjust their own state or territory public health responses and prepare for possible increases in disease activity.

During the influenza season, NISC meets fortnightly to discuss the trends in influenza data, identify the populations at risk of infection, and define the severity of the season. This information is used to develop public health messaging, inform clinicians and hospitals about the current season and respond to media enquiries. Additionally, NNDSS data are retrospectively analysed to provide guidance in developing national health response plans and operations in the event of an influenza pandemic.

As NNDSS can add new business rules without impacting the functionality of jurisdictional notification systems, it has the potential to provide an early alert for unusual changes in the number of influenza notifications. To achieve this, the Department of Health should consider developing an algorithm that notifies NNDSS
users when influenza notifications have reached or surpassed predefined thresholds within a given time period.

There are several limitations with this evaluation. Firstly, whilst 75% of NISC members participated, not all jurisdictions and surveillance system managers or co-ordinators were represented. Additionally, if time had permitted consultations could have included other users and providers of the NNDSS such as laboratories, treating doctors, influenza specialist groups, other researchers and institutions. The analysis of representativeness could have included comparisons with other community influenza surveillance system such as Flutracking to strengthen the findings.

Finally, the analysis of timeliness was unable to account for variations in the reporting of ‘true onset’ date. As this data field is completed by the treating doctor, the date of the real onset of the disease could be interpreted as the date the person presented to the doctor or hospital, rather than the data they first displayed symptoms, which could have occurred days beforehand. This limitation would have influenced the result in the timeliness analysis, potentially underestimating the actual time it takes for a case of laboratory-confirmed influenza to be reported to the NNDSS.

11. Conclusion

The NNDSS serves an important function in the surveillance of influenza in Australia. In this evaluation, I found that the NNDSS is an acceptable, simple and useable system. It provides high quality data for the national surveillance of laboratory-confirmed influenza and is perceived as a highly valuable surveillance system by stakeholders. Laboratory-confirmed influenza notifications in the NNDSS contribute to four of the national influenza surveillance objectives. Areas that could currently be strengthened are detailed in the recommendations below.
12. **Recommendations**

Based on this evaluation, I recommend the Australian Department of Health consider the following:

**Influenza specific**

1. Review and improve the dissemination of laboratory-confirmed influenza reporting. Currently the annual influenza scheme report is five years out of date and the NNDSS annual report is two years. The annual reports should be made available no more than 10 months after the reporting year (for example the analysis of 2013 should be publically available by October 2015)

2. Evaluate if laboratory testing data for influenza can be utilised for denominators for national reporting of influenza.

3. Investigate applying an algorithm to notify when predetermined threshold of laboratory-confirmed influenza notifications are reached or surpassed within a defined time period.

4. Investigate the representativeness of laboratory-confirmed influenza notifications sub-typed in Australia. If required, develop a strategy to improve the representativeness by engaging with PHLN and other key laboratory stakeholders.

**NNDSS System coordination and resources**

1. Review summary data available on the Communicable Disease Australia website to consider providing de-identified line listed data or aggregated data by week and include subtyping data for influenza A viruses.

2. Review data specifications in consultation with jurisdictional data managers.

3. Develop and circulate a document detailing the historical changes to the NNDSS.

4. Clarify the purpose for collecting all requested data elements by explaining how they will be used, and periodically assess the needs of collecting the data against the burden of collecting it.

5. Develop a user guide for analysing and extracting NNDSS information from the Discoverer interface for staff within the Department of Health.
13. References


14. Appendices

Appendix 14.1- List of stakeholders

National Influenza Surveillance Committee (NISC)
Ms. Frances Birrell, Epidemiologist, Communicable Diseases Unit, Chief Health Officer Branch, Health Service and Clinical Innovation Division, Department of Health, Queensland Government

Ms. Monique Chilver, Program Manager, The Australian Sentinel Practices Research Network (ASPREN), Discipline of General Practice, School of Population Health & Clinical Practice, The University of Adelaide

Assoc Prof. Allen Cheng, Infectious Diseases Epidemiology, Department of Epidemiology and Preventive Medicine, Monash University

Mr. David Coleman, Surveillance Coordinator, Communicable Diseases Prevention Unit, Population Health Services, Department of Health and Human Services, Tasmania

Ms. Robin Gilmour, Respiratory Epidemiologist, Communicable Diseases Branch, Health Protection, New South Wales

Mr. James Fielding, Epidemiologist & Deputy Head, Epidemiology Unit, Victorian Infectious Diseases Reference Laboratory, the Doherty Institute

Ms. Lucinda Franklin, Epidemiologist, Communicable Disease Epidemiology and Surveillance, Health Protection Branch, Victoria

Dr. Peter Markey, Head of Surveillance for the Centre for Disease Control, Department of Health, Northern Territory

Dr. David Muscatello, Principal Epidemiologist and Manager, Rapid Surveillance Systems, Public Health Intelligence Branch, New South Wales

Dr. Jane Raupach, Medical Epidemiologist, Communicable Disease Control Branch, Department of Health, South Australia

Dr. Sheena Sullivan, Epidemiologist, World Health Organization Collaborating Centre for Reference and Research on Influenza, Australia

Ms. April Witterveen, Epidemiologist, Communicable Disease Control, Health Protection Service, Australian Capital Territory
**Jurisdictional data managers and surveillance information officers**

Mr. David Coleman, Surveillance Coordinator Communicable Diseases Prevention Unit, Population Health Services, Department of Health and Human Services, Tasmania

Mr. Kym Columbine, Health Informatics Officer, Communicable Diseases Unit, Chief Health Officer Branch, Health Service & Clinical Innovation Division, Department of Health, Queensland Government

Ms. Stephanie Flak, Principal Public Health Officer, Disease Surveillance and Investigation Section, Communicable Disease Control Branch, South Australia Health, Government of South Australia

Mr. Trevor Lauer, Data Manager, Communicable Disease Epidemiology and Surveillance, Health Protection Branch, Department of Health Victoria

Dr. Peter Marky, Head of Surveillance for the Centre for Disease Control, Department of Health, Northern Territory

Mr. Paul Saunders, Research Officer, Communicable Disease Control, Department of Health, Western Australia

Ms. Paula Spokes, Acting Manager of Surveillance, Communicable Diseases Branch, Health Protection, New South Wales

**Department of Health data managers**

Mr. Mark Trungrove, NNDSS Data Manager, Vaccine Preventable Diseases Surveillance, Office of Health Protection, Australian Department of Health

Ms. Rachael Corvisy, NNDSS Assistant Data Manager, Vaccine Preventable Diseases Surveillance, Office of Health Protection, Australian Department of Health

**Department of Health influenza epidemiologists**

Ms. Kate Pennington, influenza epidemiologist and Assistant Director, Vaccine Preventable Diseases Surveillance, Office of Health Protection, Australian Department of Health

Dr. Rachel De Kluyver, virologist and influenza epidemiologist, Vaccine Preventable Diseases Surveillance, Office of Health Protection, Australian Department of Health
### Appendix 14.2- Additional table for representativeness

**Appendix Table 1:** Number of confirmed influenza hospitalisations collected by FluCAN, ILI presentation collected by ASPREN and laboratory-confirmed influenza notifications collected in the NNDSS, by age group and year, Australia, 2010-2013

<table>
<thead>
<tr>
<th>Age group</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ASPREN (n)</td>
<td>FluCAN (n)</td>
<td>NNDSS (n)</td>
<td>ASPREN (n)</td>
</tr>
<tr>
<td>1 - 4 years</td>
<td>1,915</td>
<td>38</td>
<td>1,915</td>
<td>4,569</td>
</tr>
<tr>
<td>5 - 19 years</td>
<td>3,835</td>
<td>18</td>
<td>3,835</td>
<td>7,807</td>
</tr>
<tr>
<td>20 - 49 years</td>
<td>6,458</td>
<td>143</td>
<td>6,458</td>
<td>12,109</td>
</tr>
<tr>
<td>50 - 64 years</td>
<td>1,977</td>
<td>67</td>
<td>1,977</td>
<td>3,681</td>
</tr>
<tr>
<td>65 - 74 years</td>
<td>567</td>
<td>18</td>
<td>567</td>
<td>1,429</td>
</tr>
<tr>
<td>75 years and over</td>
<td>445</td>
<td>12</td>
<td>445</td>
<td>1,370</td>
</tr>
</tbody>
</table>
Appendix 14.3 - Survey Instruments

Appendix 14.3a - National Influenza Surveillance Committee (telephone)

Purpose of the evaluation

The purpose of this evaluation is to assess the degree in which the National Notifiable Diseases Surveillance System (NNDSS) meets the objectives of monitoring the impact of influenza on the Australian Community since becoming nationally notifiable in 2001. Whilst the NNDSS is a system that captures notifications for more than 60 diseases, the survey is only asking for responses in regards to influenza notifications.

The survey has been designed to evaluate the NNDSS as a public health surveillance system. Questions in the survey are intended to capture information on the NNDSS’ ability to provide data for a range of influenza surveillance activities, its collection of notifications, the database structure and computer networks and its user interface.

Name: 

Organisation: 

Position in organisation: 

email: 

Contact phone number

Usefulness and acceptability

Definitions:

Usefulness is defined as a public health surveillance system contributing to the prevention and control of adverse health-related events, the evaluation of performance measures and determines if an adverse health event previously thought to be unimportant is actually important.

Acceptability is defined as the willingness of persons and organisations to participate in the surveillance system.
1. Do you think NNDSS meets the following objectives for influenza surveillance in Australia?

<table>
<thead>
<tr>
<th>Objective</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilitates the ability to identify patterns and trends of influenza</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facilitates early detection of illnesses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enables long-term epidemiological analyses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides data for early alerts reading the onset of influenza epidemics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facilitates the characterisation of an epidemic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides information on the subtype of the circulating influenza viruses</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. For the objectives you marked **YES**, how do you think the NNDSS meets these objectives?

3. For the objectives you ticked **NO**, why do you think the NNDSS does not meet these objectives?

4. Do you use laboratory-confirmed influenza data from the NNDSS?

   - Yes (go to question 5)
   - No (go to question 8)

5. What do you use these data for?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitoring national trends</td>
<td></td>
</tr>
<tr>
<td>Influenza surveillance reporting in your jurisdiction</td>
<td></td>
</tr>
<tr>
<td>Providing comparisons</td>
<td></td>
</tr>
</tbody>
</table>
6. How often do you use these data?

- [ ] Daily
- [ ] Weekly
- [ ] Fortnightly
- [ ] Monthly
- [ ] Quarterly
- [ ] Yearly

7. How do you access these data? (go to question 9)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Australian Influenza Surveillance Report and activity update website</td>
<td></td>
</tr>
<tr>
<td>The Communicable Diseases Network Australia fortnightly surveillance reports</td>
<td></td>
</tr>
<tr>
<td>The National Influenza Surveillance Scheme Annual reports in the <em>Communicable Disease Intelligence</em> Journal</td>
<td></td>
</tr>
<tr>
<td>The NNDSS Communicable disease surveillance systems annual reports in the <em>Communicable Disease Intelligence</em> Journal</td>
<td></td>
</tr>
<tr>
<td>Data request to CDNA</td>
<td></td>
</tr>
</tbody>
</table>

8. Why don’t you use these data?

*(Please tick all that apply)*

- [ ] Difficult to access
The data available are insufficient
National influenza data are not relevant to my work
Other (please specify)

9. In relation to the surveillance of influenza, what are the **strengths** of the NNDSS?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Easy to use</td>
<td></td>
</tr>
<tr>
<td>Data are valid and complete</td>
<td></td>
</tr>
<tr>
<td>Is representative of influenza in Australia</td>
<td></td>
</tr>
<tr>
<td>Adjusts Ill to changing operation and/or information needs for influenza surveillance</td>
<td></td>
</tr>
<tr>
<td>Is a timely reporting system for influenza surveillance</td>
<td></td>
</tr>
<tr>
<td>Data on influenza is easy to access</td>
<td></td>
</tr>
</tbody>
</table>

10. In your opinion, are there any characteristics of the NNDSS that you think could be improved for the national surveillance of influenza?

11. Overall, how would you rate the effectiveness of the NNDSS to provided data for national influenza surveillance?

<table>
<thead>
<tr>
<th>Ineffective tool in providing data for national influenza surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes an effective tool in providing data for national influenza surveillance</td>
</tr>
<tr>
<td>Neither ineffective or effective tool in providing data for national influenza surveillance</td>
</tr>
<tr>
<td>Mostly an effective tool in providing data for national influenza surveillance</td>
</tr>
<tr>
<td>An effective tool in providing data for national influenza surveillance</td>
</tr>
</tbody>
</table>
**Flexibility**

**Definition:** A flexible public health surveillance system can adapt to the changing information needs or operating conditions with little time, personnel or allocated funds. The system uses a standard format for electronic data exchange that can be easily integrated with other systems.

12. Do you think the NNDSS is a flexible system?

- Yes
- No, please specify why

**Representativeness**

**Definition:** Accurately describes the occurrence of a health related event over time and its distribution in the populations by place and person.

13. In your opinion, do you think laboratory-confirmed influenza data in the NNDSS is representative of influenza cases in Australia?

- Yes
- No (please specify why)

14. In your jurisdiction, who provides laboratory-confirmed notifications of influenza?

- General Practitioners and clinicians
- Hospitals
- Public and private laboratories
**Sensitivity**

**Definition:** Sensitivity can be defined as 2 components. The first refers to case reporting and the proportion of case of a disease (or health related event) detected by the public health surveillance system. The second refers to the ability for the public health surveillance system to detect outbreaks, including the ability to monitor the changes in the number of cases over time.

15. Do you think the NNDSS has the ability to detect influenza outbreaks?

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<tr>
<td>Yes</td>
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<tr>
<td>No (please specify why)</td>
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</tbody>
</table>

**Stability**

**Definition:** Stability is the reliability (ability to collect, manage and provide data without error) and availability (ability to be operational when it is needed) of a public health system.

16. In your opinion, does the NNDSS collect, manage and provide accurate data for laboratory-confirmed influenza surveillance?

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<tbody>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No (please specify why)</td>
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</tbody>
</table>

**Simplicity**

**Definition:** The simplicity of the public health surveillance system structure and the ease of its operation.

17. In your jurisdiction, what functions are performed for laboratory-confirmed influenza notifications?

<p>| | |</p>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Add new influenza notifications</td>
<td></td>
</tr>
<tr>
<td>Update information on existing influenza notifications</td>
<td></td>
</tr>
<tr>
<td>Delete duplicate or incorrect influenza notifications</td>
<td></td>
</tr>
<tr>
<td>Transmitting data to the NNDSS influenza notification System</td>
<td></td>
</tr>
<tr>
<td>Other, please</td>
<td></td>
</tr>
</tbody>
</table>
specify________________________________________________

None of the above (got to question 23)

18. On average, how much time (in hours) during the week do you spend on these influenza related tasks?
   ____________ hours

19. Does your jurisdiction follow up cases of influenza?
   [ ] Yes
   [ ] No (go to question 24 )

20. On average, how much time (in hours) does it take you to follow up a case?
   ____________ hours

Data quality

**Definition:** The completeness and validity of the data recorded in the public health surveillance system.

21. In your opinion, the completeness of laboratory-confirmed influenza data in the NNDSS influenza notification system is:

   [ ] Poor
   [ ] Fair
   [ ] Good
   [ ] Very good
   [ ] Excellent

22. Thinking about the rating you chose for completeness, what led you to choose this rating?

   ____________________________________________________________
23. In your opinion, accuracy of laboratory-confirmed influenza data in the NNDSS influenza notification system is:

- Poor
- Fair
- Good
- Very good
- Excellent

24. Thinking about the rating you chose for accuracy, what led you to choose this rating?
Appendix 14.3b - Health Influenza Epidemiologist (electronic)

**Purpose of the evaluation**

The purpose of this evaluation is to assess the degree in which the National Notifiable Diseases Surveillance System (NNDSS) meets the objectives of monitoring the impact of influenza on the Australian Community since becoming nationally notifiable in 2001. Whilst the NNDSS is a system that captures notifications for more than 60 diseases, the survey is only asking for responses in regards to influenza notifications.

The survey has been designed to evaluate the NNDSS as a public health surveillance system. Questions in the survey are intended to capture information on the NNDSS’ ability to provide data for a range of influenza surveillance activities, its collection of notifications, the database structure and computer networks and its user interface.

**Objectives of the survey**

The objectives of the survey are to:

- Determine how useful of national influenza data collected by the NNDSS is for Commonwealth epidemiologists;
- Evaluate if the NNDSS is accepted as a national surveillance system for influenza by the Commonwealth epidemiologists;
- Identify the strengths and weakness of the NNDSS influenza notification system from the perspective of Commonwealth epidemiologists; and
- Evaluate the systems data quality, flexibility, simplicity, sensitivity, representativeness and its ability to collect, manage and provide data from the perspective of Commonwealth epidemiologists.

The survey is intended for epidemiologists responsible for influenza surveillance within Commonwealth.

**Consent for participation**

Your participation is voluntary. You may choose not to participate. If you decide to participate in this survey, you may withdraw at any time. If you decide not to participate in this study or if you withdraw from participating at any time, you will not be penalized.

The procedure involves filling in the following online survey that will take approximately 20 minutes. Any information that is obtained in connection with this study and that can identify you will remain confidential, except as required by law. If you give us your permission to use your responses in our research by completing and submitting the survey, I plan to discuss the results with the Australian Department of Health and the Australian National University. In any publication, information will be provided in such a way that you cannot be identified.
ELECTRONIC CONSENT: By clicking on the "agree" button below indicates that:
• you have read the above information
• you voluntarily agree to participate
• you are at least 18 years of age

If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button.

☐ AGREE

☐ DISAGREE

Please fill in your contact information below
Name: ____________________________
Organisation: ____________________________
Position in organisation: ____________________________
e-mail: ____________________________
Contact phone number: ____________________________

Usefulness and acceptability
Definitions:

Usefulness is defined as a public health surveillance system ability to contribute to the prevention and control of adverse health-related events, provide data to evaluate performance measures and determine if an adverse health event previously thought to be unimportant is actually important.

Acceptability is defined as the willingness of persons and organisations to participate in the public health surveillance system.
1. Do you think NNDSS meets the following objectives for influenza surveillance in Australia?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Facilitates the ability to identify patterns and trends of influenza</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facilitates early detection of illnesses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enables long-term epidemiological analyses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provides data for early alerts reading the onset of influenza epidemics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facilitates the characterisation of an epidemic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provides information on the subtype of the circulating influenza viruses</td>
</tr>
</tbody>
</table>

2. For the objectives you marked **YES**, how do you think the NNDSS meet these objectives?


3. For the objectives you ticked **NO**, why do you think the NNDSS does not meet these objectives?


4. What do you use laboratory-confirmed influenza data from the NNDSS for?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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</tbody>
</table>
5. How often do you use this data?

- Daily
- Weekly
- Fortnightly
- Monthly
- Quarterly
- Yearly

6. In relation to the surveillance of influenza, what are the strengths of the NNDSS?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>Easy to use</td>
<td></td>
</tr>
<tr>
<td>Data is valid and complete</td>
<td></td>
</tr>
<tr>
<td>Accurately describes influenza by cases demographics, time and place</td>
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</tr>
<tr>
<td>Collects, manages and provides data influenza surveillance III</td>
<td></td>
</tr>
<tr>
<td>Is representative of influenza in Australia</td>
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<tr>
<td>Adjusts III to changing operation and/or information needs for influenza surveillance</td>
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</tr>
<tr>
<td>Is a timely reporting system for influenza surveillance</td>
<td></td>
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<tr>
<td>Data on influenza is easy to access</td>
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</tbody>
</table>

7. In your opinion, are there any characteristics of the NNDSS that you think could be improved to aid the surveillance of influenza nationally?
8. Overall, how would you rate the effectiveness of the NNDSS to provide data for influenza surveillance?

- Ineffective tool in providing data for national influenza surveillance
- Sometimes an effective tool in providing data for national influenza surveillance
- Neither ineffective or effective tool in providing data for national influenza surveillance
- Mostly an effective tool in providing data for national influenza surveillance
- An effective tool in providing data for national influenza surveillance

**Simplicity**

**Definition:** The simplicity of the public health surveillance system structure and the ease of its operation.

9. Do you think accessing laboratory-confirmed influenza notification data from the NNDSS is:

- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

10. Why do you think this?

11. With regards to influenza, what do you use the BSS Data warehouse (Discoverer) for?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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<tr>
<td></td>
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</tr>
<tr>
<td>Extracting data for analysis</td>
<td></td>
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<tr>
<td>Calculating rates and proportions</td>
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<tr>
<td>Producing graphs and tables</td>
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</table>
12. In your opinion, do you think Discoverer is an easy system to use?

Yes

No (please specify why)

---

**Flexibility**

**Definition:** A flexible public health surveillance system can adapt to the changing information needs or operating conditions with little time, personal or allocated funds. The system uses a standard format for electronic data exchange that can be easily integrated with other systems.

13. Do you think the NNDSS is a flexible system?

Yes

No, please specify why

---

14. In your opinion, how easy do you think it is to for the following tasks to be completed in the NNDSS:

<table>
<thead>
<tr>
<th></th>
<th>Very Difficult</th>
<th>Difficult</th>
<th>Neutral</th>
<th>Easy</th>
<th>Very Easy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Add a field</td>
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<tr>
<td>Remove a field</td>
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<tr>
<td>Change a field</td>
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</tr>
</tbody>
</table>

---

**Representativeness**

**Definition:** Accurately describes the occurrence of a health related event over time and it distribution in the populations by place and person.

15. Do you think the data captured in the NNDSS for influenza is representative of all influenza case in Australia?

Yes

No (please specify why)
16. In your opinion, what do you think could be done to improve the representativeness of influenza notifications in the NNDSS?

\[\text{Free text box}\]

**Sensitivity**

**Definition:** Sensitivity can be defined on 2 levels. The first refers to case reporting and the proportion of case of a disease (or health related event) detected by the public health surveillance system. The second refers to the ability for the public health surveillance system to detect outbreaks, including the ability to monitor the changes in the number of cases over time.

17. In your opinion, what proportion of all influenza cases in Australia are captured in the NNDSS?

\[\text{Free text box}\]

18. Do you think the NNDSS has the ability to detect influenza outbreaks?

- Yes
- No (please specify why)

**Stability**

**Definition:** Stability is the reliability (ability to collect, manage and provide data without error) and availability (ability to be operational when it is needed) of a public health system.

19. In your opinion, does the NNDSS collect, manage and provide accurate data for national influenza surveillance?

- Yes
- No (please specify why)
**Data quality**

**Definition:** Data quality is the completeness and validity of the data recorded in the public health surveillance system.

20. In your opinion, the completeness of laboratory-confirmed influenza data in the NNDSS is:

- Poor
- Fair
- Good
- Very good
- Excellent

21. Thinking about the rating you chose for completeness, what led you to choose this rating?

22. In your opinion, the accuracy of laboratory-confirmed influenza data in the NNDSS is:

- Poor
- Fair
- Good
- Very good
- Excellent

23. Thinking about the rating you chose for accuracy, what led you to choose this rating?
24. In your opinion, can laboratory-confirmed influenza data in the NNDSS be improved? Is so, how?

25. In your opinion, which 3 fields listed below are the most complete for laboratory-confirmed influenza notifications in the NNDSS:

- Onset age
- Birth date
- Sex
- Indigenous status
- Vaccination status
- Postcode
- Died from disease
- Serogroup/ subtype
- Specimen date

26. In your opinion, which 3 fields listed below are the most incomplete for laboratory-confirmed influenza notifications in the NNDSS:

- Onset age
- Birth date
- Sex
- Indigenous status
- Vaccination status
- Postcode
- Died from disease
- Serogroup/ subtype
- Specimen date
Appendix 14.3c - Jurisdictional data managers (telephone)

The purpose of this evaluation is to assess the degree in which the National Notifiable Diseases Surveillance System (NNDSS) meets the objectives of monitoring the impact of nationally notifiable diseases on the Australian Community.

The survey has been designed to evaluate the NNDSS as a public health surveillance system. Questions in the survey are intended to capture information on the NNDSS' ability to collect and store notifications and its database structure, computer networks and user interface.

The objectives of the survey are to:

- Determine the time taken to prepare NNDSS notifications for surveillance activities;
- Evaluate if the NNDSS is accepted as a national surveillance system by jurisdictional data managers;
- Identify the strengths and weakness of the NNDSS from the perspective of jurisdictional data managers; and
- Evaluate the systems data quality, flexibility, simplicity and its ability to collect, manage and provide data from the perspective of jurisdictional data managers.

The survey is intended for data managers within jurisdictional and should take 15 minutes to complete.

Contact information

Please fill in your contact information below

Name: 

Organisation: 

Position in organisation: 

email: 

Contact phone number: 

Simplicity

Definition: The simplicity of the public health surveillance system structure and the ease of its operation.
1. As a data manager, what are the main tasks you perform in relation to the data you send to the NNDSS?

2. In your jurisdiction, what system do you currently use to collect and store notifiable disease notifications?

3. In regards to data you send to the NNDSS, please indicate what functions are completed in your jurisdictional system:

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<tr>
<th>Yes</th>
<th>No</th>
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<tr>
<td>Update of records</td>
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<tr>
<td>Deletion of records</td>
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<td>New records</td>
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<tr>
<td>Other, please specify</td>
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4. Are there any additional functions you need to conduct to your jurisdiction data before it can be sent to the NNDSS?

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<tr>
<th>Yes (please specify)</th>
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5. On average how much time (in hours) do you spend each day preparing data to be sent to the NNDSS?

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<th>Hours</th>
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6. Are data sent from your jurisdiction to the NNDSS through a :

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<tr>
<th>Automated system</th>
<th>Generated system</th>
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</table>
7. In your opinion, are the data specifications used for the NNDSS useful?
   - Yes
   - No (please specify why)

8. Do you think these data specifications could be improved? If so how?

9. Is there any other information the Commonwealth could provide that would help you complete your tasks for data to be sent to the NNDSS?

Flexibility

**Definition:** A flexible public health surveillance system can adapt to the changing information needs or operating conditions with little time, personal or allocated funds. If the system uses a standard format for electronic data exchange that can be easily integrated with other systems.

10. Do you think the NNDSS is a flexible system?
   - Yes
   - No (please specify)
11. With regards to your jurisdictions system, how easy is to:

<table>
<thead>
<tr>
<th></th>
<th>Very Difficult</th>
<th>Difficult</th>
<th>Neutral</th>
<th>Easy</th>
<th>Very Easy</th>
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<td>Change a field</td>
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</table>

**Stability**

**Definition:** Stability is the reliability (ability to collect, manage and provide data without error) and availability (ability to be operational when it is needed) of a public health system.

12. In your opinion, does the NNDSS collect, manage and provide accurate data for national surveillance activities?

- Yes
- No (please specify)

**Data quality**

**Definition:** Data quality is the completeness and validity of the data recorded in the public health surveillance system.

13. Do you receive NNDSS job reports?
- Yes
- No (go to question 17)

14. Do you read/check the NNDSS job reports?
- Yes
- No (please specify why)
15. Do you use the NNDSS job reports to amend errors identified in records?
   Yes
   No (please specify why)

16. Who amends the errors reported by the NNDSS job reports?

17. What are the major issues your jurisdictions encounters when sending data to the NNDSS?

18. In your jurisdiction, what risks exist that could interrupt or halt data transference to the NNDSS?

19. For your jurisdiction, which three fields listed below are the most COMPLETE for disease notifications:
   - Birth date
   - Sex
   - Indigenous status
   - Vaccination status
   - Postcode
   - Died from disease
   - Place of acquisition country
   - Serogroup/ subtype
   - Specimen date
   - Laboratory confirmation method
Appendix 14.3d - Health data managers (electronic)

The purpose of this evaluation is to assess the degree in which the National Notifiable Diseases Surveillance System (NNDSS) meets the objectives of monitoring the impact of nationally notifiable diseases on the Australian Community.

The survey has been designed to evaluate the NNDSS as a public health surveillance system. Questions in the survey are intended to capture information on the NNDSS’ ability to collect and store notifications and its database structure, computer networks and user interface.

The objectives of the survey are to:

- Determine the time taken to prepare NNDSS notifications for surveillance activities;
- Evaluate if the NNDSS is accepted as a national surveillance system by Commonwealth data managers;
- Identify the strengths and weakness of the NNDSS from the perspective of Commonwealth data managers; and
- Evaluate the systems data quality, flexibility, simplicity and its ability to collect, manage and provide data from the perspective of Commonwealth data managers.

The survey is intended for data managers within Commonwealth.

Consent

Your participation is voluntary. You may choose not to participate. If you decide to participate in this survey, you may withdraw at any time. If you decide not to participate in this study or if you withdraw from participating at any time, you will not be penalized.

The procedure involves filling in the proceeding online survey that will take approximately 15 minutes. Any information that is obtained in connection with this study and that can identified you will remain confidential, except as required by law. If you give us your permission to use your responses in our research by completing and submitting the survey, I plan to discuss the results with the Australian Department of Health and the Australian National University. In any publication, information will be provided in such a way that you cannot be identified.
ELECTRONIC CONSENT: Please select your choice below.
Clicking on the "agree" button below indicates that:
• you have read the above information
• you voluntarily agree to participate
• you are at least 18 years of age
If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button.

☐ AGREE
☐ DISAGREE

Contact information
Please fill in your contact information below

Name:  
Organisation:  
Position in organisation:  
Contact phone number:  
Email address:  

Data manager tasks
1. As a data manager, what are the main tasks you perform in relation to NNDSS data?

   
   

2. Are there any additional database maintenance, management cleaning, collation or analysis that you need to conduct on data received by the NNDSS?
   Yes (please specify) (Go to question 3)
   No (go to question 4)
3. What system(s) do you use to perform these tasks?

Simplicity
Definition: The simplicity of the public health surveillance system structure and the ease of its operation.

4. On average how much time (in hours) do you spend each day preparing NNDSS data for use?
   ________ Hours

Flexibility
Definition: A flexible public health surveillance system can adapt to the changing information needs or operating conditions with little time, personal or allocated funds. If the system uses a standard format for electronic data exchange that can be easily integrated with other systems.

5. Do you think the NNDSS is a flexible system?

   Yes
   No (please specify)

6. With regards to the NNDSS, how easy is to:

<table>
<thead>
<tr>
<th></th>
<th>Very Difficult</th>
<th>Difficult</th>
<th>Neutral</th>
<th>Easy</th>
<th>Very Easy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Add a field</td>
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<tr>
<td>Remove a field</td>
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<tr>
<td>Change a field</td>
<td></td>
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</tbody>
</table>

7. What processes need to be completed before a NNDSS field can be added, removed or changed?
**Stability**

**Definition:** Stability is the reliability (ability to collect, manage and provide data without error) and availability (ability to be operational when it is needed) of a public health system.

8. In your opinion, does the NNDSS collect, manage and provide accurate data for national surveillance activities?

- [ ] Yes
- [ ] No (please specify)

**Data quality**

**Definition:** Data quality is the completeness and validity of the data recorded in the public health surveillance system.

9. In your opinion, the completeness of national influenza data in the NNDSS is:

- [ ] Poor
- [ ] Fair
- [ ] Good
- [ ] Very good
- [ ] Excellent

10. Thinking about the rating you chose for completeness, what led you to choose it?

11. In your opinion, the accuracy of national influenza data in the NNDSS is:

- [ ] Poor
- [ ] Fair
- [ ] Good
- [ ] Very good
- [ ] Excellent
12. Thinking about the rating you chose for accuracy, why did you choose it?

13. What are the major problems you encounter with data that is transmitted to the NNDSS?

14. What risks exist that could interrupt or halt the use of NNDSS data?

15. In your opinion, which 3 fields listed below are \textbf{the MOST COMPLETE} for influenza notifications in the NNDSS:

- Onset age
- Birth date
- Sex
- Indigenous status
- Vaccination status
- Postcode
- Died from disease
- Serogroup/ subtype
- Specimen date
Appendix 14.4 - Pilot project for influenza Seasonal and inter-seasonal denominators for surveillance reporting in Australia - Potential to use laboratory testing data

Background

Influenza has an enormous impact and extensive socio-economic burden on the Australian health care system. (1-6) In order to effectively allocate health care resources, determine public health interventions and develop cost effective programs, the incidence of influenza in Australia needs to be continually monitored. (7) One of the main sources of influenza monitoring in Australia utilises laboratory-confirmed data (notification data) provided to the National Notifiable Diseases Surveillance System (NNDSS). These data are used in conjunction with several other surveillance systems including sentinel influenza-like-illness reports from general practitioners, community services and emergency departments and influenza associated hospitalisations to provide a picture of the impact influenza has on the Australian population during and between influenza seasons.

However this reliance on notification data for influenza reporting has been met with criticism. It is argued that notification data cannot provide an accurate picture regarding the incidence of influenza as the method ignores the potential influence of testing on apparent influenza activity significance. It has been argued that notification data could be enhanced by analysing testing denominator data. Lambert et al (2010) examined the use influenza-negative laboratory testing data to provide dominators for reporting in Queensland. (8) They concluded that the testing data would account for the regional or temporal differences for the number of tests performed for influenza, provide a more complete picture of influenza during seasonal and pandemic periods and improve our epidemiological knowledge of the disease. (8)

The Australian Department of Health (Health) is looking to extend on this project and evaluate if influenza laboratory testing data can be utilised as seasonal and inter-seasonal denominators for national reporting activities. In order to assess if laboratory testing data can be utilised, Health is seeking to conduct a retrospective data analysis pilot project using laboratory testing data from Queensland (Qld).

Aim

To determine if influenza laboratory testing data can generate seasonal and inter-seasonal denominators for national surveillance reporting in Australia.
Objectives
The objectives of this pilot project are to identify:

- Determine if laboratory testing data in Qld can be provided to Health;
- Determine the number of laboratories required for representative sample.
- Determine if laboratory testing data can be utilised to inform influenza activity; and
- Review the project's outcome and provide recommendations.

Methods
Both the public and private laboratories will be approached to supply influenza testing data. Data will be collected and aggregated for the final analysis. To determine the utility of laboratory data, Health intends to engage with the Influenza Surveillance Strategy Working Group (ISSWG) to devise methods to calculate the baselines and thresholds. This methodology will be evaluated at the end of the project.

Data
For this project, Health will ask Qld laboratories to provide influenza testing information for the years 2006 to 2012. This six year period has been chosen to understand testing practices that may have occurred in a moderate influenza season (2006), during and after a severe domestic influenza season(2007 to 2008) and during and after the 2009 influenza pandemic (2009 to 2012).

The type of data I will need for project will include:

Weekly data
Weekly testing data is being sought to provide Health with the ability to establish denominators for influenza in both seasonal and inter-seasonal periods. This data will enable Health to understand changes in testing behaviour and any effect on interpretation of influenza notification data. Data that will be requested from laboratories includes:

- number of non-reactive influenza tests results per week from 2006 to 2012; and
- number of reactive influenza tests per week from 2006 to 2012.

Annual data
Aggregated annual data is being requested to provide Health with a picture of hospital and community (eg GPs) testing patterns in Australia, the type of testing performed, and information regarding the capacity of Australian laboratories to subtype influenza A infections. Data that will be requested from laboratories includes:
• proportion of tests performed for cases presenting in the community or in hospital;
• proportion of positive influenza A tests that were subtyped; and
• proportion of tests performed as Nucleic Acid Amplification Tests (NAAT) or serology.

A template of the data request form can be found at Attachment A.

Data storage and confidentiality
All data used in the pilot project will be securely stored by Health in a restricted access directory file within the Vaccine Preventable Diseases Surveillance (VPDS) Office of Health Protection. These data will not be provided to external stakeholders and will only be accessed by staff employed by the VPDS. Any information identifying laboratories and/or individual will be removed to maintain confidentiality.

Funding and reporting
Health will not be able to provide any funding for this project. A final report will be provided to Queensland Health, PHLN, ISSWG, Communicable Diseases Network Australia, the Australian National University and the Vaccine Preventable Diseases Surveillance section of the Office of Health Protection, Health

Potential issues
Health has identified a number of issues with the project. These issues include:

• **Laboratory information systems**: Data for the project may not be available as extracting it from the laboratory information systems. This may restrict the number of laboratories able to participate in the project.

• **Respiratory panels**: The use of respiratory panel test sets in some laboratories may underestimate or overestimate the number of laboratory tests reported for influenza. Health will need to determine if these types of laboratory test sets can be utilised for the project.

• **Representativeness of private laboratories**: To achieve a representative sample, Health will need to obtain data from public as Ill as private laboratories. Issues already raised with the collection of data from private laboratories include:
  - Data and confidentiality of patients;
  - Commercial in confidence – not wanting to revel the number of test they conduct for influenza;
  - Limited resources required to extract and provide the data.
Using Medical Benefits Scheme (MBS) data as a substitute of laboratory testing data

As the only items listed for influenza pathology services on the MBS are the general items (69384 and 69496). This item is described as the “quantitation of 1 antibody to microbial antigens not elsewhere described in the Schedule” and is not limited to any disease.

The MBS division within Health have advised that data for these items cannot be extracted by disease or disease group from the MBS database. Therefore using MBS data as a substitute for laboratory testing data is not an option for this project.

Conclusions and Recommendations

The overall this project will determine if laboratory testing data can be utilised for influenza reporting activities. Recommendations about the utility of the data and how it can be integrated as a regular part of influenza surveillance reporting activities will be provided at the end of the project. An evaluation will be conducted to identify the limitations of the project and how these could be addressed in future collections.

References

Appendix 14.5 - Minute to the Assistant Secretary of the Health Emergency Management Branch for – Investigating if laboratory data can be used for influenza reporting

Australian Government
Department of Health

Minute

Rob Cameron
Assistant Secretary
Health Emergency Management Branch

Investigation if laboratory testing data to understand their effect on influenza notifications – pilot project

Purpose
That you:

- **NOTE** the current status of the project to investigate the effect that influenza testing patterns may have on laboratory confirmed influenza notifications in Australia; and
- **SIGN** the attached letters the three Queensland pathology laboratories to request influenza laboratory testing data (Attachments A, B and C):

Background
On 20 June 2014 you agreed to the submission of a paper to the Public Health Laboratory Network (PHLN) regarding the investigation into using influenza laboratory testing data to inform national influenza reporting, pending consultation with Dr Gary Lum (Attachment D).

Current situation
The original project proposal aimed to collect laboratory testing data nationally. Following consultations with Dr Lum, it was agreed that the initial scope of the project should be reduced and a pilot project conducted using data from both private and public laboratories in Queensland.

A revised project proposal for the pilot is at Attachment E.

We have consulted our colleagues at Queensland Health to seek their advice on how to attain laboratory testing data in Queensland. They have recommend that we approach the three main laboratories in Queensland: Pathology Queensland (Public), QML Pathology (Private) and Sullivan & Nicolaides Pathology (Private) to obtain the influenza laboratory testing data required for the pilot.

We are also requesting influenza testing data from the Mater Pathology group, which is a small private laboratory based at the Mater hospital. We have already approached Mater Pathology and are working through their processes to obtain the data.
Recommendation
That you:
R1 Note the current status of the project to investigate the effect that influenza testing patterns may have on laboratory confined influenza notification in Australia; and
R2 Sign the three data request letters of each laboratory at Attachments A, B and C

Rhonda Owen
Director
Vaccine preventable Diseases Surveillance
Health Emergency Management Branch

26 August 2014

Attachments
Attachment A. Data request letter - Professor Graem Nimmo Pathology Queensland.
Attachment B. Data request letter - Dr Renu Vohra, QML Pathology.
Attachment C. Data request letter – Dr Jennifer Robson, Sullivan & Nicolaides.
Attachment D. Paper for PHLN and Project proposal for national collection.
Attachment E. Project proposal for Queensland pilot.
Chapter 6
Teaching and dissemination of information
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1. Overview

Acquiring and imparting knowledge is essential when working in the field of epidemiology. The dissemination of information between healthcare workers, researchers, public health officials and other epidemiologists improves, expands and enhances our knowledge, enabling the field to develop and grow. One of the key components of the Master of Applied Epidemiology (MAE) program is to be able to impart knowledge.

In this chapter, I briefly outline the tasks I undertook to impart knowledge during my MAE placement. I describe my involvement in two teaching exercises; 1) Lessons From the Field and 2) teaching the 2014 MAE cohort, and outline my experiences in providing information whilst working within the Vaccine Preventable Diseases Surveillance section (VPDS) in the Office of Health Protection (OHP) at the Australian Government Department of Health (the Department of Health).

2. Lessons From the Field

The MAE Lessons From the Field (LFF) has two components. The first is to conduct a LFF on an issue you encountered during your field placement, and the second is to participate in the LFFs of your colleagues.

2.1. Working with Aboriginal and Torres Strait Islander data

Whilst conducting my major epidemiological project, which examined the completion of Indigenous status in the National Human Papillomavirus Register (NHVPR), I encountered a number of issues in interpreting and reporting data using Indigenous status. For my LFF, I chose the topic of how to work with Aboriginal and Torres Strait Islander data to encourage my fellow MAE colleagues to think about the issues often associated with interpreting and reporting Indigenous status information.

To facilitate the LFF, I provided my colleagues with documents detailing the project’s background, tasks and resources (Appendix 6.1). I organised a teleconference for 7 May 2014, and led discussions about:

1. The standards used for the collection of Indigenous status in Australia;
2. The barriers commonly associated with the collection of Indigenous status;
3. How to analyses data and develop rates with missing Indigenous status; and
4. How to interpret and effectively communicate these rates.

Overall, my colleagues agreed that analysing Indigenous status is difficult, particularly when the accuracy and completeness of the data is low. My colleagues acknowledged
that interpreting Indigenous status needs to be done carefully, and researchers should ensure they understand all the issues relating to its collection when interpreting the data.

After the teleconference, I provided my colleagues with standard answers to the questions raised in the LFF (Appendix 5a).

Writing this LFF has taught me how to design clear learning objectives, articulate problems effectively and structure teaching projects. It also helped me better understand the issues surrounding the collection and reporting of Indigenous status in Australia, how these affect interpretation, and identified barriers to its collection, which I was able to incorporate into my major epidemiological project.

2.2. Participation in LFFs

I participated in six LFFs during my placement. These included:

1. Writing for different audiences (Timothy Sloan-Gardner);
2. Project management (Dina Saulo);
3. Control selection (Tove Fitzgerald);
4. Sample size calculations (Anita Williams);
5. Data linkage (Kerryn Lodo); and
6. Introduction to causal diagrams (Courtney Lane).

For each of these, I provided responses, participated in discussions and gave feedback on the LFFs structure and content. By participating in each of these LFF, I learnt how to address problems with my own work. In particular, the resources provided as part of the project management session helped me to design and monitor stakeholder consultations for my major epidemiological project and surveillance evaluation. The sessions on causal diagrams and sample size calculations introduced me to new concepts and software that assisted me in completing my own projects.

3. Teaching the first year MAE cohort of 2014

During the first semester course block conducted in March of 2014, the MAE cohort of 2013 (second years) conducted a half day training session for the MAE cohort of 2014 (first years). This teaching session aimed to provide the first years with knowledge and practical experience in four major epidemiological concepts.

The second years developed 30 to 40 minute sessions on the following topics;

1. Selection and measurement bias - Anna-Jane Glynn-Robinson and Courtney Lane;
2. Critical appraisals - Timothy Sloan-Gardner and Anita Williams;
3. Interpreting time series data - Jason Agostino, Dina Saulo and Philippa Chidgzey; and

Working with Courtney Lane, we developed a 40 minute session that explored the concepts of selection and measurement bias. My role was to develop the teaching plan (Appendix 6.2a) and the presentation slides (Appendix 6.2b), contribute to the instructor guide (Appendix 6.2c) and present information about measurement bias.

Our session aimed to reinforce issues of selection and measurement bias by using a practical example. The objectives of this session were:

- Describe selection and measurement bias;
- Identify potential bias in practical situations;
- Describe effects on measures of association; and
- Identify strategies to minimise bias.

Part of the teaching experience was to obtain feedback from the participants. I was asked, on behalf of the group, to develop a student feedback form, for the first years at the end of the half-day session. The overall results of the session conducted by Courtney and myself are provided in Appendix 6.2d.

Undertaking this teaching exercise I developed a number of skills including time management and effective planning. As we only had 30-40 minutes to conduct the session, we needed to ensure the information we presented was relevant and useful. The most valuable lesson I learned from this experience was how to balance information to meet the expectations of an audience with varying knowledge backgrounds. I have also developed an appreciation for the amount of effort and time needed to develop teaching plans, presentation slides, participant documents and feedback forms.

4. Dissemination of information

4.1. Analysis of legionellosis for the 2012 and 2013 annual reports

The VPDS section manages and co-ordinates data collected on communicable diseases in Australia, through the National Notifiable Disease Surveillance System (NNDSS). Each year, a report on the status of Australia’s notifiable diseases is produced using these data. Chapters are managed by disease group and are reviewed
by external experts before being published in the *Communicable Diseases Intelligence* Journal (CDI).

During my placement, I was responsible for the analysis of legionellosis in the 2012 and 2013 *Australia’s notifiable diseases status: Annual report of the National Notifiable Diseases Surveillance System*. I performed data cleaning and analysis in Excel, produced tables and graphs and wrote the final analyses (Appendix 6.3). At the time of completing my placement, the 2012 Annual Report had been published in CDI and the 2013 was in press.

Writing this section of the chapter developed my understanding of *Legionella* infection in Australia, and provided context to my data analysis project. By conducting the analysis for two annual reports, I became familiar with extracting, using and analysing NNDSS, data and writing for the Australian Government.

### 4.2. Rotavirus Working Group (RWG) paper

The Communicable Disease Network Australia (CDNA), convened a time limited working group to evaluate and improve the performance and reporting of rotavirus surveillance activities in Australia. As the secretariat for this working group I was asked to produce and present a paper that described the rotavirus notifications within the NNDSS (Appendix 6.4). This paper outlined which jurisdictions provided rotavirus notifications to the NNDSS, what data were available and presented an epidemiological analysis of rotavirus in Australia.

Working closely with this working group gave me the opportunity to strengthen my skills in data analysis, and improve my understanding of rotavirus. These activities also provided me with valuable secretariat skills and improved my understanding of the functions and capabilities of working groups at a national level.

### 4.3. Presentation to a Bangladesh delegation

In 2014, a delegation from Bangladesh visited the Department of Health to learn about Australia’s disease control systems and the MAE program. The delegation included representatives from the Ministry of Health, the Institute for Epidemiology Disease Control and Research, and the Bangabandhu Sheikh Mujib Medical University. I was asked to present to the delegation and provide them with an overview of communicable disease surveillance in Australia, describe the NNDSS, outline the surveillance conducted by VPDS section, and describe my MAE experience (Appendix 6.5).

This experience further strengthened my understanding of communicable disease surveillance in Australia and the surveillance activities conducted within VPDS section.
It also advanced my skills in presenting, providing me with the confidence to present at the Public Health Association of Australia (PHAA) 43rd Annual Conference in September 2014.

5. Other Public Health Experiences

5.1. Watch officer for the National Incident Room

While working in the National Incident Room (NIR) as Watch Officer (WO), I analysed information provided by other federal departments, jurisdictional health departments and international National Focal Points (NFP), to inform the Health Emergency Management Branch (HEMB) about notifications of communicable disease and events of potential public health significance. I provided jurisdictional health departments with information to conduct contact tracing and informed International NFPs of travel-related communicable disease notifications relevant to their countries.

In my role as WO, I learnt how the Australian Government responds to events of public health significance, the roles and responsibilities of federal, jurisdictional and local governments and developed skills in using event based information and management systems.

5.2. Surveillance and reporting of the Avian Influenza A (H7N9) outbreak in China

In March 2013, the Chinese Government informed the World Health Organization (WHO) that a novel Avian Influenza A strain (H7N9) had been identified in humans. As part of the response to this outbreak, VPDS section undertook international surveillance using information from WHO, ProMED, FluTrackers and other relevant sources of information.

My role was to conduct this surveillance, create an Excel database to track confirmed cases, develop maps to display the geographical spread of infection and update epidemiological information. I produced epidemiological curves, tables and graphs and assisted in writing the daily situational reports and briefings to the Chief Medical Officer. I also assisted in writing travel advice for the Department of Foreign Affairs and Trade Smartraveller website and updated the Department of Health’s Avian Influenza webpage.

This experience taught me how to undertake international surveillance, develop a database to efficiently track cases of infection, and write to a range of audiences, including the general public, my colleagues and OHP executives.
6. Appendices

Appendix 6.1 Lessons From the Field; Working with Aboriginal and Torres Strait Islander data

The LFF will be conducted by teleconference on 7 May 2014. Please save your response to the questions in a Word file and send to back to anna.glynn-robinson@health.gov.au by COB Wednesday 30 April 2014.

Please also send me the telephone number you wish to be called on for the teleconference.

Learning Objectives

By the end of this LFF participants should be able to:

- Understand the complexities of working with Aboriginal and Torres Strait Islander data;
- Describe the national standards of collecting Indigenous Status in health data sets;
- Describe barriers in collection of Indigenous status in health data sets; and
- Complete age-specific rates for Aboriginal and Torres Strait Islander females using the Australian Bureau of Statistics (ABS) Estimated Residential Population (ERP).

Background

It is estimated that 50% to 80% of genital Human Papillomavirus (HPV) transmission occurs after a person has engaged in unprotected sexual intercourse with a person who has an active HPV infection.\(^1\) Most infections of HPV resolve spontaneously in approximately 12 to 24 months. However, a small proportion (around 3% to 10 %) of infections persist, producing cellular abnormalities, precancerous disease and in some cases progressing to cancer.\(^2\)

Cervical cancer is the most common HPV-associated cancer in Australia.\(^5\) It was estimated that prior to the introduction of the National HPV Vaccination Program (the Program) in 2007, the rate of cervical cancer in Australia was 6.8 per 100,000 population, with a mortality rate of 1.8 per 100,000 population.\(^6\) Early investigations have indicated that since the introduction of the Program in Victoria there has been a decrease of 0.4% in the incidence of high grade cervical lesion in female’s younger than 18 years of age.\(^8\)
The Program was introduced in Australia for females in April 2007 and consisted of two components: an ongoing school based program for females enrolled in grade seven and eight; and a time limited catch-up program which ceased on 31 December 2009, for women aged 12 to 26 years. During the period of 2007 to 2009 around 83% of females aged 12 to 17 years were vaccinated with at least one dose and 70% completed all three doses. In 2013, the Program was expanded to include males, with the vaccine available in schools for males enrolled in grade seven and eight; and as a time-limited catch up program for males aged 14 to 15 years, due to end in 2014.

Evidence indicates that Aboriginal and Torres Strait Islander females have higher rates of cervical cancer than non-Indigenous females in Australia. Recent analysis shows the incidence of cervical cancer in Aboriginal and Torres Strait Islander females is twice that of non-Indigenous women and the mortality rate is 5 times higher.

To reduce the burden cervical cancer amongst Aboriginal and Torres Strait Islander females and prevent any further widening of the gap, equity in vaccination coverage is required. To determine if this equity is being achieved we need to monitor HPV vaccination coverage by Indigenous status.

**National Human Papillomavirus Vaccination Program Register (NHVPR)**

The National HPV Vaccination Program Register (NHVPR) is a confidential database that supports the Program by collecting data on HPV vaccinations administered in Australia. Established in 2007, the NHVPR contains records of HPV vaccines to females from 2006 and for males from 2013. Data are provided to the NHVPR by jurisdictional health departments, local government councils (school-based Program), General Practitioners (GP), Nurses, Aboriginal health works and other immunisation providers. Information on HPV vaccinations are provided to the register under the provisions of the National Health Amendment 2007 (National HPV Vaccination Program Register).

The information that is collected in the NHVPR includes: name, gender, date of birth; address; vaccine brand; vaccine provider’s number; vaccine dose number; date of vaccination; consumer reference number; Indigenous status; Medicare number; country of residence; consent date (on school-based HPV consent forms); name and contact details of consenting parent or guardian (on school-based HPV consent forms); school details (on school-based HPV consent forms); and provider contact details.
Scenario

You are working for the Australian Government Department of Health (the Department of Health) and you have been asked to provide an estimation of HPV vaccination coverage in Aboriginal and Torres Strait Islander females in 2009 using data from the NHVPR. These estimates will be used to assist the Immunisation Branch in their evaluation of the Program.

Your director thinks this will be a good project as part of your MAE training. The Immunisation Branch has asked that the estimates of vaccine coverage be provided as age-specific rates. To ensure the data you provide to the Immunisation Branch is interpreted correctly, your director has asked that you provide a short explanation about how Indigenous status is collected in Australia and the barriers faced in collecting this information.

She also mentions that Indigenous status is known to be underreported in the NHVPR and may affect the vaccine coverage estimates. She wants you to be very careful how you present these estimates, as the information could be misleading.

Task 1: Investigate the standards used to collect Indigenous status in Australian Health data sets

1. According to the Australian national standards, how should Indigenous status be asked? (Hint- see the Australian Institute of Health and Welfare website)

   ‘Are you [is the person] of Aboriginal or Torres Strait Islander origin?’

   - No
   - Yes, Aboriginal
   - Yes, Torres Strait Islander
   - Yes, Both Aboriginal and Torres Strait Islander

   If the fourth box is not included, then a respondent should be asked to tick both Yes boxes if they identify as an Aboriginal and Torres Strait Islander.

2. Do all jurisdictions use the recommended national categories for Indigenous identification on their HPV vaccine consent forms? (these forms can be found on the HPV school programme website)

   No, questions for Indigenous status on the HPV vaccination consent forms vary amongst the jurisdictions.

3. Which jurisdictions use different categories?
The Australian Capital Territory, Tasmania, South Australia and Western Australia.

4. List the categories used by jurisdictions that differ from the recommended national categories.

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Question asked on form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>Aboriginal/Torres Strait Islander</td>
</tr>
<tr>
<td>NSW</td>
<td>Indigenous status:</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes, Aboriginal</td>
</tr>
<tr>
<td></td>
<td>Yes, Torres Strait Islander</td>
</tr>
<tr>
<td></td>
<td>Yes, Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>NT</td>
<td>Ethnicity:</td>
</tr>
<tr>
<td></td>
<td>Non-Aboriginal</td>
</tr>
<tr>
<td></td>
<td>Aboriginal</td>
</tr>
<tr>
<td></td>
<td>Torres Strait Islander</td>
</tr>
<tr>
<td></td>
<td>Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>QLD</td>
<td>Aboriginal</td>
</tr>
<tr>
<td></td>
<td>Aboriginal and Torres Strait Islander (TSI)</td>
</tr>
<tr>
<td></td>
<td>TSI</td>
</tr>
<tr>
<td></td>
<td>Not Aboriginal or TSI</td>
</tr>
<tr>
<td></td>
<td>Not stated/unknown</td>
</tr>
<tr>
<td>SA</td>
<td>Aboriginal/Torres Strait Islander</td>
</tr>
<tr>
<td>TAS</td>
<td>Is your child of Aboriginal or Torres Strait Islander origin?</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>VIC</td>
<td>Is the person of Aboriginal or Torres Strait Islander consent?</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Aboriginal</td>
</tr>
<tr>
<td></td>
<td>Torres Strait Islander</td>
</tr>
<tr>
<td></td>
<td>Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>WA</td>
<td>Aboriginal</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>

Task 2: Investigate the barriers associated with the collection of Indigenous status in Australian health data sets

You now have a better understanding of how Indigenous status is collected on HPV vaccination consent forms in Australia. However you are still unsure why it is poorly reported to the NHVPR. If there are national standards for asking this question and every jurisdiction asks for Indigenous identification, then surely the data should be better than it currently is.
You decide you need to investigate what the barriers are that could affect the collection of Indigenous status in the NHVPR.

5. What would be your research question to investigate the barriers in collecting Indigenous status?

What barriers impede the collection of Indigenous status in the HPV vaccination consent forms?

6. Find 2 resources (these can be research articles or grey literature) that provided you with information about some of the barriers in collecting Indigenous status in Australia.


These are just a few of the resources available. There are many other resources including government reports, opinion pieces, and editorials.

7. From these resources, list the main barriers that could be associated with the collection of Indigenous status in the NHVPR. This should be no more the half a page.

- Not seen as relevant to providing or obtaining health care;
- Fear of racial discrimination;
- Healthcare staff assuming Indigenous status is too sensitive to ask;
- Misconception as to why the question is being asked;
- Failure to ask the question consistently;
- Lack of appropriate categories for self-identification;
- Best practice guidelines to ask Indigenous status are not followed;
- Indigenous status is recorded based on appearance of the person;
- Distrust in how the data will be used and disseminated; and
- Healthcare staff don’t understand the value or need for the question to be answered.

**Task 3: Data analysis**

Now that you have a good understanding of how Indigenous status is collected and the barriers often encountered with its collection, you’re ready to calculate rates. Whilst you know how to calculate age-specific rates, you are aware that providing age-specific rates for Aboriginal and Torres Strait Islander populations requires careful interpretation as the Estimated Residential Population (ERP) numbers used as denominators for this group are often unstable.

Lucky for you, there are only 50 females in 2009 who received a HPV vaccine, so the analysis shouldn’t be too difficult. However, you have just noticed the only population data you have available from the ABS to calculate the age-specific rates is the 2006 ERPs for females in single year age groups by Indigenous status. You realise, this is going to be trickier than you thought.

Using the information provided in the attached excel spread sheet answer the following questions.

8. How can you use the 2006 ERPs to calculate the 2009 age-specific rates?

*There are two ways you could use the 2006 ERP for calculation of age specific rates.*

**First method- Baseline assumption**

This method assumes that the changes in the population structure have not varied significantly overtime (in this case 2006 to 2009). This method assumes, for example, the population structure of 12 year olds in 2006 is similar to the population structure for 12 year olds in 2009.

Using this method, the age-specific rate for 12 year old girls is calculated by:

\[
\text{number of 12 year old girls vaccinated in 2009} \times 100,000 \]

\[
\text{population of 12 year old girls in 2006 mid-year ERP} \]

**Second method – Birth cohort analysis**

This method assumes that the number of people born in one year has remained relatively similar over time. For example, the population of girls born in 1997 has
remained the same, thus this population is the same as the number of 12 year old girls in 2009 (these girls would have been born in 1997). Using this example age specific rates would be calculated as follows:

\[
\frac{\text{population of girls born in 1997 with a vaccine dose}}{\text{population of girls born in 1997}}
\]

This method assumes that your denominator correspond to the year of birth. So if your denominator is mid-year 2006 ERPs, your denominator would then be 9 year old girls, as this would have been the age of the 12 year old girls in 2006.

To calculate the rate we use the following calculation:

\[
\frac{\text{number of 12 year old girls vaccinated in 2009}}{\text{population of 9 year old girls in 2006 mid-year ERP}} \times 100,000
\]

This method is commonly used in vaccination coverage estimates. As some vaccines are only required once in their lifetime for protection, this method provides a population coverage estimate.

9. Calculate the age-specific rates for Australia and provide the results in a table similar to the one below.

### Table 1: Ages specific rates for female HPV vaccinations by Indigenous status, Australia, 2009

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Indigenous (n)</th>
<th>Non-Indigenous (n)</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 – 9 Years</td>
<td>15.87 (3)</td>
<td>0.27 (1)</td>
<td>1.29 (5)</td>
</tr>
<tr>
<td>10 - 14 Years</td>
<td>0.00 (0)</td>
<td>2.49 (16)</td>
<td>5.94 (40)</td>
</tr>
<tr>
<td>15 - 19 Years</td>
<td>3.76 (1)</td>
<td>0.31 (2)</td>
<td>0.74 (5)</td>
</tr>
</tbody>
</table>

An alternate way to provide the data in table 1 would be to consider those eligible for the HPV vaccination in the school and catch-up Programmes.

### Table 2: Age specific rates of female eligible for the school HPV vaccination per 100,000 population and total number of vaccinated persons (N), by Indigenous status, 2009

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Rate per 100,000 population (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Indigenous</td>
</tr>
<tr>
<td>12-13 years</td>
<td>0.00 (0)</td>
</tr>
<tr>
<td>14-15 years</td>
<td>8.16 (1)</td>
</tr>
</tbody>
</table>

As part of these calculations, we could age-standardise the results to adjust for the difference in age structures between the two populations. I have provided the
methodology of direct standardisation below. I chose direct standardisation as it is the method recommended by the AIHW and ABS. Whilst indirect could be used in this example, it is generally only used when the population is small and rates of disease are small, or the age-specific rates for the population being studied are not known.

**Direct standardisation:**

The following equation for direct standardisation is:

\[
SR = \frac{\text{SUM} (r_i * P_i)}{\text{SUM} P_i}
\]

Where:
- \( SR \) is the age-standardised rate for the population being studied
- \( r_i \) is the age-group specific rate for age group \( i \) in the population being studied
- \( P_i \) is the population of age group \( i \) in the standard population

To calculate the age-standardised rates we need to first calculate the expected numbers of each age group in the entire Indigenous and non-Indigenous female populations. Whilst we only have vaccination notifications for females aged 9-15 years, age-standardisation adjusts for the difference in the age across the entire population.

**Table 3:** Calculations for age standardisation for Aboriginal and Torres Strait Islander females, Australia, 2009

<table>
<thead>
<tr>
<th>5-Year Age Group</th>
<th>Observed Notifications</th>
<th>Indigenous population</th>
<th>Age specific rate</th>
<th>Standard Population</th>
<th>Expected Notifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>0</td>
<td>31,673</td>
<td>0.0000000</td>
<td>1282357</td>
<td>0.0</td>
</tr>
<tr>
<td>5-9</td>
<td>3</td>
<td>31,801</td>
<td>0.0000943</td>
<td>1351664</td>
<td>127.5</td>
</tr>
<tr>
<td>10-14</td>
<td>0</td>
<td>31,433</td>
<td>0.0000000</td>
<td>1353177</td>
<td>0.0</td>
</tr>
<tr>
<td>15-19</td>
<td>1</td>
<td>26,614</td>
<td>0.0000376</td>
<td>1352745</td>
<td>50.8</td>
</tr>
<tr>
<td>20-24</td>
<td>0</td>
<td>22,122</td>
<td>0.0000000</td>
<td>1302412</td>
<td>0.0</td>
</tr>
<tr>
<td>25-29</td>
<td>0</td>
<td>18,620</td>
<td>0.0000000</td>
<td>1407081</td>
<td>0.0</td>
</tr>
<tr>
<td>30-34</td>
<td>0</td>
<td>18,546</td>
<td>0.0000000</td>
<td>1466615</td>
<td>0.0</td>
</tr>
<tr>
<td>35-39</td>
<td>0</td>
<td>18,136</td>
<td>0.0000000</td>
<td>1492204</td>
<td>0.0</td>
</tr>
<tr>
<td>40-44</td>
<td>0</td>
<td>15,734</td>
<td>0.0000000</td>
<td>1479257</td>
<td>0.0</td>
</tr>
<tr>
<td>45-49</td>
<td>0</td>
<td>13,011</td>
<td>0.0000000</td>
<td>1358594</td>
<td>0.0</td>
</tr>
<tr>
<td>50-54</td>
<td>0</td>
<td>10,196</td>
<td>0.0000000</td>
<td>1300777</td>
<td>0.0</td>
</tr>
<tr>
<td>55-59</td>
<td>0</td>
<td>7,554</td>
<td>0.0000000</td>
<td>1008799</td>
<td>0.0</td>
</tr>
<tr>
<td>60-64</td>
<td>0</td>
<td>5,115</td>
<td>0.0000000</td>
<td>822024</td>
<td>0.0</td>
</tr>
<tr>
<td>65-69</td>
<td>0</td>
<td>3,576</td>
<td>0.0000000</td>
<td>682513</td>
<td>0.0</td>
</tr>
<tr>
<td>70-74</td>
<td>0</td>
<td>2,430</td>
<td>0.0000000</td>
<td>638380</td>
<td>0.0</td>
</tr>
<tr>
<td>75+</td>
<td>0</td>
<td>3,173</td>
<td>0.0000000</td>
<td>1114641</td>
<td>0.0</td>
</tr>
<tr>
<td>Grand Total</td>
<td>4</td>
<td>259,734</td>
<td>0.0000154</td>
<td>19413240</td>
<td>178.3</td>
</tr>
</tbody>
</table>
Table 3: Calculations for age standardisation for non-Indigenous females, Australia, 2009

<table>
<thead>
<tr>
<th>5-Year Group</th>
<th>Age</th>
<th>Observed Notifications</th>
<th>Non-Indigenous Population</th>
<th>Age-specific rate</th>
<th>Standard Population</th>
<th>Expected Notifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>0</td>
<td>637,648</td>
<td>0.0000000</td>
<td>1282357</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>5-9</td>
<td>1</td>
<td>653,157</td>
<td>0.0000015</td>
<td>1351664</td>
<td>2.1</td>
<td></td>
</tr>
<tr>
<td>10-14</td>
<td>16</td>
<td>681,239</td>
<td>0.0000235</td>
<td>1353177</td>
<td>31.8</td>
<td></td>
</tr>
<tr>
<td>15-19</td>
<td>2</td>
<td>689,033</td>
<td>0.0000029</td>
<td>1352745</td>
<td>3.9</td>
<td></td>
</tr>
<tr>
<td>20-24</td>
<td>0</td>
<td>723,531</td>
<td>0.0000000</td>
<td>1302412</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>25-29</td>
<td>0</td>
<td>696,460</td>
<td>0.0000000</td>
<td>1407081</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>30-34</td>
<td>0</td>
<td>748,090</td>
<td>0.0000000</td>
<td>1466615</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>35-39</td>
<td>0</td>
<td>766,937</td>
<td>0.0000000</td>
<td>1492204</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>40-44</td>
<td>0</td>
<td>771,590</td>
<td>0.0000000</td>
<td>1479257</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>45-49</td>
<td>0</td>
<td>754,066</td>
<td>0.0000000</td>
<td>1358594</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>50-54</td>
<td>0</td>
<td>684,947</td>
<td>0.0000000</td>
<td>1300777</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>55-59</td>
<td>0</td>
<td>635,851</td>
<td>0.0000000</td>
<td>1008799</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>60-64</td>
<td>0</td>
<td>493,166</td>
<td>0.0000000</td>
<td>822024</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>65-69</td>
<td>0</td>
<td>395,284</td>
<td>0.0000000</td>
<td>682513</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>70-74</td>
<td>0</td>
<td>327,264</td>
<td>0.0000000</td>
<td>638380</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>75+</td>
<td>0</td>
<td>757,184</td>
<td>0.0000000</td>
<td>1114641</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>Grand Total</td>
<td>19</td>
<td>9,777,799</td>
<td>0.0000019</td>
<td>19413240</td>
<td>37.8</td>
<td></td>
</tr>
</tbody>
</table>

To calculate the standard rate for each population using the direct method:

Indigenous = 178.3/19,413,240*100,000 = 0.199 per 100,000

Non-indigenous = 37.8/19,413,240*100,000 = 0.195 per 100,000

Comparative Ratio = 1.99/1.95 = 1.02

Interpretation:

After controlling for the confounding effects of age, the vaccination coverage of Indigenous females was 2% higher than non-indigenous females in 2009.

Note on standardisation:

One thing to note with age standardisation, in some cases it is more informative to report the age-specific rates of the age groups of interest, rather than attempting to convey the differences through one or two figures. Of course this will depended what your data looks like.

If you are unsure if direct age standardisation is for you, check out “Principles on the use of direct age-standardisation in administrative data collections; for measuring the gap between Indigenous and non-Indigenous Australian" by the Australian Institute of Health and Welfare. This document is very helpful in understanding how to do direct standardisation and when it is appropriate.

10. What caveats would you need to provide with the table? (Hint use information from the ABS website)
Notes:
1. Indigenous status has been self-reported.
2. HPV Vaccination doses administered through general practice and in other community settings may be incompletely notified to the NHVPR. The extent of under notification differs by jurisdiction.
3. Population is Estimated Resident Population (ERP) provided by the Australian Bureau of Statistics (ABS) requested as single year age groups by Indigenous status.
4. Single year of age experimental Indigenous population estimates may be subject to errors that cannot be adjusted for in the population estimates compilation process.
5. The Census Post Enumeration Survey adjusts for net undercount by Indigenous status by single year of age and sex.
6. Excludes consumers who do not wish their details to be recorded on the NHVPR.
7. HPV Vaccination doses administered through general practice and in other community settings may be incompletely notified to the NHVPR. The extent of under notification differs by jurisdiction.

*Note this task can be completed in Excel or Stata. If you use Stata please provide the Stata Do-file. If you use excel please provide the excel spread sheet and provide the formula you used to calculate the age specific rates.

Task 4 – Bringing it all together

You’re finally ready to provide the Immunisation Branch with the estimates they have requested. However you feel you can’t just provide the estimates without any context about the collection of Indigenous status for the NHVPR and potential issues with the data.

To ensure the estimates are used and interpreted for the Program evaluation correctly, write a short paragraph for the Immunisations Branch that includes:

- Estimated age-specific rates for vaccine coverage;
- Caveats in interpreting the data;
- Rationale as to why Indigenous status may be underreported in the NHVPR; and
- If, in your opinion, this information should be used as part of the evaluation.

The Human Papillomavirus Virus (HPV) Vaccination program was introduced in Australia for females in April of 2007. The program consisted of two components; 1) an ongoing school based program for females enrolled in grade seven and eight (12 to 13
years); and 2) a time limited catch-up program which ceased on 31 December 2009, for women aged 14 to 26 years.

In 2009, the NHVPR received 50 female HPV vaccination notifications, whose ages ranged from 9 to 15 years. We compared vaccination coverage rates by Indigenous status and found rates for the school based Program (12 to 13 years) were higher in non-Indigenous females at 2.3 per 100, population compared to Indigenous at 0.0 per 100,000 population. Inversely, rates for females in the catch up program (14 to15 years) were considerably higher for Indigenous at 8.2 per 100,000 population, compared to the non-Indigenous at 1.8 per 100,000 population. However due to high number of notifications (63%) with incomplete Indigenous status, these rates should be interpreted with caution.

There are many social reasons which may have contributed to low reporting of Indigenous status in 2009. Some of the most common include the willingness of individuals to provide the information, perception that the information is irrelevant to health, fear of discrimination and the perception of being racist by asking the question. Inconsistency in how the question was asked may have also played a role. Under half of all jurisdictions in Australia currently ask Indigenous status as it is recommended in the Australian National standards (AIHW 2009).

Given the low completion rate of Indigenous status in 2009, the rates presented in the report will have underestimated the vaccination coverage in both the Indigenous and non-Indigenous female populations. For this reason we do not recommend using these estimates to evaluate the 2009 HPV vaccination programs.

Resources for task

Websites that will help you with your tasks

- NHVPR - www.hpvregister.org.au/
- GP registration to NHVPR- www.hpvregister.org.au/health-professionals/how-to-notify-hpv-doses
- HPV School Vaccination Program- hpv.health.gov.au/the-program/#.U1cacW-i1cY
Reference list


Appendix 6.2a Teaching MAE - Session Outline

Proposal of training for first year MAE students

Selection and Measurement bias

As part of the MAE program, scholars are asked to conduct teaching session. For the MAE cohort of 2013 this teaching session is to be presented to the 2014 cohort. This training session will be conducted over half a day and has been divided into 4 sections. The training plan below outlines the aims, objectives and teaching outline for the “selection and measurement bias” portion of the training session. The training will be conducted in March of 2014 and this section will run for approximately 40 mins.

Background

Developing and conducting epidemiological studies often requires a substantial amount of forethought and planning. One of the major aspects that need to be considered in any epidemiological study is the issue of bias. In order to produce results and reports that are as scientifically accurate as possible, bias needs to be identified, its effect on study outcomes recognized and strategies developed to minimise its impact. In this teaching session we will cover the concepts of selection and measurement bias.

Proposed teaching plan

Aim

To define selection and measurement bias and identify issues with these biases associated with epidemiological study design and analysis, using practical examples.

Learning objectives

By the end of this session participants should be able to:

- Describe selection and measurement bias;
- Identify potential bias in practical situations;
- Describe how bias can affect measures of association; and
- Identify strategies to minimise bias in study design.
Teaching outline

Section 1: Introduction (5 mins)

- Describe what selection and measurement bias are and how they differ; and
- Identify selection and measurement bias in epidemiological studies.

Section 1: Exercise (15 mins)

Using a case study participants will be asked identify potential sources of bias including one source each of selection and measurement bias (10 mins). Class discussion will go through the sources of bias identified by individuals (5 mins).

Section 2: Effects and minimisation (5 mins)

- Describe how selection and measurement bias affect measures of association; and
- Outline the types of strategies commonly used to minimise bias.

Section 2: Exercise (15 mins)

Participants will be divided into groups and given a selection or measurement bias identified in section one. Participants will be asked to identify the effects of the bias allocated to the group and asked to identify potential minimisation strategies. Class discussion will go through what the groups identified as potential effects and minimisations strategies (10 mins for individual group discussion and 5 mins for class discussion).

Conclusion- (2 Mins)

- Review of major concepts;
- Outline of session’s learning objectives; and
- Questions.

Case study

The General Practice Sentinel Surveillance (GPSS) system will be used as the case study. This surveillance system is used to monitor the epidemiology of laboratory confirmed influenza in Victoria by describing the onset, duration and relative severity of annual influenza seasons, and providing samples to laboratories for the characterisation of circulating viruses in Victoria.
Selection Bias

What is Bias?

Bias is....

• Systematic
• Incorrect measurement
• Incorrect selection
• Errors in analytical epidemiology
• Errors in interpretation
• Results in inaccurate measures of frequency or association

Types of Bias in Epidemiology

• Measurement bias
  – Systematic error in variables under study

• Selection bias
  – Systematic differences between those included & not included in a study

Framework for Identifying Selection Bias

GPSS Participating Sites 2012
Case Study Summary

- GPs volunteer in exchange for clinical audit points
- Patients must attend GP
- ILI patients; fever, cough and malaise/fatigue
- ILI patients swabbed at GP discretion
- Swab influenza positive = case
- Swab influenza negative = control

Framework for Identifying Selection Bias

Reference Population: People in Victoria
Source Population: People attending participating general practitioners during the influenza season
Study Population: People who present with influenza-like illness within four days of symptom onset
Subjects: People who provide;
- A nasal or throat swab
- Onset date
- Vaccination status

Case Study

Exercise 1

- Identify potential sources of selection bias (15 mins)

Selection Bias – Internal Validity

Effect
- Biases estimate if participation depends on
  - Risk factors
  - Exposure and outcome

Minimisation strategies
- Accurate inclusion and exclusion criteria
- Selection of controls
- Statistical techniques
- Collect data about non-respondents
- Disclose especially where you can’t control!

Case Study

Selection Bias – External Validity

Effects
- Reduces ability to apply results to the reference population
- Effect modification by selection and participation factors

Minimisation strategies
- Clearly define selection and eligibility criteria
- Oversample if required
- Think it through
- Disclose especially where you can’t control!

Exercise 2

- Discuss amongst your group the effects of this bias and how you could minimise it (10 mins)
- Report back to the class
<table>
<thead>
<tr>
<th>Take Home Messages</th>
<th>Resources to Help</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Define your populations before you start</td>
<td>• Bias in Occupational Epidemiology Studies – Pearce N, Checkoway H &amp; Kriebel D; 2006, in Occupational Environmental Medicine, vol. 64</td>
</tr>
<tr>
<td>• Think about</td>
<td>• Field Epidemiology – Gregg M</td>
</tr>
<tr>
<td>– Who could be missing</td>
<td></td>
</tr>
<tr>
<td>• Plan for bias in your study design!</td>
<td></td>
</tr>
<tr>
<td>• Can be tricky, if unsure ask, ask, ask!</td>
<td></td>
</tr>
<tr>
<td>• Always disclose identified bias</td>
<td></td>
</tr>
</tbody>
</table>
Measurement and Selection Bias Case Study

Calculations of Influenza Incidence using

Victorian

General Practice Sentinel Surveillance

(GPSS)

Instructors’ Guide

Note: This case study is based on a real-life sentinel surveillance system in Victoria, Australia. However, aspects of the case study have been fabricated to assist in meeting the desired teaching objectives and place the events in an engaging and practical context for participants.

The authors of this case study would like to acknowledge staff at the Victorian Infectious Diseases Reference Laboratory (VIDRL) who co-ordinate the GPSS system and provided advice on this case study, especially Kristina Grant, James Fielding, Kylie Carville and Heath Kelly.
Learning Objectives

After completing this study the participant should be able to:

1. Define selection bias;
2. Identify selection bias in a practical situation;
3. Describe how bias can affect measures of association; and
4. Identify strategies to minimise selection bias in study design

Developed by Courtney Lane and Anna Glynn-Robertson, February 2014 National Centre for Epidemiology & Population Health (NCEPH), Australian National University
Background

*Instructor's note:* Students to read the background section as a group. Slide with the framework is to be up on the PowerPoint during this time. Students will have been told to keep this framework in mind when thinking about the following information.

You have recently arrived back in Melbourne from your first MAE course block. In your absence your supervisor has identified the perfect project for you. She’d like you to calculate the incidence of laboratory confirmed influenza in Victoria during 2013.

Your supervisor tells you that in Victoria, the General Practice Sentinel Surveillance (GPSS) system is used to monitor the epidemiology of laboratory confirmed influenza, identify the onset, duration and relative severity of annual influenza seasons and provide samples for characterisation of strains circulating in Victoria. (3) Your supervisor thinks you should be able to use the data collected by the GPSS in your study.

However, you’ve been to course block and you know that before you jump into your analysis you should think about your study design and try to identify the potential sources of selection bias in your data.

You decide that first thing you’re going to do is take a closer a look at how the GPSS system works, how people are selected into the study and who are likely to be your study participants!

**General Practitioner Recruitment**

General practitioners (GPs) are recruited to participate through advertisement in GP circulars and targeted recruitment in underrepresented areas. (1) In return for participation GPs receive continual professional development points from the Royal Australian College of General Practitioners and the Australian College of Rural and Remote Medicine. (2)

*Instructor's note:* Pause to put up map of the general practices.

**Influenza Like Illness Surveillance**

Throughout each influenza season participating GPs are asked to report the total number of patients they see each week and the number of these that presented with influenza like illness (ILI). (4) To be included as a case of ILI, a patient must meet the case definition of fever (reported or observed), cough and fatigue/malaise.

*Instructor's note:* Pause to put up syndrome pyramid.
ILI Patient Swabbing

GPs are asked to obtain a throat or nasal swab from an unspecified number of patients presenting with ILI. These swabs are tested in the laboratory for the presence of influenza and other respiratory viruses.

Selection of patients to swab is at the discretion of the GP. However, it is advised only for those presenting within four days of symptom onset, as the longer the delay between the onset of symptoms and swabbing, the less likely it is influenza virus will be recovered from the provided sample.

The GP also provides information on the swabbed patient’s age, sex, symptoms and onset date, influenza vaccination status, date of vaccination, presence of comorbidities which predispose to severe influenza illness and, since 2011, the receipt of seasonal influenza vaccination in the previous year.\(^{(5)}\)

With this information in hand, you identify your populations;

_Instructor's note: Once students have read this section – get them to identify populations in the diagram below then show our answers on the PowerPoint._

Reference Population:
People in Victoria

Source Population:
People who attend a medical consultation at a general practice participating in the GPPSS system

Study Population:
People who present with influenza like illness within four days of symptom onset during the flu season and have swab taken at the GPs discretion

Study Subjects:
Study population who provide onset data and receive influenza positive laboratory result
Exercise One: Identifying Potential Sources of Bias

Using the diagram and information provided above, what potential sources of selection bias can you identify in your study?

**Selection bias:**

- The sampling frame may not be representative of the full spectrum of clinical disease due to influenza like illness (ILI) as those with severe or very mild disease are unlikely to present to general practitioners.

- Selection of who is swabbed (and thus included in the study) is decided by the GP and is not systematic.

- Selection of GP practices: GPs volunteer to participate, not geographically representative or randomly selected (size, patient compositions are all likely to vary).

Present your findings to the class.

You're shocked at the number of selection biases you've identified, you're not sure if you should continue. Is this really the project for you? You present your list to your supervisor. She is aghast. While impressed with your thoroughness and thoughtfulness, she had no idea there were so many potential sources of bias in your study!

Your supervisor wants to know what the effects of the biases you identified might be and how you might minimise them in your analysis. She tells you that a very large sum of money has just become available to strengthen the GPSS system. She asks you if there are any changes that could be made to the design of the system in order to more accurately estimate the incidence of laboratory confirmed influenza in Victoria?

Exercise Two: Bias Effects and Minimisation

What are the likely effects of these biases on your incidence estimate and how are you going to minimise these in your analysis? Are there any changes you could make to system design in order to help address these biases?

In your groups you will be allocated an identified selection bias. Describe what you think the effects on your estimates are likely to be and what could be done to minimise these effects in both the design or analysis phases.
The sampling frame may not be representative of the full spectrum of clinical disease due to influenza like illness (ILI) as those with severe or very mild disease are unlikely to present to general practitioners.

- **Effects:** Limit the generalisability of the results to all manifestations of influenza illness.

  - **NB:** Disease severity, likelihood of presentation to GP may also vary by additional factors such as age and gender, which may further alter the effects of this bias. Working age adults likely to be overrepresented in the system – need to obtain GP certificates.

- **Minimisation:** In an ideal world, extend the sampling frame to include severe cases by including cases presenting to hospitals and mild cases who wouldn’t present for health care (ie. Sampling non-ILI cases but this would require a complete redesign of the system). More realistically, collecting some measure of disease severity so it can be controlled for in analysis.

- **Selection of who is swabbed (and thus included in the study) is decided by the GP and is not systematic.**

  - **Effects:** As above – may limit generalisability if certain age groups and/or disease severities are more likely to be swabbed. May also bias estimates if these factors are also related to vaccination status (which age, disease severity and presence of comorbidity may be).

  - **Minimisation:** Institute systematic selection of presenting ILI patients to be swabbed (random or exhaustive). Collection of covariates for comparison to presenting ILI patients that are not swabbed to ascertain extent of potential selection biases.

- **Selection of GP practices: GPs volunteer to participate, not geographically representative or randomly selected (size, patient compositions are all likely to vary).**

  - **Effects** – As above, may limit generalisability if patient characteristics change. If not geographically representative and distribution of influenza strains varies geographically may over or under represent VE for all of Victoria.

  - **Minimisation:** Can be minimised by design. Stratifying by type of GP (say geographical area, size of clinic) may help identify effects of non-representative sample.

Present your findings to the class.

Your supervisor decides that while these selection bias minimisation steps are vitally important, any major study design changes certainly won’t be implemented before the end of your MAE. You are going to have to make do with the data you have. How you know this will be okay because you’ve thought about bias early, identified potential sources, minimised what you can and acknowledged the likely effect of those you can’t.
Further Reading:

For further reading on GPSS and influenza surveillance in Australia consult the following publications (MAE graduates in bold):


References:


**Instructor’s notes for potential additional questions;**

VE\% = (1 - Odds Ratio) x 100. Where the odds ratio is the odds of patients with laboratory confirmed influenza having been vaccinated divided by the odds of patients without laboratory confirmed influenza being vaccinated.

Laboratory testing is conducted via respiratory multiplex PCR panel. Cases positive for influenza c are excluded.
Appendix 6.2d Teaching MAE - Evaluation Forms  
Master of Philosophy (applied epidemiology) Scholars 2013 Cohort

Please take a few moments to answer the following questions about each of the teaching sessions conducted by the MAE scholars on 7 March 2014. There are 4 evaluations tables and an overall training feedback page. Please ensure you fill in each table and the overall training evaluation. Once you have finished please place the form in the box provided.

Session 1: Selection and Measurement Bias

*Please insert emoticon into the appropriate box: for example 😊 😊😊😊😊

<table>
<thead>
<tr>
<th>Session</th>
<th>Hells yeah</th>
<th>Sweet</th>
<th>Can’t say could go either way</th>
<th>Twas not so good</th>
<th>I don’t speak Dutch</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information well presented</td>
<td>6</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meet sessions objectives</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speed was appropriate</td>
<td>3</td>
<td>4</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Materials/Handouts were useful</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Power-point slides were useful</td>
<td>5</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case study useful</td>
<td>6</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Presenters</th>
<th>Hells yeah</th>
<th>Sweet</th>
<th>Can’t say could go either way</th>
<th>Twas not so good</th>
<th>I don’t speak Dutch</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explained points clearly</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Made the session interesting</td>
<td>5</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Answered questions well</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledgeable in content areas</td>
<td>5</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Presented well</td>
<td>6</td>
<td>3</td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall rating</th>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall rating for the session</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Do you have any further comments regarding this session?

- Great case study.
Appendix 6.3 Rotavirus working group paper

Data analysis of current rotavirus notifications held within the NNDSS

This paper provides an overview of rotavirus notifications within the National Notifiable Disease Surveillance System (NNDSS) as of 25th July 2014. Data presented are from five jurisdictions; New South Wales (NSW), Queensland (QLD), South Australia (SA), Tasmania (TAS) and Western Australia (WA). Rotavirus notifications are collected in the Northern Territory (NT) but were not available at the time of analysis. Victoria (VIC) and the Australian Capital Territory (ACT) do not collect rotavirus notifications as the disease is not notifiable in their respective states.

This data analysis has been prepared for the Rotavirus Working Group.

Rotavirus data in the NNDSS

Table one provides the year in which the NNDSS received rotavirus notifications from each reporting jurisdiction. QLD and WA have provided notifications since 2006, with the first notifications received from January for QLD and August for WA. Notifications for SA were received from May 2008, for TAS from February 2009 and NSW from April 2010.

<table>
<thead>
<tr>
<th></th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSW</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NT</td>
<td></td>
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<tr>
<td>QLD</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>SA</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>TAS</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>VIC</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>WA</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Notes:
1. Rotavirus is not notifiable in the ACT or VIC. Current as of 25 July 2014.
2. Rotavirus is notifiable in the NT, but no data had been transmitted to the NNDSS as at 25 July 2104.

Completion of key rotavirus variables in the NNDSS

Table two displays the completeness (valid code provided in the field) of three key variables in rotavirus notifications by reporting jurisdiction. Serogroup was the most incomplete variable in all jurisdictions. The completion of the vaccination status and Indigenous status differed by jurisdiction, with NSW having the lowest completion rates for both variables.
Table 2: Completion of key rotavirus variables in notifications, by jurisdiction, Australia, 2006 to 30 June 2014

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Indigenous status (%)</th>
<th>Serogroup (%)</th>
<th>Vaccination status (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>21.9</td>
<td>0.1</td>
<td>31.9</td>
</tr>
<tr>
<td>QLD</td>
<td>100</td>
<td>0.0</td>
<td>100</td>
</tr>
<tr>
<td>SA</td>
<td>100</td>
<td>0.0</td>
<td>67.5</td>
</tr>
<tr>
<td>TAS</td>
<td>99.6</td>
<td>0.0</td>
<td>83.9</td>
</tr>
<tr>
<td>WA</td>
<td>85.2</td>
<td>11.9</td>
<td>89.6</td>
</tr>
</tbody>
</table>

Note: *Vaccination status includes fully vaccinated, partially vaccinated, not vaccinated for the disease, no vaccine given, not applicable, unknown and not recorded.

Epidemiological analysis

2010 was the first year in which all five jurisdictions (NSW, QLD, SA, TAS & WA) provided notified case of rotavirus to the NNDSS. Between the years 2010 and 2012, rotavirus notification numbers ranged from 3,170 in 2011 to 3,773 in 2012. In 2013 the numbers of rotavirus notifications dropped to 2,914. As of 25 July 2014, there have been 1,217 notified cases of rotavirus from the 5 reporting jurisdictions.

Rotavirus notifications from 2010 to 2013 display a seasonal trend, with most cases notified during the winter and spring months. On average, notification numbers increased from July and peaked between August and November (Figure 1). Across all the reporting jurisdictions, this trend was consistent with small variations occurring in 2010 for QLD and 2013 for SA where notifications peaked later in the year.
Figure 1: Epidemiological curve of rotavirus notifications, by jurisdiction, diagnosis year and month, Australia, 2006 to 30 June 2014

Table 3 provides the counts and notification rates of rotavirus for each reporting jurisdiction. Over the period of 2006-2013 the highest notifications rates for QLD were in 2006, WA in 2007, SA and TAS in 2010 and NSW in 2012.

Table 3: Counts and rates per 100,000 of rotavirus notifications, by jurisdiction, Australia 2006 to 30 June 2014

<table>
<thead>
<tr>
<th>Year</th>
<th>NSW n</th>
<th>rate per 100,000</th>
<th>QLD n</th>
<th>rate per 100,000</th>
<th>SA n</th>
<th>rate per 100,000</th>
<th>TAS n</th>
<th>rate per 100,000</th>
<th>WA n</th>
<th>rate per 100,000</th>
<th>Australia n</th>
<th>rate per 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>0</td>
<td>0.0</td>
<td>2509</td>
<td>61.3</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>236</td>
<td>11.5</td>
<td>2745</td>
<td>44.6</td>
</tr>
<tr>
<td>2007</td>
<td>1</td>
<td>0.0</td>
<td>1190</td>
<td>28.4</td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>738</td>
<td>34.9</td>
<td>1929</td>
<td>30.6</td>
</tr>
<tr>
<td>2008</td>
<td>1</td>
<td>0.0</td>
<td>1078</td>
<td>25.0</td>
<td>134</td>
<td>8.4</td>
<td>0</td>
<td>0.0</td>
<td>427</td>
<td>19.6</td>
<td>1640</td>
<td>20.3</td>
</tr>
<tr>
<td>2009</td>
<td>12</td>
<td>0.2</td>
<td>899</td>
<td>20.8</td>
<td>435</td>
<td>27.0</td>
<td>52</td>
<td>10.3</td>
<td>418</td>
<td>18.7</td>
<td>1816</td>
<td>11.5</td>
</tr>
<tr>
<td>2010</td>
<td>1379</td>
<td>19.3</td>
<td>815</td>
<td>18.5</td>
<td>837</td>
<td>51.4</td>
<td>121</td>
<td>23.8</td>
<td>618</td>
<td>27.0</td>
<td>3770</td>
<td>23.6</td>
</tr>
<tr>
<td>2011</td>
<td>1060</td>
<td>14.7</td>
<td>1390</td>
<td>31.0</td>
<td>455</td>
<td>27.8</td>
<td>78</td>
<td>15.2</td>
<td>187</td>
<td>7.9</td>
<td>3170</td>
<td>19.6</td>
</tr>
<tr>
<td>2012</td>
<td>1756</td>
<td>24.0</td>
<td>947</td>
<td>20.7</td>
<td>622</td>
<td>37.6</td>
<td>98</td>
<td>19.1</td>
<td>350</td>
<td>14.4</td>
<td>3773</td>
<td>22.9</td>
</tr>
<tr>
<td>2013</td>
<td>492</td>
<td>6.6</td>
<td>1171</td>
<td>25.2</td>
<td>798</td>
<td>47.8</td>
<td>107</td>
<td>20.9</td>
<td>346</td>
<td>13.7</td>
<td>2914</td>
<td>17.4</td>
</tr>
<tr>
<td>2014</td>
<td>202</td>
<td>2.7</td>
<td>376</td>
<td>8.0</td>
<td>423</td>
<td>25.3</td>
<td>41</td>
<td>7.9</td>
<td>175</td>
<td>6.9</td>
<td>1217</td>
<td>7.3</td>
</tr>
</tbody>
</table>

Notes:
*Australian rates calculated based on an aggregated total of reporting jurisdictions. Denominators for each year are as follows:
  a. 2006 and 2007 - total population of QLD and WA.
  b. 2008 - Total population of QLD, SA and WA.
  c. 2009-2014 - total population of NSW, QLD, SA, TAS and WA.
From 2006 to 30 June 2014, notification rates were higher in children less the 1 year of age and 1 to 4 years of age compared with all other age groups. Rates for the less than 1 year age group rose from 202 per 100,000 population in 2009 to 334 per 100,000 population in 2011, before steadily declining from 2012. Notification rates for children 1 to 4 years of age declined from 175 per 100,000 population in 2006 to 96 per 100,000 in 2009. The rates then increased in 2010 to 183 per 100,000 population before steadily declining to 99 per 100,000 population in 2013.

Figure 2: Crude rate of rotavirus notifications per 100,000 population, by age and year of diagnosis, Australia, 2006 to 30 June 2014

Notes:
1. 2006 and 2007 - includes notifications from QLD and WA.
2. 2008 – includes notifications from QLD, SA and WA.
3. 2009-2013- includes notifications from NSW, QLD, SA, TAS and WA.
Appendix 6.4 Presentation slides for the Bangladesh delegation

National Communicable Disease Surveillance

The National Notifiable Diseases Surveillance System (NNDSS)

Anna Glynn-Robinson
Masters of Philosophy in Applied Epidemiology (MAE) Scholar
Vaccine Preventable Diseases Surveillance Section
Office of Health Protection
Department of Health

Outline

- Australia’s health system
- Regulations
- Why we conduct national surveillance
- Communicable Disease Surveillance System (NNDSS)
- Vaccine Preventable Diseases Surveillance
- Masters of Applied Epidemiology placement

Public health

- States and Territories
  - public health response and actions
  - all have public health legislation
- Australian Government
  - monitor issues of public health concern
  - coordination of the public health response
  - compliance with international regulations and responsibilities.

Legislation

- Quarantine Act 1908
- International Health Regulations 2005
- National Health Security Act 2007
- National Health Security Agreement 2008

The Public Health Framework

- Prevention
  - legislation
  - infection control, immunisation program,
  - public communication
  - surveillance systems
- Preparedness
  - plans
  - surveillance systems
  - stockpiles
  - legislation
  - exercises and training
- Response
  - activation
- Recovery
  - returning to normal operations
  - surveillance systems

Communicable Disease Response

Events of Public Health Significance
What are we looking for?

- Early alert of emerging issues
- New diseases
- Changes in current diseases
  - Incidence
  - Variations on normal background disease levels
  - Rare disease alerts
- Severity
- Demographics
- Circulating strains
- Sensitivity/resistance

Surveillance systems

- Routine passive surveillance systems - indicator based surveillance
  - National Notifiable Disease Surveillance System (NNDSS)
  - Hospital data from emergency presentations
  - GP sentinel data collection (ASPREN)
  - Enhanced surveillance
  - Register data
- Routine active surveillance systems
  - Paediatric hospital admissions for rare diseases or severe complications
  - Sentinel hospital admissions for influenza - FluCAN
- Laboratory surveillance
  - Active, passive & sentinel
- Rumour surveillance
- Outbreak management system - NetEpi

The NNDSS

- 69 diseases on National Notifiable Disease List (NNDL)
- 41 core fields (5 mandatory)
- Enhanced data eg. country of birth, residency status, site of infection, risk factors
- NNDSS data available on web
- Fortnightly to CDNA
- Annual NNDSS reports published in CDI
- Data provided to other users

Notifiable Diseases

- Bacterial – Legionellosis, TB
- STI’s & BBV– Chlamydia, Hepatitis C
- Traditional VPDs- Measles, Pertussis, Influenza
- Gastrointestinal Diseases- Campylobacter, Listeria
- Quarantinable – Plague, Rabies
- Vector-borne- Chikungunya, Dengue
- Zoonoses- Q-fever, Australian Bat Lyssavirus

Detecting events: person, place and time

<table>
<thead>
<tr>
<th>Confirmation status</th>
<th>Age</th>
<th>Sex</th>
<th>Indigenous status</th>
<th>Residential postcode</th>
<th>Place of acquisition</th>
<th>Organism details, genotype</th>
<th>Vaccination status</th>
<th>Vaccine type</th>
<th>Date(s) of vaccination(s)</th>
</tr>
</thead>
</table>

National Health Security Agreement 2008

6-36
What’s the data used for?
- International obligations
- Government Communications – media, briefings
- Initiate public health response
  - outbreak investigation
  - media alert
- Inform public health response
  - who, what, where, when
- Inform policy
  - vaccine schedules, strains, recipients
- Inform research
  - new vaccines
- Informing Government & Public
  - National health status reporting

National Surveillance functions
- Data Collection
  - who: Data managers
  - with: S&T, National Surveillance Committee, Case Definition Working Group
- Data Cleaning
  - who: Data managers & epidemiologists
  - with: S&T data managers and surveillance managers
- Data analysis
  - who: Epidemiologists
  - with: S&T surveillance managers, researcher groups
- Data Interpretation
  - who: epidemiologists
  - with: policy groups, research groups

National Surveillance functions (cont.)
- Reporting
  - who: epidemiologists
  - with: policy groups, research groups, expert groups
  - NNDS Annual Report
  - Annual reports: Influenza, TB, IPD, STI/BBV (Kirby Institute)
- Data sharing
  - who: data managers, epidemiologists
  - with: Research centres (Kirby Institute, NCIRS), researchers, students, vaccine companies, other Departments (AIHW), public
  - Australia’s youth, Australia’s Health, NHA Indicators

Vaccine Preventable Diseases Surveillance (VPDS)

Influenza
- Seasonal
- Pandemic
- Asian

Bacterial
- Antimicrobial Resistance
- IPD
- Legionellosis
- Leprosy
- Tuberculosis

Traditional VPDs
- Diphtheria
- HBI
- Measles
- Mumps
- Pertussis
- Polio
- Pertussis
- Rubella
- Congenital Rubella
- Tetanus
- Varicella

STIs and BBVs
- Post implementation – HPV national vaccination program (2007)
- National BBV and STI Strategies (2014-17)
- Antimicrobial resistance in gonococcal infections.

Influenza
- Monitored year round
- Activity and severity monitored through variety of surveillance systems

Tuberculosis
- Monitor active TB cases
- Identify at risk populations to prioritize interventions
- Lateral TB infection screening

VPDS (Cont.)

STIs & BBVs
- Post implementation – HPV national vaccination program (2007)
- National BBV and STI Strategies (2014-17)
- Antimicrobial resistance in gonococcal infections.

Influenza
- Monitored year round
- Activity and severity monitored through variety of surveillance systems

Tuberculosis
- Monitor active TB cases
- Identify at risk populations to prioritize interventions
- Lateral TB infection screening

Measles
- Measles elimination achieved by Australia
- All new cases are imported or related to an imported case

Poliomyelitis
- Assessment of risk transmission should an importation occur
- Review all polio-related import permits
- New DHPP policy requiring most visa applicants to provide proof of vaccination from deemed to have active polio transmission
  - Pakistan, Cambodia, Syria, Afghanistan, Equatorial Guinea, Ethiopia, Iraq, Israel, Somalia and Nigeria
My MAE Experience

Anna Glynn-Robinson
Masters of Philosophy in Applied Epidemiology (MAE) Scholar
Placement: Australian Department of Health

MAE Placement
- Vaccine Preventable Diseases Surveillance
- 2 year placement (2013 to 2014)
- 4 major projects
  - Notified Legionellosis in Australia, 2001 to 2012
  - Evaluation of the NNDSS for influenza surveillance
  - Gastroenteritis outbreak in the ACT
  - Indigenous status in the HPV vaccine register

MAE Placement (cont.)
- Annual reports- Legionellosis 2012 and 2013
- Pilot investigating influenza laboratory testing data
- Rumour surveillance for H7N9
- International report for CDNA
- CDI paper for gastroenteritis investigation
- Secretariat for Rotavirus working group
- Teaching – MAE and surge capacity
- Watch Officer

Lesson from the MAE
- Concepts of national surveillance
- Using national data
- Stata coding
- Planning effectively
- Engaging with a range of stakeholders
- Writing for a range of audience

List of resources
- CDNA fortnightly reports
- NNDSS Annual Reports:
- CDI Annual reports :
- Australian Influenza Surveillance Report:
- Kirby Institute publications:
  http://kirby.unsw.edu.au/publications

Thank you