Communicable Diseases Epidemiology

A thesis submitted for the Degree of

Master of Philosophy in Applied Epidemiology

of the Australian National University

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September 2019

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Communicable Disease Branch
Health Protection NSW

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Funded by
Australian National University
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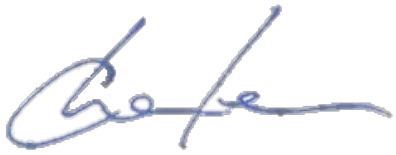
Statement of Originality

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



Charlee J. Law

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Dedication

This is for Uncle Owen “Ray”, thank you for getting me here.

And for my wild and beautiful son, Henry Owen Kato.

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Acknowledgements

Acknowledgement of Country

Today we stand in footsteps millennia old.

May we acknowledge the Traditional Owners

whose cultures and customs have nurtured,

and continue to nurture, this land,

since men and women

awoke from the great dream.

We honour the presence of these ancestors

who reside in the imagination of this land

and whose irrepressible spirituality

flows through all creation.

Presented with the kind permission of Jonathan Hill, Filipino-Australian poet.

Personal acknowledgements

I could not have finished the Master of Applied Epidemiology program (MAE) without support and participation from communities, public health units, the National Centre of Epidemiology and Public Health, colleagues in the Communicable Diseases Branch, and my MAE cohort. For academic support, I gratefully acknowledge my academic supervisor, Dr Tambri Housen. Tambri was an excellent mentor and took the time to understand me in a way that she could identify my strengths and areas where I could build capacity. The result of this mentorship was a meaningful experience in the MAE. If I ever supervise someone in the future, I truly hope to emulate these qualities.

I sincerely thank Dr Vicky Sheppeard, who guided me through my time at the Communicable Diseases Branch. Vicky placed me in roles and responsibilities that I would always initially worry were out of my depth, and then realise that I was in fact quite capable of managing the task. Because of this, I will leave the MAE knowing there has been a subtle but paradigm shift around how I perceive my capabilities. I am most grateful for the support and wisdom of Dr Kirsty Hope, who carefully reviewed all of my work and helped me make major changes and condense my long chapters. No time was inconvenient, she always was happy to read over my chapters and provide sound advice. It is an understatement how much I appreciate Kirsty for her intelligence, sincerity, and mentorship. I also thank Keira Glasgow for her role in my professional development. I admired her audacity and disposition to bang on the door about public health issues close to us both.

I acknowledge the support, perspectives and involvement of the Aboriginal community-based organisations that were involved in the Q fever investigation. I extend my heartfelt thanks to the Aboriginal Health and Medical Research Council of New South Wales (NSW), and for the representation we received from Walgett and Brewarrina Aboriginal Medical Services. In particular, I thank members of the Aboriginal Research Advisory Group: Bianca Cochrane-Owers, Carl Mason, Cheryl Wasley, Jess Spencer, Ray Lovett and Ray Robinson. I also thank Christine Corby for facilitating this participation and Katrina Ward for her feedback. Special thanks to those who worked closely with me on other projects, including Mark Ferson, Su Reid, Rhydwyn McGuire and the rest of the Australian Immunisation Register Working Group; as well as Melanie Middleton, Ellen Donnan and the NSW Rheumatic Heart Disease Network.

Finally, thank you so much Harry, for your love and support; the balance you helped maintain in our home, weighted against the ebb and flow of my projects.

Abstract

In March 2017 I commenced the Master of Applied Epidemiology program, hosted in the Communicable Diseases Branch at Health Protection New South Wales (NSW). Presented in this bound volume are four research projects: an epidemiological study, data analysis study, outbreak response, and an evaluation of a public health surveillance system. I was also heavily involved in routine public health work including on-call, outbreak investigations and follow-up of laboratory notifications.

The epidemiological study was an audit that estimated true immunisation coverage of NSW children at one year of age on the Australian Immunisation Register (AIR), and explored reasons associated with under-reporting. Our estimate of true coverage was 96.2% with a 95% Confidence Interval 95.9%-96.4%; 2.1% higher than AIR reported coverage of 94.1%. The under-reporting was mainly due to data errors at the provider level and duplicate records. Included is a peer-reviewed article that I wrote and published on the subject in the Australian and New Zealand Journal of Public Health.

The data analysis project investigated the over-representation of Aboriginal people diagnosed with Q fever in NSW, particularly in Western NSW. Following indirect standardisation, we found that Aboriginal people across Western NSW were notified with Q fever almost 35% more often as non-Indigenous people living in the same area. Aboriginal people reported working in occupations such as shearing at a much younger age than non-Indigenous people. Aboriginal community governance over the public health actions that arose from this analysis is provided in detail.

I evaluated the NSW Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD) Surveillance System, including the RHD Register. Using open ended and closed question surveys, network consultation and analysis of data, the system was found to be useful in improving the management of ARF/RHD. Recommendations for improving attributes were made based on the *Updated Guidelines for Evaluating Public Health Surveillance Systems* by the United States Centers for Disease Control and Prevention.

I led an investigation into a large protracted outbreak of *Salmonella* Typhimurium with a novel multi-locus variable number tandem repeat analysis type profile that affected 235 people in the Australian Capital Territory, NSW and Queensland from 10 October 2018 to 31 May 2019. The chapter describes the outbreak investigation including epidemiological, environmental and laboratory components, and control actions taken.

I had the opportunity to teach and present my research during the MAE and through concurrent employment as an academic tutor. I delivered presentations at local, state, national and international conferences throughout the placement, and produced a Lesson from the Field competency with the Gamilaraay title ‘nginda MAE waala wiitha’ (throwing the MAE into the fire); an acknowledgement of the feeling many peers felt undertaking data linkage projects with inconsistent or missing data. I saw an opportunity to start a conversation about reasons why Aboriginal and Torres Strait Islander identity data may be missing in datasets, which prompted the group to explore why an individual may identify in one place and not another.

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Acronyms

ACT	Australian
AIR	Australian Immunisation Register
ANZJPH	Australian and New Zealand Journal of Public Health
ARF	Acute Rheumatic Fever
CDB	Communicable Diseases Branch
CDNA	Communicable Diseases Network Australia
CI	Confidence Interval
LHD	Local Health Districts
MAE	Master of Philosophy in Applied Epidemiology
NSW	New South Wales
RHD	Rheumatic Heart Disease
TEPHINET	Training Programs in Epidemiology and Public Health Interventions Network
QLD	Queensland
WGS	Whole Genome Sequencing

Main prologue

Being alive is marvellous isn't it.

Sure, it's not the easiest ride. For starters, living comes with more fine print than anything else in the universe. From the moment you are born, you are expected to navigate your fleshy shell throughout space and time, all the while ensuring that fourteen body systems (that you know absolutely nothing about) are working in perfect harmony. Then you have to grow, and as you do, so will your responsibilities, until one day you are doing it all on your own. That's the rules. The rest of the fine print is about how you have to master this without thinking about it, as well as a bunch of other things I'll never understand, like how to do a tax return by myself or perfectly boil an egg. In summary, just being alive is very busy, even when we think we are doing nothing. Life is so consuming that unless in certain circumstances, one does not have much time to focus on being dead.

But let me ask you, just how many times have you cheated death?

I'm not talking about the time you choked on broccoli at a family gathering, or when some idiot on their mobile phone nearly crashed into your car. I'm talking about those bona fide moments where you brushed the fingertips of debilitating illness or death, by avoiding measles, meningococcal disease or diphtheria. You were meant to die when you were two, but your vaccinations repelled pertussis. This momentum has kept up your entire life, as you ducked away from tetanus, heated the life out of your contaminated food, or made influenza's song quieter. Right now, you are probably so busy going about your day that you, a giant Goliath, have completely forgotten that the world and its billions of microscopic David's are completely out to get you.

So how is it, that you and I haven't died already?

The short answer is that we've got a lot of people behind us. Hundreds upon thousands of people, all with the common goal of not dying, developed the vaccines and medicines you took, educated the health professionals you needed, or improved the safety of your food.

But don't get too comfortable, because things can slip through the cracks. People still get sick and die from preventable diseases. At times entire groups of people become unwell from a common source. And unfortunately, there are diseases lingering out there that should have been eliminated already. This bound volume is a collection of stories about some of those diseases, and the people who responded them. Along the way you will witness me do my best to play the roles I was given, as a leader, follower, student, and now scribe. I will highlight both success and failure from these past two years and hope this adds another (albeit small) lantern along that well-worn path to the knowledge base of communicable diseases control.

Chapter 1

Introduction

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Introduction

This chapter is an overview of my placement at Health Protection NSW, including the routine activities and project work undertaken to complete MAE requirements.

Overview of the Experience in Health Protection NSW

On 20 March 2017, I commenced a placement at the Communicable Diseases Branch (CDB) at Health Protection NSW. Health Protection NSW sits under the Population and Public Health Division of the NSW Ministry of Health, the central driver of the NSW public health system. A key function of the Ministry is to support the NSW Health Cluster which encompasses 230 public hospitals across fifteen Local Health Districts (LHDs). (1) The overarching legislative framework for public health and infectious diseases is the *Public Health Act 2010* and *Public Health Regulation 2012*. (2, 3)

Health Protection NSW are responsible for monitoring and coordinating the public health responses to notifiable infectious diseases and environmental threats. The CDB has six areas: Tuberculosis and Rheumatic Heart Disease, Respiratory and Vaccine Preventable Diseases, Surveillance Systems, Blood-borne Viruses and Sexually Transmitted Infections, Immunisation, and Enteric and Zoonoses. (1) The Director, Dr Vicky Sheppeard was also my MAE supervisor. My other supervisor was Dr Kirsty Hope in the Enteric and Zoonotic Diseases Team. I was involved in all daily aspects of the Enteric and Zoonotic Diseases Team. This included attending meetings, report writing and involvement in the response to notifiable communicable diseases of enteric or zoonotic nature.

Other projects and tasks undertaken during my placement were as follows:

- On-call for Enteric and Zoonotic Diseases
- Weekly surveillance and reporting on *Cryptosporidium* during Summer and Autumn 2017
- Preparation of a joint report between NSW Health and the NSW Food Authority on *Salmonella* surveillance
- Preparation of information for quarterly OzFoodNet reports
- Attended CDNA fortnightly meetings and prepared the CDNA jurisdictional status report for NSW every fortnight
- Attended weekly Communicable Diseases Branch surveillance meetings
- Attended monthly Bug Breakfast presentations and coordinated the monthly Epi Grand Rounds for NSW
- Public health experience for a week at South Eastern Sydney Local Health District
- Interviewing measles and *Salmonella* Typhimurium cases and contacts

<u>MAE Competencies</u>

There were coursework and research project requirements to complete the MAE. The coursework was done in blocks at ANU and included the following subjects:

1. Outbreak Investigation
2. Public Health Surveillance
3. Issues in Applied Epidemiology
4. Analysis of Public Health Data
5. Research Design and Methods

To apply theoretical knowledge gained from course work, four projects were undertaken, plus a teaching requirement (Table 1).

Projects

1. Designing and conducting an epidemiological study
2. Analysis of a public health dataset
3. Response to an acute public health problem or threat
4. Evaluation of a public health surveillance system

Teaching requirement

1. Prepare at least one and participate in “Lessons from the field”
2. Prepare and conduct a lesson for first year MAE students

Other inclusions

A core requirement was for one or more of the four projects to include:

1. Literature review
2. A report to a non-scientific audience (community or other stakeholder), as a press release, ministerial brief or lay sheet
3. Preparation of an advanced draft of a paper for publication in a national or international peer-reviewed journal
4. An abstract and oral presentation of the project at a national or international scientific conference

Table 1 Description of competencies achieved through the epidemiological study, analysis of a public health dataset, evaluation of a public health surveillance system and outbreak investigation four key projects required to complete the Degree of Master of Philosophy.

Key competency	Description of study	Literature review	Report to a non-scientific audience	Journal article	An abstract and oral presentation	Lessons from the field
Design and conduct an epidemiological study	An Audit of the Australian Immunisation Register	✓	Media release Ministerial brief	✓	Long oral 9th Southeast Asia and Western Pacific Bi-Regional Training Programs in Epidemiology and Public Health Interventions Network (TEPHINET) Scientific Conference. Vientiane, Laos. November 5-9, 2018	
Analysis of a public health dataset	Investigation into increased Q fever notifications in Aboriginal people living in Western NSW Local Health District	✓	Lay sheet for public		Short oral 16th National Immunisation Conference 2018. Adelaide, South Australia. June 5-7, 2018	Nginda MAE waala wiitha! The implications of investigating diseases with limited data
Outbreak investigation	Multi-state outbreak of Salmonella Typhimurium caused by a novel multi-locus variable number tandem repeat analysis type, 2018-19		Evidence summary for NSW Food Authority and egg producer		Rapid fire presentation Communicable Disease Control Conference 2019. Canberra, Australian Capital Territory. November 19-21, 2019.	
Evaluation of a public health surveillance system	Evaluation of the NSW Acute Rheumatic Fever and Rheumatic Heart Disease Surveillance System, including the Rheumatic Fever Register	✓				

Public Health Impact Summary

The epidemiological project "**A question of coverage or underreporting? An Audit of the Australian Immunisation Register**" had a positive public health impact, particularly from a programs perspective. We estimated that the true immunisation coverage for children at 1 year of age on the AIR was 96.2% (CI:95.9-96.4), 2.1% higher than the AIR reported coverage. While the difference may only be a couple of per cent in absolute terms, from a public health policy and program perspective the difference was significant, particularly when this determined whether state and national program indicators had been met. Underreporting at the provider level was an important contributor to underestimation of true coverage on AIR. The paper was published in the ANZJPH which may have impact on the level of data errors in AIR uploading (at provider level) and duplicate records.

The analysis of a public health dataset project "**Investigation into increased Q fever notifications in Aboriginal people living in Western NSW Local Health District**" had multiple public health impacts. As the study had a focus on Aboriginal people, it was carried out on the foundations of Aboriginal governance through community consultation in the form of an Aboriginal Advisory Group. I performed an analysis of Q fever notifications of Aboriginal and non-Aboriginal people living in Western NSW LHD with the principal objective to interpret exposure data to identify factors and other explanatory variables that may have driven the disproportionate rate of Aboriginal people diagnosed with Q fever. I established and consulted closely with an Aboriginal Research Advisory Group who identified priorities in the data and messaging channels to target for Q fever prevention and awareness campaigning.

The **"Multi-state outbreak investigation of *Salmonella* Typhimurium caused by a novel multi-locus variable number tandem repeat analysis (MLVA) type, 2018-2019"** demonstrated the power of MLVA to detect clusters and point source outbreaks, and the role of whole genome sequencing (WGS) to determine whether clusters originated from a single source. The outbreak showed that despite acceptable compliance at the industry level, *Salmonella* can still enter the food production chain. For this reason, the responsibility of *Salmonella* prevention and control lies with the entire egg production chain, from farm to plate. Many clusters in this outbreak were related to businesses using centralised kitchens, which shows that regulatory activities in storefront businesses may have little impact if the centralised food processor or distributor is not complying with food safety measures. Many cases reported eating eggs at home, indicating that public egg safety awareness should remain a public health priority.

The "**Evaluation of the NSW Acute Rheumatic Fever and Rheumatic Heart Disease Surveillance System, including the Rheumatic Fever Register"** resulted in a number of changes made to improve these systems in NSW. Methods of reporting were improved for key stakeholders, and the evaluation has drawn topics for the consideration of NSW Health to improve the monitoring and reporting of ARF/RHD in NSW.

References

1. NSW Health. Ministry of Health 2019 [cited 2019 10 Jan]. Available from: www.health.nsw.gov.au.
2. Public Health Act 2010 No 127, NSW [statute on the Internet]. (c2019).
3. Public Health Regulation 2012, NSW [statute on the Internet]. (c2019).

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Chapter 2

Epidemiological study

A question of coverage or underreporting? An audit of the Australian Immunisation Register

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Chapter 2 Table of Contents

Acronyms

ABS	Australian Bureau of Statistics
ACIR	Australian Childhood Immunisation Register
AIR	Australian Immunisation Register
ANU	Australian National University
ANZJPH	Australian and New Zealand Journal of Public Health
ARIA+	Accessibility and remoteness index of Australia
DTPa	Diphtheria-tetanus-pertussis-containing vaccine
GP	General practice
Hib	*Haemophilus influenzae* type b
HREC	Human Research Ethics Committee
IRSD	Index of relative socio-economic disadvantage
LHD	Local health district
LTFU	Lost to follow-up
MAE	Master of Philosophy in Applied Epidemiology
NIP	National Immunisation Program
NSW	New South Wales
PHU	Public health unit
SA3	Statistical areas level 3
SEIFA	Socio-economic indicators for areas
SESLHD	South Eastern Sydney Local Health District
TEPHINET	Training Programs in Epidemiology and Public Health Interventions Network

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Prologue

Sometime around October 2016, a remarkable group of people came together to talk about the Australian Immunisation Register (AIR), the national system used to assess immunisation coverage and enable the mobilisation of targeted programs and resources toward populations with low vaccination coverage. The expertise around the table included those who had previously researched underreporting on the AIR, coordinators and analysts of state-wide immunisation programs, nurses who had delivered community-based immunisation programs, and biostatistics; the kind of perspectives that can only be cultivated through years of experience. Together they became the AIR Working Group, with the aim to quantify the magnitude of under-reported immunisations on the AIR for NSW children at one year of age.

Due to a series of constraints the project was put on hiatus until May 2017, when I was given the opportunity to pick up the project with the role of lead investigator. The state-wide audit provided a positive result for NSW, estimating that true immunisation coverage was higher than expected. From a program perspective this had important implications for NSW Health. Although I was given the autonomy to manage this project, everyone in the AIR working group made a significant contribution to this research. I truly believe the findings of our study will have great utility in advocating for the mobilisation of public health resources towards areas that genuinely experience low coverage and assert that reported immunisation coverage estimates for this age group should only be considered as a minimum estimate of coverage.

MAE role

As the lead investigator the approach I used to reach these competencies included designing and conducting a state-wide audit which required significant stakeholder participation. I worked closely with the AIR Working Group to form an appropriate research question and strategy to answer this. To meet our main objective to estimate true immunisation coverage of children in NSW at one year of age, and determine reasons for under-reporting I developed a protocol and literature review and obtained ethics approval. I developed a questionnaire and audit tool closely assisted by Su Reid, Salwa Gabriel, Colleen Gately and Jody Stephenson. Attached to this was a project summary (Appendix B) and expression of interest (Appendix C) for interviewers in the LHDs. Rhydwyn McGuire was an essential force in the biostatistical side of the research, choosing the appropriate outcome factors methodology for collecting data, as well as assisting me to interpret the results of the study.

I conducted a very small pilot study, and when the main audit tool (Appendix D) and questionnaire (Appendix E) was distributed I provided oversight and assistance to public health unit staff who were undertaking interviews. I collected and cleaned the returned data and wrote a report with recommendations appropriate for the target audience (policy makers, government stakeholders and the scientific community). I wrote and submitted a manuscript as lead author for publication in the ANZJPH. This included managing feedback from multiple authors and liaising with the journal. I presented our findings at the 9th Southeast Asia and Western Pacific Bi-regional Training Programs in Epidemiology and Public Health Interventions Network (TEPHINET) Scientific Conference in Vientiane, Laos, from 5-9 November 2018.

Lessons learnt

Publication submission and development

The manuscript submitted to the ANZJPH was returned with minimal changes from the reviewers. I managed the response to questions from the reviewers and ensured that milestones were met. This process was completely novel to me, and I gained very much from it which will help me when publishing in the future.

Coordinating a multi-jurisdictional and multi-level working group

The AIR Working Group was established in 2016 and included participants across NSW. Membership included time-poor, high-level public health staff. The working group was challenging to navigate at times and required careful forward planning and negotiation. All members had worked on immunisation and/or the AIR at some level, bringing many different perspectives, knowledge and opinions. It was a challenge ensuring that these experiences could be considered and balanced in the study. A PHU Director chaired the meetings and this assisted in ensuring meetings were kept on track.

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Introduction

Since its establishment in 1996, the AIR has been a crucial tool in assessing immunisation coverage on local, state and national levels. Despite the strengths and improvements of the AIR, systematic issues such as errors and underreporting persist, generating much interest toward the mechanisms behind these problems. (1-4) Over the last decade NSW has adopted many major immunisation policy initiatives. In 2009 we joined the National Partnership on Essential Vaccines, where states and territories committed to working towards 95% vaccination coverage (5, 6). In 2012 the NSW Aboriginal Immunisation Healthcare Worker program was launched, with the overarching goal of improving timely vaccination of Aboriginal and Torres Strait Islander children (5); and in 2016 the Australian Governments 'No Jab No Pay' policy was implemented (7), generating controversy and interest in its effectiveness. In this research, we raised the hypothesis that we may now see improved coverage estimates and less error in reporting due to drivers such as these.

This chapter is comprised of the manuscript published in the June 2019 edition of the Australian and New Zealand Journal of Public Health (ANZJPH) (1) and an additional section expanding on the methodology, sampling frame and limitations of the study. The manuscript is a contemporary analysis of the magnitude of underreporting immunisation encounters on the AIR for NSW children at one year of age. Overall, the study acted as a coordinated version of an activity that is undertaken routinely by public health units (PHUs) in local health districts (LHDs) throughout the state in accordance with their normal responsibilities and processes in order to (a) improve immunisation coverage; (b) improve AIR recording of encounters; (c) understand barriers to childhood

immunisation and (d) understand barriers to reporting of encounters.

We raised the question about whether vaccine coverage areas, socio-economic status, or the provider's location would have any significant impact on underreporting. We discovered that for our sample, it was none of the above; it was actually the local health district that the child was based in that would influence whether their encounter was recorded incorrectly on AIR. We found most of the errors on AIR were due to errors in transmitting the child's immunisation encounter at the provider level or duplicate records. Other Australian research has highlighted that these types of errors are historical, and hence remain highly relevant. (3, 4, 8) We discovered our estimated true immunisation coverage for NSW children at one year of age is 96.2%, which exceeds the national coverage target and the AIR reported estimate of 94.1%. (6) We also believe these findings will have great utility in advocating for the mobilisation of public health resources towards areas that are truly impacted by low immunisation coverage, and assert that reported immunisation coverage estimates for this age group should be considered as a minimum estimate of coverage only.

<u>Further information about sampling frame and sample size calculations</u>

The sample was created using stratified random sample of September 2017 quarter data taken from the AIR. The sample size was selected to give 80% power for each of the following questions at a 5% significance level, taking the conservative assumption assuming that 50% of children reported as overdue were incorrectly recorded:

1. Does underreporting vary by reported local coverage level (low, medium, high)?
2. Does underreporting vary by socio economic status (low, medium, high)?
3. Does underreporting vary by provider setting (urban or rural and remote)?

The highly significant p-value of the Wald told us that overall, the local health district the child was based in was an important determinant of whether vaccines were correctly reported to the register. When exploring which test to use to analyse these variables, the group-wise Wald test in our opinion was the strongest because it did not increase the risk of a type-2 error on the basis of multiple comparisons.

The strata and sample size for each stratum was calculated using constrained optimisation, implemented in the R Package Sampling Strata, which minimised the required sample size while answering our research questions. The final sample was selected using a random number generator. In order to produce an approximate estimate before the third quarter overdue vaccine data was available, we calculated an approximate sample size based on a simple random sample. We assumed that 50% of children would be underreported, and maximum reported population of 3000, and that loss to follow-up would be 10%. On the basis of these numbers we would need to sample 380 children.

Although the baseline sample was powered for a good result, some LHDs expressed interest in over-sampling or auditing all overdue records in their jurisdiction. The over-sampling would result in tighter confidence intervals or assist where there were future plans for an LHD based analysis. To understand the effect that over-sampling would have at an LHD level, the biostatistician provided four approximate simulations to describe the potential effect of oversampling across health districts. For simplicity, a model district example assumed there were:

- No lost to follow-up and no duplicate records in this calculation, using simple random sample methods; and

- The LHD had an average level of vaccination, and an example with 88% recorded vaccination, which was the lowest recorded LHD coverage level in 2016.

The simulations were as follows:

1. **Using the main sample**, the study was powered to provide a maximum confidence interval width of 2.7 percentage points for an LHD with the average recorded rate of vaccination. That is, if the true percentage of children who were fully vaccinated is 96% then the confidence interval would be expected to be approximately (94.6, 97.4).
2. **Using the main sample and an extra sample** in a LHD with an average level recorded vaccination, the width of the confidence interval would tighten to 1.3 percentage points, so that the new confidence intervals would be expected to be approximately (95.3, 96.7).
3. **Using the main sample** with a lower level of coverage (example of 88% vaccination coverage) would produce a confidence interval width of 4.7. Assuming the true vaccination rate is 94% we would expect confidence intervals of approximately (91.6, 96.3).
4. **Using the main and extra sample** with a lower level of coverage the confidence interval width tightens to 1.3. Assuming the true vaccination rate is 94% we would expect confidence intervals of approximately (93.3, 94.7). The fact this has the same confidence width as scenario 2 is purely coincidence.

Public health units received their sample in early October and had four weeks to follow up overdue children, to allow for over-sampling for those LHDs who wished to do so. After the survey was conducted, the stratified sample was reweighted to account for

loss to follow-up. The data was probability weighted on the basis of the population and the population was estimated through the total number of children in the right age group according to the AIR.

Overall, the analysis showed that areas with the least amount of error had dedicated programs aimed at following up overdue children, and areas with no active follow up programs experienced the highest proportions of incorrect reporting. In consideration of this we recommended developing systematic data cleaning methods that do not rely on local resourcing.

An expansion on the limitations of the study

This cross-sectional study provided a snapshot in time, raising the prospect that if another time frame had been sampled, different results may be uncovered. Although we were able to ascertain whether children were accurately recorded as overdue on the AIR, we lost an additional level of detail about the antigen type and dose number when the 491 records were returned. This was due to information bias through inaccurate recording by interviewers and incomplete or missing data. The benefit of having this detail could focus public health resources on a specific disease.

Another limitation relates to children who are vaccinated overseas. If there was no written record of the vaccination and no option for follow-up, the child was listed as overdue, which could introduce bias into our final estimate. We conducted a sensitivity analysis that highlighted that even in an extreme scenario; the estimated true coverage for NSW would continue to exceed both the AIR coverage estimate and the national aspirational target for immunisation for the 1 year of age cohort. This study was not tailored to measure specific factors relating to Aboriginal and Torres Strait Islander

status or people from culturally and linguistically diverse backgrounds, who may have different drivers influencing immunisation coverage.

Manuscript: Children overdue for immunisation: a question of coverage or reporting? An audit of the Australian Immunisation Register

Australian and New Zealand Journal of Public Health, 06/2019, Volume 43, Issue 3
First published: 08 April 2019 https://doi.org/10.1111/1753-6405.12891

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Abstract

Objective

Vaccinations in Australia are reportable to the Australian Immunisation Register (AIR). Following major immunisation policy initiatives, the New South Wales (NSW) Public Health Network undertook an audit to estimate true immunisation coverage of NSW children at 1 year of age, and explore reasons associated with under-reporting.

Methods

Cross-sectional survey examining AIR immunisation records of a stratified random sample of 491 NSW children aged 12-<15 months at 30 September 2017, >30 days overdue for immunisation. Survey data were analysed using population weights.

Results

Estimated true coverage of fully vaccinated 1 year old children in NSW is 96.2% (CI:95.9-96.4), 2.1% higher than AIR reported coverage of 94.1%. Of the children reported as overdue on AIR, 34.9% (CI:30.9-38.9) were actually fully vaccinated. No significant association was found between under-reporting and socio-economic status, rurality or reported local coverage level. Data errors in AIR uploading (at provider level) and duplicate records contributed to incorrect AIR coverage recording.

Conclusions

Despite incentives to record childhood vaccinations on AIR, under-reporting continues to contribute to significant underestimation of true coverage in NSW.

Implications for public health

More reliable transmission of encounters to AIR at provider level and removal of duplicates are required.

Introduction

In 1996 the Australian Childhood Immunisation Register (ACIR) was launched by the Australian Government to record the immunisation status of children less than 7 years of age. (3) In 2016, the ACIR became the Australian Immunisation Register (AIR), an all-of-life immunisation register designed to include all vaccines on the National Immunisation Program (NIP) schedule as well as most privately purchased vaccines. (9) The AIR is used to assess local, state and national immunisation coverage, which in turn enables the mobilisation of targeted programs and resources to areas with lower coverage. At the individual level, the AIR identifies vaccinations that are overdue and required to be followed up to ensure children are fully vaccinated.

To be considered by the AIR to be fully vaccinated at 12 months of age on the NIP (prior to 1 July 2018), children must have three doses of diphtheria-tetanus-pertussis-containing vaccine (DTPa); three doses of polio vaccine; three doses of *Haemophilus influenzae* type b (Hib) vaccine; three doses of hepatitis B vaccine and three doses of pneumococcal conjugate vaccine. Two doses of PRP-OMP - containing Hib vaccine is also considered fully vaccinated (Table 1). (10)

Table 1 Vaccines and dosages required to be considered fully vaccinated at 12 months of age on the National Immunisation Program (NIP)

Vaccine	Number of doses
Diphtheria-tetanus-pertussis-containing vaccine (DTPa)	3
Polio vaccine	3
Haemophilus influenzae type b (Hib) vaccine	3*
Hepatitis B vaccine	3
Pneumococcal conjugate vaccine	3

*2 doses of PRP-OMP – containing Hib vaccine is considered fully vaccinated

Immunisation coverage varies substantially across NSW. Historical surveys, conducted prior to the 'No Jab No Pay' policy found imprecision in ACIR reported coverage. (2-4, 8) Coverage figures based on the Register cited in parliament and the media do not acknowledge that these estimates are lower than true coverage reported in these studies. (4) This raises the potential for undue public concern and perception of risk, as well as inappropriate resource mobilisation toward populations that may not require interventions as much as others. With the introduction of the 'No Jab No Pay' policy in 2015, (7) families of children who are not recorded as fully vaccinated on the AIR may be ineligible to receive Commonwealth benefits including the child care rebate, child care benefits and a family tax benefit. (11) In NSW and some other states, children must be recorded on the AIR as fully vaccinated to access childcare services. (7, 12)

We postulated that as incorrect reporting on AIR may leave families financially disadvantaged, records on the AIR may have become more accurate, so an audit was conducted to determine whether the accuracy of AIR coverage estimates had improved. The primary aim of the audit was to provide a better estimate of immunisation coverage in NSW for children at one year of age by identifying those who were genuinely overdue on the AIR. Secondary objectives included identifying reasons for AIR underreporting and exploring whether the rate of underreporting varied by reported local coverage level, socio economic status or provider setting (urban or rural and remote).

Methodology

Ethics approval was granted by Australian National University as a Low-Risk Expedited E1 Protocol on 21/08/2017: Protocol 2017/570.

i. Selection and Description of Participants

The audit examined the provider- and/or parent- held immunisation records of a sample of NSW children listed on the AIR as >30 days overdue. The cross-sectional sample frame comprised all children aged 12-<15 months (birth cohort 1 July to 30 September 2016), residing in NSW, and recorded on the AIR as overdue as at 30 September 2017 for at least one immunisation. These children were identified using the AIR011A report (13) extracted in early October 2017. Using the 'third dose assumption' in our definitions allowed our coverage estimates to be compared to national reporting. (14) The third dose assumption aims to minimise the impact of underreporting on AIR coverage estimates due to delays registering the child onto Medicare by assuming that children are fully vaccinated if they have a record of receiving the third dose of a vaccine, regardless of whether a record exists of their previous doses. (15) Children without at least one of the following contact details were excluded: parental email address, phone number or provider information.

ii. Technical information

Taking the conservative assumption that 50% of children reported as overdue were incorrectly recorded, a stratified random sample (16) was selected to provide 80% power at a 5% significance level for each of the planned analyses to

detect a significant difference between overall NSW coverage according to the AIR and the audit. In addition, analyses were undertaken at a smaller geographical area level, based on Australian Bureau of Statistics (ABS) Statistical Area Level 3 (SA3) to detect differences in under-reporting between: areas of low (bottom third of SA3 areas<92%), medium (middle third of SA3 regions 92-94%) and high (top third of SA3 regions>94%) reported coverage; areas of low, medium and high socioeconomic status tertiles. We used the 2011 Index of Relative Socio-Economic Disadvantage (IRSD) which is an indicator value of the ABS Socio-Economic Indicators for Areas (SEIFA) (17), and provider setting (urban/rural and remote) according to the Accessibility and Remoteness Index of Australia (ARIA+). (18) We chose SA3 areas to assess coverage for this study as they reflect meaningful regional areas of the state instead of focusing on population alone; areas are segmented into standardised regions with similar characteristics in socio-economic status and geography. These areas usually have a population of 30,000 to 130,000 and generally share borders with other administrative boundaries such as State Regional Development Areas or at least one Local Government Area. (19)

iii. Statistical methods

The strata and sample size for each stratum were calculated using constrained optimisation, implemented in the R Package Sampling Strata. (20) This allowed us to minimise the required sample size while answering our research questions. The final sample was selected using a random number generator. A stratified

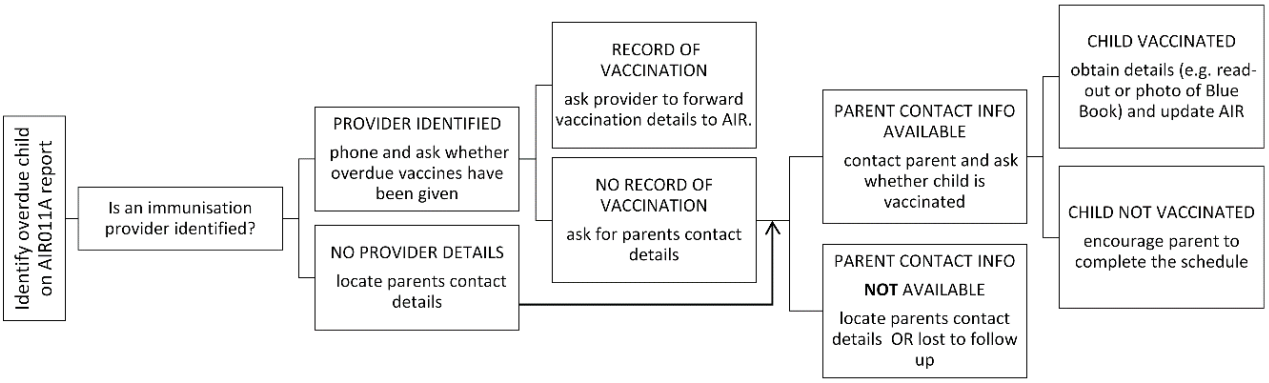
random sample (main sample) was selected by local health district (LHD) of residence. Where resources were available, public health unit staff in each LHD could opt to survey extra records sampled in order to improve precision of estimates at LHD level and overall. Including this extra sample, a total of 491 records were surveyed (Figure 2). After the survey was conducted, the stratified sample was reweighted to account for loss to follow-up. For each coverage estimate we calculated 95% confidence intervals and used a Wald test for association to gain an overall p-value for differences in coverage over multiple parameters.

iv. Data collection – provider level

Details of children in the main and extra samples were provided to each public health unit via secure file transfer for follow-up in accordance with an audit tool developed to capture the relevant information from provider and parent-held records of children recorded on AIR as overdue.

Figure 1 summarises the audit process. Public health unit staff interviewed immunisation providers by telephone using a standardised questionnaire. Providers were asked questions about the type of practice (general practice (GP), Aboriginal health service, council clinic, community health centre, public/private hospital, public health unit or flying doctor service). If the provider type was a general practice, further questions were asked about how many GPs and authorised nurse immunisers were in the practice to gauge the size of the provider setting.

Figure 1 Interview process for the NSW audit of the Australian Immunisation Register



If the overdue vaccines had in fact been administered, the provider was asked: the date of vaccination; where the child received the vaccine (at the practice, overseas, another provider or other); and where the vaccines were recorded in the child's medical record (immunisation tab or clinical notes). The interviewer then confirmed whether this was a data error (error in transmission of information from child's medical record to the AIR) or a clinician's error (human error in putting incorrect vaccination information in the child's medical record, or incorrect vaccine or dose administered). The provider was asked to forward any corrected vaccination details to the AIR. Providers were also asked whether the child's medical record indicated the reasons why a vaccination had not been administered (child sick, medical contradiction, parental hesitancy, parental refusal, family overseas, 'other' or unknown). In addition, the provider was asked about their primary method for transmitting immunisation encounters to the AIR.

v. Data collection – parents and guardians

If the provider did not hold a record of administration of the overdue vaccine(s), or if the provider was unable to be reached, up to three attempts were made to contact the child's parents. Parents who were contacted and stated that their child was vaccinated were asked where the child received the vaccine (overseas, another provider, or 'other: specify'), the provider's name and date of vaccination. Where a vaccination was recorded, parents were asked to provide evidence of the vaccination and Medicare details so the interviewer could correct the AIR record. Evidence of completed vaccination required the parent to read out to the interviewer details from their parent-held child health record (Blue Book) or other evidence such as overseas vaccination record with antigens compatible with the NIP schedule. When parents claimed the child was fully vaccinated but were unable to provide documentation of the record, the child was classified as not fully vaccinated. Children of parents who were unable to be contacted after three attempts were listed as 'lost to follow-up' (LTFU).

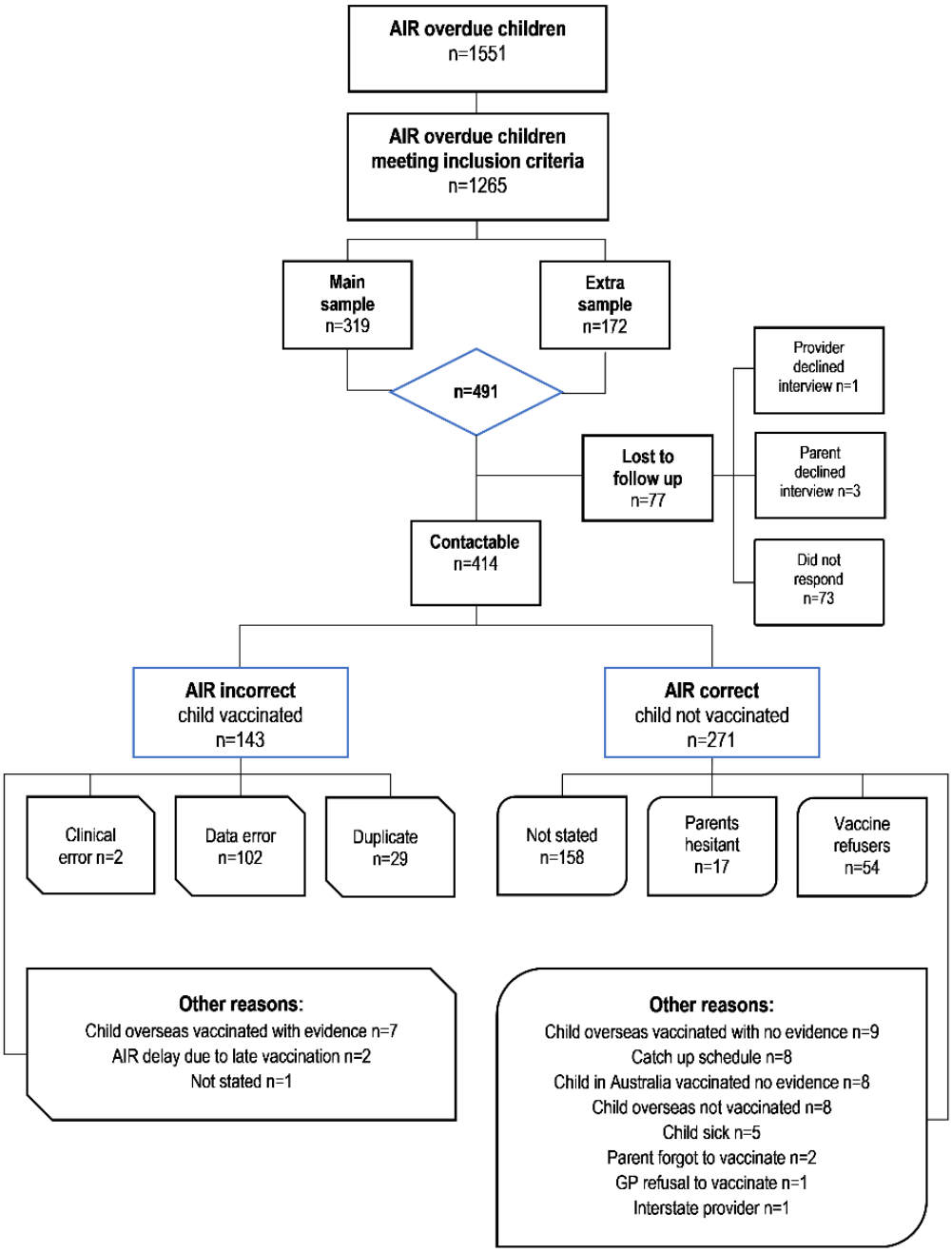
Results

i. Primary results

Of the 25,934 children born from 1 July to 30 September 2016 and recorded on the AIR as residing in NSW, 1551 (6.0%) were reported as not fully vaccinated at 30 September 2017. Of the 1551 records, 286 were excluded (24 had insufficient residential address information to be assigned a SEIFA or ARIA+ index value; and 262 had no contact information including phone number, provider number or email address), leaving 1265 records to sample from (Figure 2).

Of these, 491 were randomly selected for audit. Seventy seven (15.7%) were classified as lost to follow up. One GP and parents of three children declined to be interviewed, and for the remaining 73 cases the interviewer made at least three attempts to contact the parent, provider or both, with no answer or response to voice messages or email. Of the 414 children whose immunisation status was able to be confirmed, 271 were correctly recorded on AIR as not fully vaccinated and 143 had evidence of being fully vaccinated (detailed in medical record or parental-held Blue Book).

Figure 2 Sampling frame flowchart for the NSW audit of the Australian Immunisation Register.



ii. Reasons for non-vaccination

Although it was not a requirement for parents to be asked or to offer reasons for being overdue for vaccination, information was obtained for 113 (41.7%) of the 271 children in the sample confirmed as not fully vaccinated.

Reasons given were vaccine refusal (n=54); parental hesitancy (n=17); vaccinated overseas with no evidence of vaccination (n=9); child overseas and not vaccinated (n=8); vaccinated in Australia with no record (n=8); currently on a catch-up schedule (n=8); child sick at the time (n=5); parent forgot to vaccinate (n=2); GP refused to vaccinate (n=1); and interstate provider (n=1).

iii. Reasons for error on AIR

Of the 143 children incorrectly recorded as overdue on the AIR, 29 had duplicate AIR records (due to children having two Medicare numbers or name errors). Vaccinations of 102 children were not recorded on the AIR due to presumed data transmission errors, and two were due to clinician errors, where incorrect doses had been recorded in one case and no reason offered for the second. Seven children had evidence of being vaccinated overseas; two children had received vaccines which were slightly delayed by documented illness. At the time of sampling, the encounter had not reached AIR for these two children. The reason was not stated for one child. Practices experiencing data errors used a range of patient record software brands and versions.

iv. Coverage calculations

Overall, after adjustment for loss to follow-up from the defined sample, 34.9% (95%CI: 30.9-38.9%) of overdue children were actually up-to-date for vaccination, leading to an estimate of true coverage in this cohort of 96.2% (95%CI: 95.9-96.4%), compared to the AIR based coverage of 94.1% (Table 1). We found significant variability between LHDs in whether vaccinations were incorrectly recorded on AIR, with the proportion of children incorrectly recorded as overdue ranging between 12% and 54% (Table 1). Level of incorrect reporting was not associated with coverage level, rurality or socioeconomic status (Table 2). However, for the Aboriginal or Torres Strait Islander children in the sample, reporting error was significantly less than for non-Indigenous children (Table 2).

v. Sensitivity analysis

A sensitivity analysis was conducted to determine whether non-response would affect the conclusions of the study, and how it would affect true coverage estimates (Table 3). In the first scenario, lost to follow up records were set as 'fully vaccinated' (AIR incorrect), giving a true coverage estimate of 96.8% (CI: 96.6, 97.0). In the second scenario, lost to follow up records were set as 'not vaccinated' (AIR correct), changing the true coverage estimate to 95.8% (CI: 95.6, 96.0). A third scenario was created where those who claimed to be vaccinated but had no evidence of the encounter (AIR correct) were set as truly vaccinated (AIR incorrect). This had little effect on the true coverage estimate, which was slightly increased to 96.4% (CI: 96.2, 96.7).

The sensitivity analysis highlighted that even in an extreme scenario the estimated true coverage for 1 year old children in NSW would continue to exceed both the AIR coverage estimate of 94.1% and the Australian Governments national aspirational immunisation target of 95% coverage. (5)

Table 2 Sensitivity analysis accounting for children overdue for immunisation on the Australian Immunisation Register who claimed to be vaccinated with no evidence, or were lost to follow up

All NSW	n=	% Incorrectly reported	95% CI	Reported coverage	True coverage	95% CI
Reported results (excluding 77 LTFU)	414	34.9	(30.9,38.9)	94.1	96.2	(95.9,96.4)
Counting vaccinated without evidence as yes (excluding 77 LTFU)	414	39.6	(35.5,43.7)	94.1	96.44	(96.2,96.7)
Including LTFU as fully vaccinated	491	45.8	(41.9,49.6)	94.1	96.80	(96.6,97.0)
Setting LTFU as not vaccinated	491	29.0	(25.5,32.5)	94.1	95.81	(95.6,96.0)

Discussion

In this cohort of one-year-old NSW children 34.9% (95% CI: 30.9-38.9%) recorded as overdue on AIR were found to be incorrectly assessed as overdue. Thus the true immunisation coverage in NSW is estimated at 96.2% (95% CI: 95.9-96.4%), 2.1% higher than the AIR estimate of 94.1%. Despite the policy incentives for families to ensure that their children are fully immunised, (7, 11) national recorded coverage remains inaccurate. (5) Research prior to the 2015 policy change found that in 2001 a cohort of children from South Eastern Sydney Local Health District (SESLHD) aged 12-<15 months old, reported to have an immunisation coverage rate of 81% on the ACIR had a true coverage rate of at least 91%. (4, 8) A similar study in Waverley and Sydney City local

government areas in 2013 found that 33% of the cohort reported to be overdue for a vaccination were not overdue. This boosted the coverage rate of that area from 87% to 91%, a 4% difference. (4) The current audit found a lower underreporting rate that was fairly homogenous over most of the factors tested, with local coverage rates (low, medium and high), socio-economic status (low, medium and high) and provider setting (urban/rural and remote) having no statistically significant association. Underreporting did vary significantly by local health district and Aboriginality. This may reflect the impact of existing programs for all Aboriginal infants in NSW (21) and that in some local health districts immunisation providers routinely review the status of children shown as overdue on AIR, correcting missing data and recalling overdue children. (22, 23)

Earlier research suggested that the primary reason for underreporting in the AIR was due to immunisation providers being unable to submit the patient vaccine encounter details in a timely manner. (3, 4, 8) Encounter forms are now an infrequent method of reporting with primary care patient record systems transmitting vaccination records directly to the AIR, usually on the same day. The introduction of medical practice software may alter the coverage estimates of the AIR positively through automatic notification, or negatively if there are systematic errors with data transfer or data errors. Later studies undertaken in the era of widespread use of electronic patient record systems have found lower, but consistent levels of underreporting in the range of 2-4%, (2, 4) similar to this audit. The local study by Ferson & Orr 6 found that key contributors to undercounting in the AIR included lack of knowledge by GPs about the reporting process, incorrect data entry and systematic issues relating to medical practice software feeding into the AIR. (4)

The main factor found to contribute to contemporary underreporting is an error in data transmission of information from the child's medical record to the AIR. Almost three-quarters (102 of 143) of the incorrect classifications of children as overdue on the AIR were due to data transmission errors. We were unable to identify a consistent cause for data errors, which appeared unrelated to the brand or version of patient record software used, however examination of specific software or transmission errors was beyond the scope of this study.

The second most common source of AIR inaccuracy was duplicate records, responsible for 20% of errors. Duplicates may occur on the AIR when a child has more than one Medicare number, or encounters are entered without a Medicare number. Other duplicates arose through errors in birth dates, use of different surnames, or in situations such as foster care. If PHU staff were able to locate the duplicate records pair (whether the pair was in the sample or not) they updated the AIR to consolidate them into one complete record. The AIR uses registration data from Medicare to calculate the denominator. Duplicate records artificially inflate the denominator, which in turn reduces estimated immunisation coverage. Clinician errors, either human error entering information in the child's medical record or incorrect vaccine dose recorded, appear to be rare causes of being assessed as not fully vaccinated, with only two instances detected in our sample.

Twenty-four children who had moved overseas permanently were recorded as overdue on AIR. This information was reported by the provider or other family members (remaining parent, grandparent). Parents of 16 children who were living overseas claimed their child was up-to-date with vaccinations. Of these, seven were able to

provide evidence of vaccination and were thus moved to the 'AIR incorrect: child vaccinated' category.

As these children live overseas, leaving them on the AIR adds to underestimation of coverage as they contribute to the denominator without being able to contribute to the numerator irrespective of whether they are vaccinated, unless a parent and a local provider take the trouble to manually register the overseas vaccines with the AIR. The procedure to remove children from the AIR when they are overseas requires an immunisation provider to tick a "returned mail indicator" within the child's AIR record, or to contact the AIR in writing. The Department of Human Services advises that this will then remove the child from state coverage reports.

There were 54 children in the sample whose parents reported they had chosen not to vaccinate. Many of these children were already known to the health services so were not re-contacted. Some parents who were contacted offered reasons why they have not vaccinated their children. One parent stated a family history of allergic reaction to Boostrix® and another stated that a family member had died as a result of an adverse reaction to an unspecified vaccination. One family was not willing to vaccinate their child, citing cultural reasons.

A further 17 children had not been fully vaccinated as their parents were hesitant to vaccinate, some delaying their children's vaccinations until 'later'; vaccinating slowly, one vaccine at a time; or selectively choosing some vaccines.

This study shows that in NSW the national aspirational target of 95% fully vaccinated coverage (5) has been achieved for children at one year of age, but confirms that despite policy settings encouraging accurate recording of vaccinations on the AIR,

underreporting continues at around 2%. For Aboriginal children, and in regions where resources are dedicated to ensuring accurate and timely recording of vaccination on AIR, error rates are lower. (5, 21-23) Given the persistence of reporting errors in the absence of active local programs to clean and correct AIR records, consideration should be given to developing cost effective centralised automated measures to identify and correct errors and duplicate records. Until this can be routinely achieved at a national level, AIR coverage data for children at 1 year of age should be treated as the minimum estimated coverage level for that age group. Similar audits in the future may assess the magnitude of underreporting in other age cohorts and provide further evidence of undercounting to enrich our understanding of how sociodemographic or practice level characteristics may contribute to underreporting.

Limitations

As this study is cross-sectional, the prospect is raised that if another time frame had been sampled, different results may be uncovered. However, given the similarity between this and other relatively recent local audits we do not expect that would occur. The 77 records that were lost to follow up may have introduced non-response bias into the study, and was countered by conducting a sensitivity analysis that indicated that conclusions of the study were not materially affected (Table 3). We aimed to minimise interviewer bias by providing a questionnaire with mostly closed form responses. Possibly of greater importance is that the underreporting estimate at one year of age is not generalisable to other age groups. As children become older they are increasingly likely to enrol in early childhood education which should prompt correction of data

transmission and clinician errors, as they are required to be recorded as fully vaccinated on the AIR to enrol in childcare in NSW and to receive Australian Government financial assistance to attend. Thus, if overdue children were sampled at 2 or 5 years of age the underreporting rate is likely to be lower. Lastly, this study was not tailored to measure specific factors relating to people from culturally and linguistically diverse backgrounds, with potentially different drivers influencing recorded immunisation coverage.

Conclusion

Despite widespread use of electronic patient record systems and policy settings encouraging accurate recording of childhood vaccinations, publicly reported coverage estimates at one year of age are approximately 2% lower than true vaccination rates. This systematic underestimating of coverage should be clearly conveyed whenever AIR coverage estimates are quoted. Data transmission errors were the most frequent cause for errors on the AIR; however other factors included duplicate records and children living overseas. Reasons for correctly recorded incomplete vaccination included vaccine hesitancy or refusal, lack of documentary evidence/records of vaccination, delays due to illness or children on catch up schedules. Cost effective measures should be developed to routinely identify and correct common errors leading to incomplete or duplicate records on the AIR.

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Appendices

Appendix A. Article published in the ANZJPH

Children overdue for immunisation: a question of coverage or reporting? An audit of the Australian Immunisation Register

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In 1996, the Australian Childhood Immunisation Register (ACIR) was launched by the Australian Government to record the immunisation status of children younger than seven years of age.[1] In 2016, the ACIR became the Australian Immunisation Register (AIR), an all-of-life immunisation register designed to include all vaccines on the National Immunisation Program (NIP) schedule as well as most privately purchased vaccines.[2]

The AIR is used to assess local, state and national immunisation coverage, which in turn enables the mobilisation of targeted programs and resources to areas with lower coverage. At the individual level, the AIR identifies vaccinations that are overdue and required to be followed up to ensure children are fully vaccinated.

To be considered by the AIR to be fully vaccinated at 12 months of age on the NIP (prior to 1 July 2018), children must have three doses of diphtheria-tetanus-pertussis-containing vaccine (DTPa); three doses of polio vaccine; three doses of *Haemophilus influenzae* type b (Hib) vaccine; three doses of hepatitis B vaccine and three doses of pneumococcal conjugate vaccine. Two doses of PRP-OMP - containing Hib vaccine is also considered fully vaccinated.[3]

Abstract

Objective: Vaccinations in Australia are reportable to the Australian Immunisation Register (AIR). Following major immunisation policy initiatives, the New South Wales (NSW) Public Health Network undertook an audit to estimate true immunisation coverage of NSW children at one year of age, and explore reasons associated with under-reporting.

Methods: Cross-sectional survey examining AIR immunisation records of a stratified random sample of 491 NSW children aged 12≤15 months at 30 September 2017 who were >30 days overdue for immunisation. Survey data were analysed using population weights.

Results: Estimated true coverage of fully vaccinated one-year-old children in NSW is 96.2% (CI:95.9-96.4), 2.1% higher than AIR reported coverage of 94.1%. Of the children reported as overdue on AIR, 34.9% (CI:30.9-38.9) were actually fully vaccinated. No significant association was found between under-reporting and socioeconomic status, rurality or reported local coverage level. Data errors in AIR uploading (at provider level) and duplicate records contributed to incorrect AIR coverage recording.

Conclusions: Despite incentives to record childhood vaccinations on AIR, under-reporting continues to be an important contributor to underestimation of true coverage in NSW.

Implications for public health: More reliable transmission of encounters to AIR at provider level and removal of duplicates would improve accuracy of reported coverage.

Key words: immunisation, immunisation schedule, infant, public health practice, communicable diseases

Immunisation coverage varies substantially across NSW. Historical surveys, conducted prior to the 'No Jab No Pay' policy, found imprecision in ACIR-reported coverage.[1,4-6] Coverage figures based on the Register cited in parliament and the media do not acknowledge that these estimates are lower than true coverage reported in these studies.[6] This raises the potential for undue public concern and perception of risk, as well as inappropriate resource mobilisation toward populations that may not require interventions as much as others.

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Submitted: October 2018; Revision requested: January 2019; Accepted: February 2019
The authors have stated they have no conflict of interest.

Aust NZ J Public Health. 2019; Online; doi: 10.1111/1753-6405.12891

With the introduction of the 'No Jab No Pay' policy in 2015,[7] families of children who are not recorded as fully vaccinated on the AIR may be ineligible to receive Commonwealth benefits including the child care rebate, child care benefits and a family tax benefit.[8] In NSW and some other states, children must be recorded on the AIR as fully vaccinated to access childcare services.[7,9]

We postulated that as incorrect reporting on AIR may leave families financially disadvantaged; records on the AIR may have become more accurate, so an audit was conducted to determine whether the accuracy of AIR coverage estimates had improved.

The primary aim of the audit was to provide a better estimate of immunisation coverage in NSW for children at one year of age by identifying those who were genuinely overdue on the AIR. Secondary objectives included identifying reasons for AIR under-reporting and exploring whether the rate of under-reporting varied by reported local coverage level, socioeconomic status or provider setting (urban or rural and remote).

Methods

Ethics approval was granted by Australian National University as a Low-Risk Expedited E1 Protocol on 21/08/2017: Protocol 2017/570.

Selection and description of participants

The audit examined the provider- and/or parent-held immunisation records of a sample of NSW children listed on the AIR as >30 days overdue. The cross-sectional sample frame comprised all children aged 12≤15 months (birth cohort 1 July to 30 September 2016), residing in NSW, and recorded on the AIR as overdue as at 30 September 2017 for at least one immunisation. These children were identified using the AIR011A report[10] extracted in early October 2017. Using the 'third dose assumption' in our definitions allowed our coverage estimates to be compared to national reporting.[11] The third dose assumption aims to minimise the impact of under-reporting on AIR coverage estimates due to delays registering the child onto Medicare by assuming that children are fully vaccinated if they have a record of receiving the third dose of a vaccine, regardless of whether a record exists of their previous doses.[12] Children without at least one of the following contact details were excluded: parental email address, phone number or provider information.

Technical information

Taking the conservative assumption that 50% of children reported as overdue were incorrectly recorded, a stratified random sample[13] was selected to provide 80% power at a 5% significance level for each of the planned analyses to detect a significant difference between overall NSW coverage according to the AIR and the audit. In addition, analyses were undertaken at a smaller geographical area level, based on Australian Bureau of Statistics (ABS) Statistical Area Level 3 (SA3) to detect differences in under-reporting between: areas of low (bottom third of SA3 areas<92%), medium (middle third of SA3 regions 92–94%) and high (top third of SA3 regions>94%) reported coverage; areas of low, medium and high socioeconomic status tertiles. We used the 2011 Index of Relative Socio-Economic Disadvantage (IRSD), which is an indicator value of the ABS Socio-Economic Indicators for Areas (SEIFA);[14] and provider setting (urban/rural and remote) according to the Accessibility and Remoteness Index of Australia (ARIA+).[15] We chose SA3 areas to assess coverage for this study as they reflect meaningful regional areas of the state instead of focusing on population alone; areas are segmented into standardised regions with similar characteristics in socioeconomic status and geography. These areas usually have a population of 30,000 to 130,000 and generally share borders with other administrative boundaries such as State Regional Development Areas or at least one Local Government Area.[16]

Statistical methods

The strata and sample size for each stratum were calculated using constrained optimisation, implemented in the R Package Sampling Strata.[17] This allowed us to minimise the required sample size while answering our research questions. The final sample was selected using a random number generator. A stratified random sample (main sample) was selected by local health district (LHD) of residence. Where resources were available, public health unit staff in each LHD could opt to survey extra records sampled in order to improve precision of estimates at LHD level and overall. Including this extra sample, a total of 491 records were surveyed (Figure 2). After the survey was conducted, the stratified sample was reweighted to account for loss to follow-up. For each coverage estimate we calculated 95% confidence intervals and used a Wald test for association to gain an overall p-value for differences in coverage over multiple parameters.

Data collection – provider level

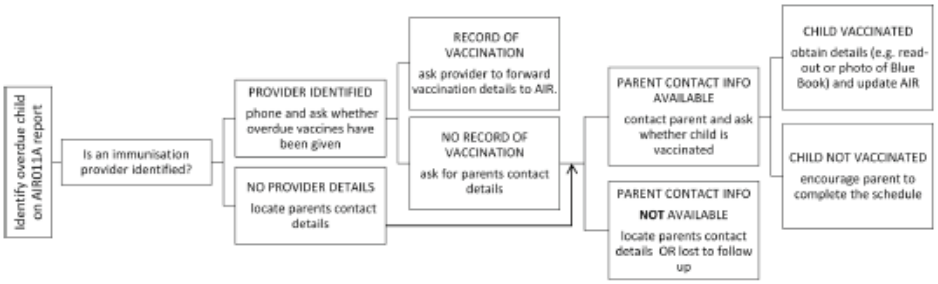
Details of children in the main and extra samples were provided to each public health unit via secure file transfer for follow-up in accordance with an audit tool developed to capture the relevant information from provider and parent-held records of children recorded on AIR as overdue.

Figure 1 summarises the audit process. Public health unit staff interviewed immunisation providers by telephone using a standardised questionnaire. Providers were asked questions about the type of practice (general practice [GP], Aboriginal health service, council clinic, community health centre, public/private hospital, public health unit or flying doctor service). If the provider type was a general practice, further questions were asked about how many GPs and authorised nurse immunisers were in the practice to gauge the size of the provider setting.

If the overdue vaccines had in fact been administered, the provider was asked: the date of vaccination; where the child received the vaccine (at the practice, overseas, another provider or other); and where the vaccines were recorded in the child's medical record (immunisation tab or clinical notes). The interviewer then confirmed whether this was a data error (error in transmission of information from child's medical record to the AIR) or a clinician's error (human error in putting incorrect vaccination information in the child's medical record, or incorrect vaccine or dose administered). The provider was asked to forward any corrected vaccination details to the AIR.

Providers were also asked whether the child's medical record indicated the reasons why a vaccination had not been administered (child sick, medical contradiction, parental hesitancy, parental refusal, family overseas, 'other' or unknown). In addition, the provider was asked about their primary method for transmitting immunisation encounters to the AIR.

Figure 1: Audit process for NSW public health network interviewers.



Data collection – parents and guardians

If the provider did not hold a record of administration of the overdue vaccine(s), or if the provider was unable to be reached, up to three attempts were made to contact the child's parents. Parents who were contacted and stated that their child was vaccinated were asked where the child received the vaccine (overseas, another provider, or 'other: specify'), the provider's name and date of vaccination. Where a vaccination was recorded, parents were asked to provide evidence of the vaccination and Medicare details so the interviewer could correct the AIR record. Evidence of completed vaccination required the parent to read out to the interviewer details from their parent-held child health record (Blue Book) or other evidence such as overseas vaccination record with antigens compatible with the NIP schedule. When parents claimed the child was fully vaccinated but were unable to provide documentation of the record, the child was classified as not fully vaccinated.

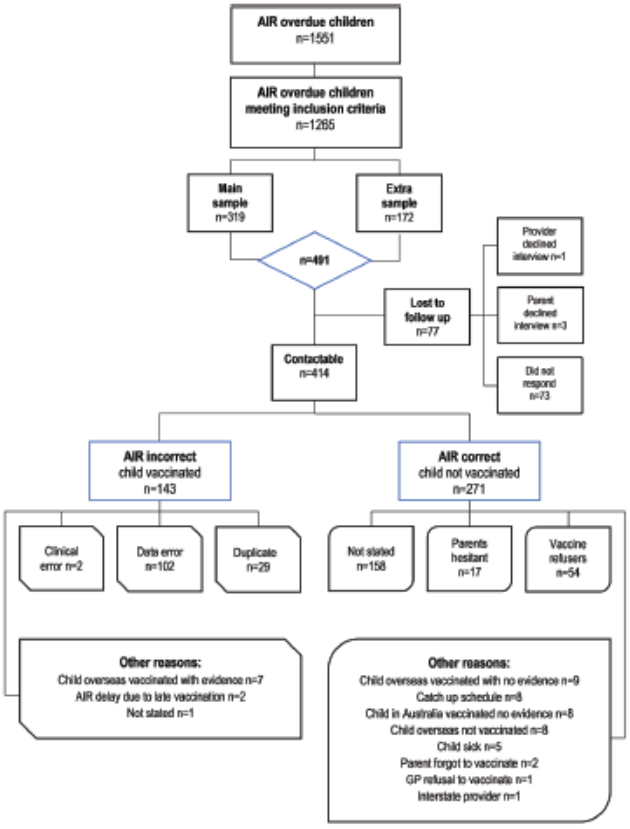
Children of parents who were unable to be contacted after three attempts were listed as 'lost to follow-up' (LTFU).

Results

Primary results

Of the 25,934 children born from 1 July to 30 September 2016 and recorded on the AIR as residing in NSW, 1,551 (6.0%) were reported as not fully vaccinated at 30 September 2017. Of the 1,551 records, 286 were excluded (24 had insufficient residential address information to be assigned a SEIFA or ARIA+ index value; and 262 had no contact information including phone number, provider number or email address), leaving 1,265 records to sample from (Figure 2).

Figure 2: Flowchart depicting sampling frame and outcome.



Of these, 491 were randomly selected for audit. Seventy-seven (15.7%) were classified as lost to follow-up. One GP and parents of three children declined to be interviewed, and for the remaining 73 cases the interviewer made at least three attempts to contact the parent, provider or both, with no answer or response to voice messages or email.

Of the 414 children whose immunisation status was able to be confirmed, 271 were correctly recorded on AIR as not fully vaccinated and 143 had evidence of being fully vaccinated (detailed in medical record or parental-held Blue Book).

Reasons for non-vaccination

Although it was not a requirement for parents to be asked or to offer reasons for being overdue for vaccination, information was obtained for 113 (41.7%) of the 271 children in the sample confirmed as not fully vaccinated.

Reasons given were vaccine refusal (54); parental hesitancy (17); vaccinated overseas with no evidence of vaccination (9); child overseas and not vaccinated (8); vaccinated in Australia with no record (8); currently on a catch-up schedule (8); child sick at the time (5); parent forgot to vaccinate (2); GP refused to vaccinate (1); and interstate provider (1).

Reasons for error on AIR

Of the 143 children incorrectly recorded as overdue on the AIR, 29 had duplicate AIR records (due to children having two Medicare numbers or name errors). Vaccinations of 102 children were not recorded on the AIR due to presumed data transmission errors, and two were due to clinician errors, where incorrect doses had been recorded in one case and no reason offered for the second. Seven children had evidence of being vaccinated overseas; two children had received vaccines that were slightly delayed by documented illness. At the time of sampling, the encounter had not reached AIR for these two children. The reason was not stated for one child. Practices experiencing data errors used a range of patient record software brands and versions.

Coverage calculations

Overall, after adjustment for loss to follow-up from the defined sample, 34.9% (95%CI: 30.9-38.9%) of overdue children were actually up-to-date for vaccination, leading to an estimate of true coverage in this cohort of 96.2% (95%CI: 95.9-96.4%), compared to the AIR based coverage of 94.1% (Table 1). We found significant variability between LHDs in whether vaccinations were incorrectly recorded on AIR, with the proportion of children incorrectly recorded as overdue ranging between 12% and 54% (Table 1). Level of incorrect reporting was not associated with coverage level, rurality or socioeconomic status (Table 2). However, for the Aboriginal or Torres Strait Islander children in the sample, reporting error was significantly less than for non-Indigenous children (Table 2).

Sensitivity analysis

A sensitivity analysis was conducted to determine whether non-response would affect the conclusions of the study, and how it would affect true coverage estimates (Table 3). In the first scenario, lost to follow-up records were set as 'fully vaccinated' (AIR incorrect), giving a true coverage estimate of 96.8% (CI: 96.6, 97.0). In the second scenario, lost to follow-up records were set as 'not vaccinated' (AIR correct), changing the true coverage estimate to 95.8% (CI: 95.6, 96.0).

A third scenario was created where those who claimed to be vaccinated but had no evidence of the encounter (AIR correct) were set as truly vaccinated (AIR incorrect). This had little effect on the true coverage estimate, which was slightly increased to 96.4% (CI: 96.2, 96.7).

The sensitivity analysis highlights that even in an extreme scenario the estimated true coverage for one-year-old children in NSW would continue to exceed both the AIR coverage estimate of 94.1% and the Australian Government's national aspirational immunisation target of 95% coverage.[18]

Table 1: Percentage incorrectly recorded on the AIR, and reported vs. corrected immunisation coverage for NSW children 12 months of age, by local health district of residence, 30 September 2017.

LHD name	n=414	% Incorrectly reported*	95%CI	% AIR Reported coverage	% Corrected coverage	95%CI	*p*-value
LHD 1	24	11.8	(1.9,21.6)	95.6	96.1	(95.7,96.6)	
LHD 2	33	12.6	(1.4,23.8)	90.0	91.3	(90.1,92.4)	
LHD 3	33	18.9	(7.5,30.2)	94.5	95.5	(94.9,96.2)	
LHD 4	28	21.7	(16.3,27.0)	92.5	94.1	(93.7,94.5)	
LHD 5	29	23.0	(9.5,36.5)	93.0	94.6	(93.7,95.6)	
LHD 6	23	29.9	(13.6,46.1)	94.2	95.9	(95.0,96.9)	
LHD 7	46	30.8	(19.3,42.2)	93.5	95.5	(94.8,96.2)	
LHD 8	25	40.2	(28.9,51.5)	96.0	97.6	(97.2,98.1)	(p=<0.0001)
LHD 9	12	41.8	(25.9,57.7)	95.7	97.5	(96.8,98.2)	
LHD 10	15	41.9	(21.5,62.2)	95.4	97.3	(96.4,98.3)	
LHD 11	42	44.6	(31.7,57.5)	94.0	96.7	(95.9,97.5)	
LHD 12	16	45.1	(31.4,58.8)	96.0	97.8	(97.3,98.4)	
LHD 13	45	51.9	(39.3,64.4)	93.7	97.0	(96.2,97.8)	
LHD 14	43	54.3	(42.1,66.5)	95.8	98.1	(97.6,98.6)	
All NSW	414	34.9	(30.9,38.9)	94.1	96.2	(95.9,96.4)	

Note:
* Percentage incorrectly recorded as overdue on the Australian Immunisation Register

Discussion

Main findings

In this cohort of one-year-old NSW children, 34.9% (95%CI: 30.9-38.9%) recorded as overdue on AIR were found to be incorrectly assessed as overdue. Thus, the true immunisation coverage in NSW is estimated at 96.2% (95%CI: 95.9-96.4%), 2.1% higher than the AIR estimate of 94.1%.

Despite the policy incentives for families to ensure that their children are fully immunised,[7,8] national recorded coverage remains inaccurate.[18] Research prior to the 2015 policy change found that in 2001 a cohort of children from South Eastern Sydney Local Health District (SESLHD) aged 12≤15 months old, reported to have an immunisation coverage rate of 81% on the ACIR, had a true coverage rate of at least 91%.[5,6] A similar study in Waverley and Sydney City local government areas in 2013 found that 33% of the cohort reported to be overdue for a vaccination were not overdue. This boosted the coverage rate of that area from 87% to 91%, a 4% difference.[6]

The current audit found a lower under-reporting rate that was fairly homogenous over most of the factors tested, with local coverage rates (low, medium and high), socioeconomic status (low, medium and high) and provider setting (urban/rural and remote) having no statistically significant association.

Under-reporting did vary significantly by local health district and Aboriginality. This may reflect the impact of existing programs for all Aboriginal infants in NSW[19] and that in some local health districts immunisation providers routinely review the status of children shown as overdue on AIR, correcting missing data and recalling overdue children.[20,21]

Earlier research suggested that the primary reason for under-reporting in the AIR was due to immunisation providers being unable to submit the patient vaccine encounter details in a timely manner.[1,5,6] Encounter forms are now an infrequent method of reporting with primary care patient record systems transmitting vaccination records directly to the AIR, usually on the same day. The introduction of medical practice software may alter the coverage estimates of the AIR positively through automatic notification, or negatively if there are systematic errors with data transfer or data errors. Later studies undertaken in the era of widespread use of electronic patient record systems have found lower, but consistent levels of under-reporting in the range of 2–4%,[4,6] similar to this audit. The local study by Ferson and Orr[6] found that key contributors to undercounting in the AIR included lack of knowledge by GPs about the reporting process, incorrect data entry and systematic issues relating to medical practice software feeding into the AIR.[6]

The main factor found to contribute to contemporary under-reporting is an error in data transmission of information from the child's medical record to the AIR. Almost three-quarters (102 of 143) of the incorrect classifications of children as overdue on the AIR were due to data transmission errors. We were unable to identify a consistent cause for data errors, which appeared unrelated to the brand or version of patient record software used; however, examination of specific software or transmission errors was beyond the scope of this study.

The second most common source of AIR inaccuracy was duplicate records, responsible for 20% of errors. Duplicates may occur on the AIR when a child has more than one Medicare number, or encounters are entered without a Medicare number. Other duplicates arose through errors in birth dates, use of different surnames, or in situations such as foster care. If PHU staff were able to locate the duplicate records pair (whether the pair was in the sample or not) they updated the AIR to consolidate them into one complete record.

Table 2: Incorrect recording on AIR by vaccine coverage area, rurality, SEIFA and Aboriginal status, for NSW children at one year of age, 30 September 2017.

Measure	Variable	n=414	% Incorrectly reported*	95%CI	% AIR Reported coverage	% Corrected coverage	95%CI	p-value
Coverage area	Low coverage <92%	66	36.7	(26.5, 46.9)	–	–	–	
	Mid coverage 92-94%	120	33.5	(25.9, 41.1)	–	–	–	p=0.9
	High coverage >94%	228	35.4	(30.2, 40.5)	–	–	–	
Rurality (ARIA+)	Major City	268	34.9	(30.1, 39.8)	–	–	–	
	Inner regional, outer regional, remote and very remote	146	34.6	(30.3, 38.9)	–	–	–	p=0.9
SEIFA†	Low SEIFA	170	37.2	(30.7, 43.6)	–	–	–	
	Mid SEIFA	147	29.8	(23.5, 36.1)	–	–	–	p=0.2
	High SEIFA	97	37.9	(29.4, 46.3)	–	–	–	
Aboriginal status	Aboriginal or Torres Strait Islander	37	23.5	(13.6, 33.4)	94.2	95.6	(95.0,96.1)	
	Neither Aboriginal or Torres Strait Islander	359	34.2	(29.9, 38.4)	94.1	96.1	(95.9,96.4)	p=0.007
	Unknown status	18	63.5	(45.3, 81.7)	–	–	–	–

Notes:
** Percentage incorrectly recorded as overdue on the Australian Immunisation Register*
† SEIFA—2011 Index of Relative Socio-Economic Disadvantage (IRSD)
– Not applicable to analysis

The AIR uses registration data from Medicare to calculate the denominator. Duplicate records artificially inflate the denominator, which in turn reduces estimated immunisation coverage.

Clinician errors, either human error entering information in the child's medical record or incorrect vaccine dose recorded, appear to be rare causes of being assessed as not fully vaccinated, with only two instances detected in our sample.

Twenty-four children who had moved overseas permanently were recorded as overdue on AIR. This information was reported by the provider or other family members (remaining parent, grandparent). Parents of 16 children who were living overseas claimed their child was up-to-date with vaccinations. Of these, seven were able to provide evidence of vaccination and were thus moved to the 'AIR incorrect: child vaccinated' category.

As these children live overseas, leaving them on the AIR adds to underestimation of coverage as they contribute to the denominator without being able to contribute to the numerator, irrespective of whether they are vaccinated, unless a parent and a local provider take the trouble to manually register the overseas vaccines with the AIR. The procedure to remove children from the AIR when they are overseas requires an immunisation provider to tick a 'returned mail indicator' within the child's AIR record, or to contact the AIR in writing. The Department of Human Services advises that this will then remove the child from state coverage reports.

There were 54 children in the sample whose parents reported they had chosen not to vaccinate. Many of these children were already known to the health services so were not re-contacted. Some parents who were contacted offered reasons why they have not vaccinated their children. One parent stated a family history of allergic reaction to Boostrix®

Table 3: Sensitivity analysis accounting for children claimed to be vaccinated with no evidence and lost to follow up (LTFU).

All NSW	n=	% Incorrectly reported*	95%CI	% Reported coverage	% Corrected coverage	95%CI
Reported results (excluding 77 LTFU)	414	34.9	(30.9,38.9)	94.1	96.2	(95.9,96.4)
Counting vaccinated without evidence as fully vaccinated (excluding 77 LTFU)	414	39.6	(35.5,43.7)	94.1	96.4	(96.2,96.7)
Including LTFU as fully vaccinated	491	45.8	(41.9,49.6)	94.1	96.8	(96.6,97.0)
Setting LTFU as not vaccinated	491	29.0	(25.5,32.5)	94.1	95.8	(95.6,96.0)

Note:
** Percentage incorrectly recorded as overdue on the Australian Immunisation Register*

and another stated that a family member had died as a result of an adverse reaction to an unspecified vaccination. One family was not willing to vaccinate their child, citing cultural reasons.

A further 17 children had not been fully vaccinated as their parents were hesitant to vaccinate, some delaying their children's vaccinations until 'later'; vaccinating slowly, one vaccine at a time; or selectively choosing some vaccines.

This study shows that in NSW the national aspirational target of 95% fully vaccinated coverage[18] has been achieved for children at one year of age but confirms that despite policy settings encouraging accurate recording of vaccinations on the AIR, under-reporting continues at around 2%. For Aboriginal children, and in regions where resources are dedicated to ensuring accurate and timely recording of vaccination on AIR, error rates are lower.[18-21] Given the persistence of reporting errors in the absence of active local programs to clean and correct AIR records, consideration should be given to developing cost-effective centralised automated measures to identify and correct errors and duplicate records. Until this can be routinely achieved at a national level, AIR coverage data for children at one year of age should be treated as the minimum estimated coverage level for that age group.

Similar audits in the future may assess the magnitude of under-reporting in other age cohorts and provide further evidence of undercounting to enrich our understanding of how sociodemographic or practice level characteristics may contribute to under-reporting.

Limitations

As this study is cross-sectional, the prospect is raised that if another time frame had been sampled, different results may be uncovered. However, given the similarity between this and other relatively recent local audits we do not expect that would occur.

The 77 records that were lost to follow-up may have introduced non-response bias into the study and was countered by conducting a sensitivity analysis that indicated that conclusions of the study were not materially affected (Table 3).

We aimed to minimise interviewer bias by providing a questionnaire with mostly closed form responses.

Possibly of greater importance is that the under-reporting estimate at one year of age is not generalisable to other age groups. As children become older, they are increasingly likely to enrol in early childhood education, which should prompt correction of data transmission and clinician errors, as they are required to be recorded as fully vaccinated on the AIR to enrol in childcare in NSW and to receive Australian Government financial assistance to attend. Thus, if overdue children were sampled at two or five years of age the under-reporting rate is likely to be lower.

Lastly, this study was not tailored to measure specific factors relating to people from culturally and linguistically diverse backgrounds, with potentially different drivers influencing recorded immunisation coverage.

Conclusion

Despite widespread use of electronic patient record systems and policy settings encouraging accurate recording of childhood vaccinations, publicly reported coverage estimates at one year of age are approximately 2% lower than true vaccination rates. This systematic underestimating of coverage should be clearly conveyed whenever AIR coverage estimates are quoted. Data transmission errors were the most frequent cause for errors on the AIR; however, other factors included duplicate records and children living overseas. Reasons for correctly recorded incomplete vaccination included vaccine hesitancy or refusal, lack of documentary evidence/records of vaccination, delays due to illness or children on catch-up schedules.

Cost-effective measures should be developed to routinely identify and correct common errors leading to incomplete or duplicate records on the AIR.

Acknowledgements

We would like to dedicate this paper to the memory of Karen Orr, an outstanding worker for childhood immunisation in New South Wales.

The authors would like to acknowledge the NSW Public Health Network AIR Study Group: Lisa Allchin, Katie Anagnostou, Sue Botham, David Boucher, Sophie Carey, Hayley Carra, Kwendy Cavanagh, Trisha Collins, Rachelle Deaker, Michelle Dives, Bridget Doyle, Michelle Ferguson-Hannah, Linda Granger, Sheila Hamm, Wendy Holmes, Essi Huhtinen, Andrew Ingleton, Jane Jelfs, Emily Keighran, Judith Kennedy, Liz Kirk, Julie McLean, Dee McNamara, Jackie Milsom, Amy Nicholson, Clare Pearson, Juhel Pritchard, Tania Simpson, Angela Shirlaw, Jane Thomas, Marianne Trent, John Turahui, Natasa Veselinovic, Cheryl Wasley, Kristie Waters, Jennifer Wedd and Robert Whybrow.

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Appendix B. Project summary

PROJECT SUMMARY
AUSTRALIAN IMMUNISATION REGISTER (AIR) STATE-WIDE AUDIT

Primary Investigator:	Charlee Law, Master of Applied Epidemiology Scholar
Contact:	Charlee.Law@moh.health.nsw.gov.au; (02) 9391 9723
Co-investigators	AIR Working Group, NSW Health

Project Title

How accurate is the AIR estimate of immunisation coverage for NSW children 12-<15 months of age?

Summary

NSW Health is undertaking an audit to provide a better estimate of immunisation coverage in NSW for children 12-<15 months of age.

The primary objective of this study is to quantify the percentage of children in NSW aged 12-<15 months who are not genuinely overdue on the AIR.

The secondary objectives are:

- To identify reasons for underreporting on the AIR
- To understand if the rate of underreporting varies by reported coverage level, socio economic status (measured through SEIFA indicator values) (13) and provider status (Metro/rural and large vs. small practices).

Expectations of the study

- A better estimate of true immunisation coverage in NSW
- Indicators for underreporting on the AIR based on factors including coverage areas (low, medium and high), socio-economic status (low, medium and high) and provider setting (rural/remote and large vs. small practices).
- Detection of changes in undercounting and possible explanations for the findings

Outputs

- A report will be written for information of NSW Health and for peer review submission and/or conference presentation
- Dissemination of findings to stakeholders of the project as well as LHDs across NSW.
- Recommendations for appropriate actions or policies (for example to review and allocate more resources toward communities with true low coverage, or conduct further research).

Timeline

The audit is planned to be undertaken across public health units from 9 October to 3 November 2017

Data receipt and analysis will commence in November with the final draft report expected to be submitted in January 2018.

Appendix C. Expression of interest

EXPRESSION OF INTEREST
AUSTRALIAN IMMUNISATION REGISTER (AIR) STATE-WIDE AUDIT

Protocol Title
How accurate is the AIR estimate of immunisation coverage for NSW children 12-<15 months of age?

Summary
NSW Health is undertaking an audit to provide a better estimate of immunisation coverage in NSW for children 12-<15 months of age. The primary objective of this study is to identify/quantify children who are not genuinely overdue on the AIR, and to identify reasons for underreporting. The research is expected to provide:

- A better estimate of true immunisation coverage in NSW
- Indicators for underreporting on the AIR based on factors including coverage areas (low, medium and high), socio-economic status (low, medium and high) and provider setting (rural/remote and large vs. small practices).
- Detection of changes in undercounting and possible explanations for the findings (e.g. No Jab No Pay)
- The NSW Health AIR Working Group is requesting assistance from LHD Immunisation Coordinators (or delegates) from NSW public health units to audit a sample of overdue children listed on the AIR in their jurisdictions from 9 October to 3 November 2017.

Timeline and outputs
The audit is planned to be undertaken across public health units from 9 October to 3 November 2017.
A report will be written for information of NSW Health which will include recommendations for appropriate actions or policies by January 2018

What would be expected of you (Audit sites)?

- To utilise guidance tools and standardised questionnaires to audit the sample of overdue AIR records provided by NSW Health
- To return completed questionnaires to NSW Health in the required timeframe for analysis

What is the role of NSW Health (AIR Working Group)?

- To attain ethics approval from Australian National University and endorsement from LHDs across NSW
- Develop a study protocol and audit tool to enable LHDs to follow up overdue children on the Register
- Download the AIR011A report for the quarter ending September 2017 at the beginning of October 2017; pre-clean, stratify, and send a sample to LHD Coordinators for follow-up
- Collect and analyse data returned from the audit sites and formulate a report that describes the extent of undercounting in the AIR and the main contributors to this

Benefits of participation
This study will assess the magnitude of underreporting in NSW and provide a better estimate of true immunisation coverage, which is currently unknown. This will subsequently provide evidence to support more effective resource mobilisation toward targeted public health programs to areas with true low coverage.
For more information please contact Charlee Law, Master of Applied Epidemiology Scholar, Charlee.Law@moh.health.nsw.gov.au; (02) 9391 9723

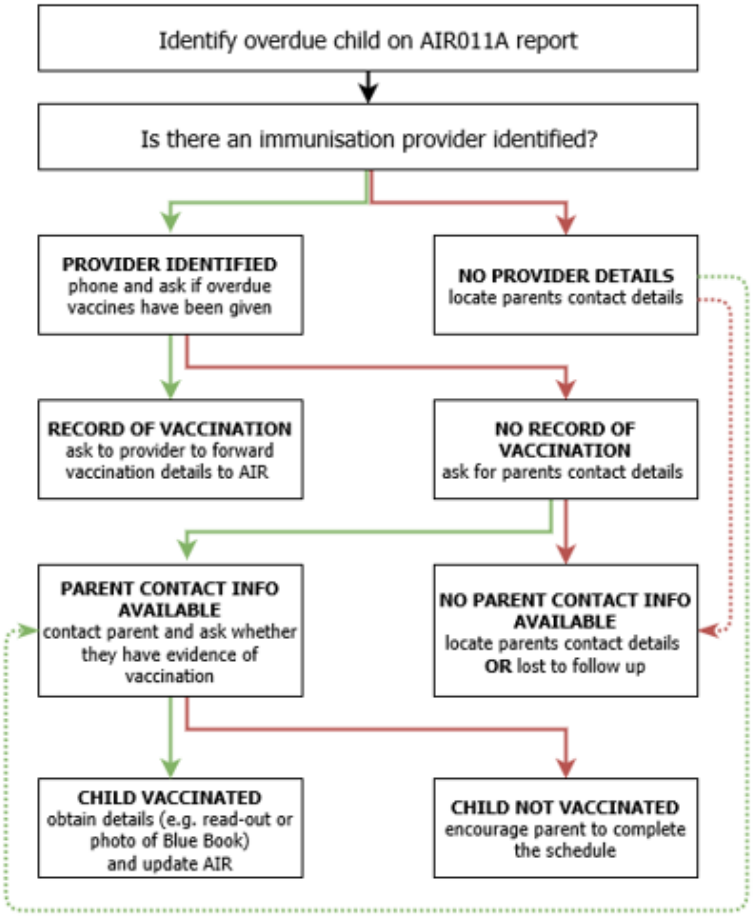
Appendix D. AIR Audit Tool

AUDIT GUIDE
Australian Immunisation Register (AIR) State-wide Audit

Thank you again for your participation in the AIR audit. Please refer to this sheet before commencing the audit in your PHU, as it provides an overview of the key actions to be aware of during this process. A follow-up protocol is provided on the next page describing the steps of the audit. If at any time you have any questions or concerns, please contact Charlee Law on the details overleaf.

Item	Information/Actions
Before you start the questionnaire	Using the spread sheet, list the ID.x number for the child at the top of the page Complete Practice (where applicable) and/or Patient Details on the front page. Ensure overdue vaccines are listed in Table A of the Questionnaire (or Table B if there is no provider number linked to the child) Fill in details written in <Black Bold> throughout the questionnaire
Following up overdue records by telephone The LHD Coordinator (or delegate), will contact the provider or parent using the questionnaire.	If there is an immunisation provider linked to the child: Using the questionnaire, phone provider, and ask appropriate staff member (e.g. GP, Authorised Nurse Immuniser, health worker) if there is a record of the encounter. If there is, ask them to forward vaccination details to AIR. Actions for this child are now complete. **If the provider cannot be reached:** • Use other contact information if available (e.g. contact details of parents). Interview parents using SECTION 5 of the Questionnaire. Children that are unable to be contacted will be deemed as LOST TO FOLLOW-UP. **If there is NOT an immunisation provider linked to the child:** • Attempt to contact the parents using SECTION 5 of the Questionnaire. Children that are unable to be contacted will be deemed as LOST TO FOLLOW-UP.
Updating overdue records onto the AIR	**Where the provider has been reached:** The PHU can correct the record, or can ask the provider to update encounter information on the AIR. **Where the parent has been reached:** The PHU will update the parents information onto the AIR
Submitting completed questionnaires	You can submit questionnaires as they are completed to Charlee.Law@moh.health.nsw.gov.au To assist with tracking, please input the ID.x number/s into the subject line of the email.

NSW AUSTRALIAN IMMUNISATION REGISTER (AIR) FOLLOW-UP PROTOCOL



Brief outline of contact details and project status

Investigator Co-investigators Contact	Charlee Law, Master of Applied Epidemiology Scholar AIR Working Group, NSW Health Charlee.Law@moh.health.nsw.gov.au; (02) 9391 9723
Project aim	To provide a better estimate of immunisation coverage in NSW for children 12-<15 months of age.
Audit timeframe	Monday 9 October to Friday 3 November 2017.
Inputs	AIR011A report sample of 12-<15 month old NSW residents, listed on the Register as >30 days overdue between July and September ('September quarter') of 2017.
Outputs	Patient encounter information: tracking to AIR or information provided by parent
Survey format	MS Word document accompanied by Excel database via secure file transfer.

Appendix E. AIR Questionnaire

XXX LHD AUSTRALIAN IMMUNISATION REGISTER (AIR) STATE-WIDE AUDIT QUESTIONNAIRE	ID: ES: Y / N
Interviewer use only	
Interviewer name:	Provider reached: ☐Yes ☐No Parent reached: ☐Yes ☐No
PRACTICE DETAILS	
Practice Name:	Practice Address:
Phone number:	Email Address:
PATIENT DETAILS	
Surname: blank out before resubmission	First Name/s): blank out before resubmission
Gender: ☐ male ☐ female	DOB: Age (months):
☐ Aboriginal ☐ Torres Strait Islander ☐ Both Aboriginal & Torres Strait Islander ☐ Neither ☐ Unknown	
PREAMBLE	
Before interview commences, ensure all overdue vaccine/s are listed on Table A at end of SECTION 2 "Hello, this is <name> calling from <public health unit name>. May I please speak with your practice/ Authorised Nurse Immuniser regarding the immunisation records for one of your patients? If no, could someone else help? "Hello <Authorised Nurse Immuniser /Dr name>, this is <name> calling from <public health unit name>. I am calling to check that the Australian Immunisation Register (AIR) has the correct record for one of your patients. To assess if the AIR has the correct record, I need to ask you a number of questions. The audit takes about 10 minutes to complete." "An ANU student is also working on this audit which is being implemented state-wide, and intends to write up the overall outcome to provide a better estimate of immunisation coverage in NSW for children 12-<15 months of age. Your information will be kept confidential; and no identifying information will be used in the report. Are you happy to participate?" ☐Yes ☐No Date_____-_____-_____ If no, Thank provider for their time and end interview. Submit questionnaire to Charlee.Law@moh.health.nsw.gov.au If yes, "Thank you. Is now a convenient time, or would you like me to call back at another time?"	
Note: If the respondent is unsure to any questions in the survey, follow this preamble:	
"As we think these questions may be important to our audit, is there someone else in the practice/clinic that I might call back and ask these questions to?" ☐Yes ☐No If yes, obtain contact name and phone number of other person to contact, then go to SECTION 4 What is their name? _____ When would be a good time to call? _____	

SECTION 2: If Yes, child is recorded as vaccinated	
"Can you please read out the following details of the child?"	
Date of birth:	
Address:	
Medicare #:	
"Can you please read out the following details of the vaccination encounter/s?" Ask questions about each vaccine by completing Table A	
Definitions for Table A Data error = error in transmission (by whatever means) of information from child's medical record to the AIR Clinical error = human error in putting information in the child's medical record, or incorrect vaccine administered If a vaccine or dose needs to be updated onto the AIR, the PHU can correct the record, or inform the provider that they may need to contact the AIR to correct the error.	
Go to SECTION 4: Methods used to transfer records onto the AIR	

Table A: Details of overdue vaccination on the AIR from provider

Vaccine listed as overdue on AIR	Dose number/s	Did child receive vaccine?	Date/s of Vaccination	Where did the child receive these vaccines?	Where are these vaccines recorded?	Who is recorded as providing these vaccines?	Was this a data or clinical error?
<Vaccine 1>		☐ Yes ☐ No		☐ At this practice ☐ Overseas ☐ Another provider ☐ Other (specify)	☐ immunisation tab ☐ clinical notes	☐ Doctor ☐ Auth Nurse Immuniser ☐ Nurse (Other)	☐ Yes, data error ☐ Yes, clinical error
<Vaccine 2>		☐ Yes ☐ No		☐ At this practice ☐ Overseas ☐ Another provider ☐ Other (specify)	☐ immunisation tab ☐ clinical notes	☐ Doctor ☐ Auth Nurse Immuniser ☐ Nurse (Other)	☐ Yes, data error ☐ Yes, clinical error
<Vaccine 3>		☐ Yes ☐ No		☐ At this practice ☐ Overseas ☐ Another provider ☐ Other (specify)	☐ immunisation tab ☐ clinical notes	☐ Doctor ☐ Auth Nurse Immuniser ☐ Nurse (Other)	☐ Yes, data error ☐ Yes, clinical error
<Vaccine 4>		☐ Yes ☐ No		☐ At this practice ☐ Overseas ☐ Another provider ☐ Other (specify)	☐ immunisation tab ☐ clinical notes	☐ Doctor ☐ Auth Nurse Immuniser ☐ Nurse (Other)	☐ Yes, data error ☐ Yes, clinical error
<Vaccine 5>		☐ Yes ☐ No		☐ At this practice ☐ Overseas ☐ Another provider ☐ Other (specify)	☐ immunisation tab ☐ clinical notes	☐ Doctor ☐ Auth Nurse Immuniser ☐ Nurse (Other)	☐ Yes, data error ☐ Yes, clinical error
<Vaccine 6>		☐ Yes ☐ No		☐ At this practice ☐ Overseas ☐ Another provider ☐ Other (specify)	☐ immunisation tab ☐ clinical notes	☐ Doctor ☐ Auth Nurse Immuniser ☐ Nurse (Other)	☐ Yes, data error ☐ Yes, clinical error
<Vaccine 7>		☐ Yes ☐ No		☐ At this practice ☐ Overseas ☐ Another provider ☐ Other (specify)	☐ immunisation tab ☐ clinical notes	☐ Doctor ☐ Auth Nurse Immuniser ☐ Nurse (Other)	☐ Yes, data error ☐ Yes, clinical error
<Vaccine 8>		☐ Yes ☐ No		☐ At this practice ☐ Overseas ☐ Another provider ☐ Other (specify)	☐ immunisation tab ☐ clinical notes	☐ Doctor ☐ Auth Nurse Immuniser ☐ Nurse (Other)	☐ Yes, data error ☐ Yes, clinical error
<Vaccine 9>		☐ Yes ☐ No		☐ At this practice ☐ Overseas ☐ Another provider ☐ Other (specify)	☐ immunisation tab ☐ clinical notes	☐ Doctor ☐ Auth Nurse Immuniser ☐ Nurse (Other)	☐ Yes, data error ☐ Yes, clinical error

NOTES (e.g. duplicate records or other problems):

SECTION 3:
If no, no record of overdue vaccines being administered

"Does the child's medical record indicate any of the following reasons why a vaccination has been delayed?"

☐ Child sick
☐ Medical contraindication
☐ Parents hesitant
☐ Parents refuse
☐ Family overseas
☐ Other (please specify) _____
☐ Unknown:

If unknown, obtain parents name and phone number below:

"We would like to phone the parents of <child's name> to check whether they received a vaccination somewhere else this year, as we want to make sure that AIR has the correct record. Have you got a phone number for the parents of <child's name>? This may be found in sibling records (if applicable)"

☐ Yes ☐ No

If no,

Thank provider for their time and end interview.

Submit questionnaire to Charlee.Law@moh.health.nsw.gov.au

If yes,

Obtain contact name and phone number of the parent:

What is the parent/s name? _____ What is their phone number? _____

Thank provider for their time and end interview, then contact parent/s by going to SECTION 5

SECTION 4: Methods used to transfer records onto the AIR

"We also want to check what method your practice/clinic uses to transfer vaccination records to the AIR, as we are looking into problems with data transfer to AIR. What is your primary method for transmitting Immunisation encounters to AIR?"

☐ Practice Software	☐ Medical Director/PracSoft, Version: _____ ☐ Best Practice, Version: _____ ☐ ZedMed, Version: _____ ☐ MedTech, Version: _____ ☐ IMPS, Version: _____ ☐ Other (Specify)_____
☐ Paper-based	☐ Immunisation encounter (purple) form ☐ Immunisation history form
☐ AIR Online	☐ AIR webpage direct ☐ via PRODA ☐ via HPOS
☐ Other (please specify)	

Thank provider for their time and end interview.

If applicable, encourage provider to (re)forward details of the overdue vaccine/s to the AIR.

Submit questionnaire to Charlee.Law@moh.health.nsw.gov.au

SECTION 5: **If there are parents, contact information linked to the child**		**ID.x number:**
Interviewer name:	Parent reached: ☐Yes ☐No	
PATIENT DETAILS		
Surname: blank out before resubmission	First Name/s): blank out before resubmission	
Gender: ☐ male ☐ female	DOB:	Age (months):
☐ Aboriginal ☐ Torres Strait Islander ☐ Both Aboriginal & Torres Strait Islander ☐ Neither ☐ Unknown		
PREAMBLE		

Before interview commences, ensure all overdue vaccine/s are listed on Table B at the end of this section

"Hello, this is <name> calling from the Immunisation team at the <public health unit name>. I am calling about <child's name's> vaccination records. The Australian Immunisation Registers shows that <child's name> may be missing some vaccinations. We are doing a state-wide audit to check whether children recorded as overdue on the Register at 12 to 15 months of age are really overdue, or whether the Register is not accurate. An ANU student is coordinating the report of this work and we hope to publish it in a medical journal. Your information will be kept confidential and no identifying information will be used in the report. "

"May I please speak with your regarding the immunisation records for <child's name>" ☐ Yes ☐ No

If no, parent declines to participate:

Recommend they contact GP to review child records

Thank parent for their time and end interview.

Submit questionnaire to Charlee.Law@moh.health.nsw.gov.au

If yes,

"Thank you. Are you currently able to locate your child's Blue Book or vaccination record?

If yes, go to next section (PARENT QUESTION SECTION).

If no, parent cannot locate the Blue Book or other vaccination record at this time:

Attempt to reschedule, giving them opportunity to locate the Blue Book or other vaccination record.

Reschedule interview time and date: ___/____/_____ _____: _____am/pm

Confirm contact number: _____

Thank parent for their time and end interview.

If no, parent cannot locate the Blue Book or other vaccination record and is unwilling to reschedule:

Recommend they contact GP to review child records

Thank parent for their time and end interview

Submit questionnaire to Charlee.Law@moh.health.nsw.gov.au

PARENT QUESTION SECTION
"Can you please check whether <child's name> received any of these vaccinations? " Read out overdue vaccine/s on Table B at the end of this section Complete Column 2 by selecting Yes or No: 'Did child receive vaccine?' Complete Column 3 by inputting the dose number
If child received any of the listed vaccination/s:
"It appears that this record of vaccination has not been recorded by the AIR. Can you please tell me where your child received these vaccines?" Complete Column 4: Overseas; Immunisation provider (specify); or Other (specify)
"Could you please supply your child's Medicare details & details of the vaccine(s) received so I may correct the Australian Immunisation Register record?" Child's Medicare number: __ __ __ __ __ __ __ __ __ __ Position number on card: __ Complete Column 5: Provider name Complete Column 6: Date of vaccination
"Would you be able to SMS a picture message or email a photo of the blue book/other record to <mobile number and/or email address>?" ☐ Yes ☐ No If no, they are unable to send a photo or provide enough evidence to give confidence about the vaccination: Recommend they contact GP to review their child's records Thank parent for their time and end interview Submit questionnaire to Charlee.Law@moh.health.nsw.gov.au If yes, they are able to send a photo or provide enough evidence to give confidence about the vaccination: Recommend they contact GP to review their child's records Thank parent for their time and end interview Submit questionnaire to Charlee.Law@moh.health.nsw.gov.au Public Health Unit update vaccination details onto the AIR
If child has not received any of the listed vaccinations:
Ensure parent is aware of the vaccines the child is overdue for, and encourage them to vaccinate their child. Thank parent for their time and end interview Submit questionnaire to Charlee.Law@moh.health.nsw.gov.au

Table B: Details of overdue vaccination on the AIR for parents

Vaccine listed as overdue on AIR	Did child receive vaccine?	Dose number	Where did the child receive these vaccines?	Provider Name	Date/s of Vaccination	Other comments
<Vaccine 1>	☐ Yes ☐ No		☐ Overseas ☐ Another provider ☐ Other (specify)			
<Vaccine 2>	☐ Yes ☐ No		☐ Overseas ☐ Another provider ☐ Other (specify)			
<Vaccine 3>	☐ Yes ☐ No		☐ Overseas ☐ Another provider ☐ Other (specify)			
<Vaccine 4>	☐ Yes ☐ No		☐ Overseas ☐ Another provider ☐ Other (specify)			
<Vaccine 5>	☐ Yes ☐ No		☐ Overseas ☐ Another provider ☐ Other (specify)			
<Vaccine 6>	☐ Yes ☐ No		☐ Overseas ☐ Another provider ☐ Other (specify)			
<Vaccine 7>	☐ Yes ☐ No		☐ Overseas ☐ Another provider ☐ Other (specify)			
<Vaccine 8>	☐ Yes ☐ No		☐ Overseas ☐ Another provider ☐ Other (specify)			
<Vaccine 9>	☐ Yes ☐ No		☐ Overseas ☐ Another provider ☐ Other (specify)			

NOTES (e.g. duplicate records or other problems

Chapter 3

Analysis of a public health dataset

Investigation into high Q fever rates in Aboriginal people living in Western NSW

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Chapter 3 Table of Contents

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Tables and figures

Tables

Figures

Acronyms

ACCHS	Aboriginal Community Controlled Health Services
AH&MRC	Aboriginal Health and Medical Research Council of NSW
AMS	Aboriginal Medical Service
ANU	Australian National University
ARA	Aboriginal Research Advisory (Group)
CDNA	Communicable Diseases Network Australia
DPI	Department of Primary Industries
EHO	Environmental Health Officer
HREC	Human Research Ethics Committee
IgA	immunoglobulin class A
IgG	immunoglobulin class G
IgM	immunoglobulin class M
LGA	Local Government Area
MAE	Master of Philosophy in Applied Epidemiology
NCIMS	Notifiable Conditions Information Management System
NQFMP	National Q Fever Management Program
NSW	New South Wales
NQFMP	National Q Fever Management Program
PCR	Polymerase chain reaction
PPE	Personal protective equipment
SAPHaRI	Secure Analytics for Population Health Research and Intelligence
TOR	Terms of Reference
Yr	Year

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Prologue

During a routine analysis of notifiable zoonotic diseases in New South Wales (NSW), the Enteric and Zoonotic Diseases team discovered an over-representation of Q fever in Aboriginal people, particularly in Western NSW local health district. (1) When I was asked to investigate this, I immediately thought a confounder was at play. Q fever is not a disease that should act differently across racial demographics. Its causative agent, Coxiella *burnetii*, (2) is too tiny to care about what mob you are from (or if you even have one), and is instead preoccupied being the Bear Grylls of its genus; surviving the most extreme conditions, gliding kilometres along the wind into a respiratory tract near you, or spelunking through the flesh and blood of an unsuspecting ruminant.

It did not make sense to describe what was occurring in Western NSW by numbers alone without understanding the situation on the ground. I formed an Aboriginal Research Advisory Group to find meaning behind the numbers. I worked with agencies who described the impact Q fever had on their client's livelihoods. I listened to personal stories about the impact of Q fever on peoples' daily lives, about relatives who became sick and even died. People who had the disease but were reluctant to tell their employers. When I considered what I had learnt along with the information I scoured from six years' worth of questionnaires and case notes, I realised that it was through these stories that we could find pathways toward meaningful action.

I present to you another onion layer to the overall story, about a fresh-faced MAE and Q fever, Australia's most prevalent and prolific vaccine-preventable zoonotic disease - that nobody has ever heard of - and most importantly, the public health action that arose from this.

Lessons learnt

Lesson 1: Ensuring Aboriginal community control in an infectious disease investigation

Our investigation focused on Aboriginal people, so ethics approval was required from the Aboriginal Health and Medical Research Council (AH&MRC). This was my first time performing an investigation that required these ethics approvals. Key principle 4.2 of the AH&MRC Guidelines for Research into Aboriginal Health stated that Aboriginal governance over the project was required.

" There must be Aboriginal community control over all aspects of proposed research including the design and conduct of the research, ownership of data, interpretation of data, and the reporting and publication of findings from research affecting the health of Aboriginal people."

- AH&MRC Guidelines for Research into Aboriginal Health 2016, page 5 (3)

It took time and negotiation to ensure this could go forward in a meaningful way. Because the investigation involved confidential medical record information, there was rigidness to how it was conducted. To ensure Aboriginal governance over the project could be upheld without releasing identifiable data, I formed an Aboriginal Research Advisory group consisting of representatives from Aboriginal Community Controlled Health Services (ACCHSs), NSW Health and a tertiary institution. The group reviewed the results from the study and identified appropriate pathways and messaging channels to report and use the findings. These messaging channels have become a part of the strategic actions for Q fever prevention in NSW over the next four years. Meaningful representation is crucial because ultimately, we know our people best. By allowing this to evolve organically rather than bureaucratically we had a good outcome, and those benefits flow to the people who are at risk of Q fever.

Lesson 2: Advocacy

Later in the investigation the Enteric and Zoonotic Diseases team received funding for Q fever awareness campaigning, with a small window of time to produce campaign materials. It was bought to my attention that the funding had pre-prescribed conditions that we could only produce tangible materials such as brochures and posters. I co-produced an information sheet about Q fever, of which the content and outlay was determined by the community to ensure maximum impact and effectiveness in communicating health messaging (0). I learned how to design and implement a consultation remotely, when I normally would have conducted it face-to-face. I also would have gone out to areas affected and held town hall meetings for health services and community to attend. The learning curve in this instance was to work with what resources are available, and advocate for changes in the way we utilise funding in future campaigns.

MAE Role

My role in this investigation was to perform an enhanced analysis of Q fever notifications of Aboriginal and non-Indigenous people living in Western NSW local health district). My tasks included:

- Desktop literature review using the PubMed database.
- Enhanced analysis of Q fever notifications reported in NSW between 2012-2017 using data from the NSW Notifiable Conditions Information Management System (NCIMS).
- Extensive data cleaning including a review of all attachments to confirmed Q fever cases on NCIMS (clinical notes, discharge summaries, questionnaires and

lab results) to improve data completeness and fill missing variables; and the merge and categorisation of animal, occupation and vaccination status variables.

- Ethics application and approval from Australian National University (ANU) and the Aboriginal Health and Medical Research Council (AH&MRC).

- Locate missing information about Western NSW cases that have not listed their Aboriginal and/or Torres Strait Islander status to ensure that we can get the most accurate results particularly as there are small numbers.

- Creation of Aboriginal Research Advisory Group which included the development of a Terms of Reference (TOR), delivery of teleconferences, follow-up to internal and external agencies and development of strategic resources to address recommendations of the group.

Abstract

Background

Higher rates of Q fever infection were notified in Aboriginal people relative to non-Indigenous people in NSW in 2015-2016. Further analysis found the majority of Aboriginal cases were located in Western NSW local health district. We sought to determine whether there was a true difference in rates and if specific factors had driven the overrepresentation of cases.

Methods

Secondary data analysis of Q fever notification data for the period 2012-2017. Data was extracted from the NSW Notifiable Disease Information Management System. Statistical analysis was conducted using STATA 15 (4) and Microsoft Excel. Data was analysed by indirect standardisation of age, sex and location, and a risk ratio exposure analysis of occupation, animal exposure and vaccination status.

Results

There was an over-representation of Q fever cases notified in Aboriginal people living in Western NSW (56.1% of all cases). The majority were under 29 years of age (66%), whereas the majority of non-Indigenous people were aged between 40-59 years (44%). Rates of Q fever in Western NSW for Aboriginal people were 16.7 per 100,000 and 13.8 per 100,000 for non-Indigenous people. The indirectly standardised rate for Aboriginal people in Western NSW was 19 per 100,000 (95%CI 12.8-26.3) and 14 per 100,000 for non-Indigenous people. The indirectly standardised morbidity ratio was 135.4 (95% CI 92.6-191.1,) indicating there were 35% more cases of Q fever in Aboriginal people in Western NSW compared to non-Indigenous people, consistent with the rest of NSW. In Western NSW, farm animals were the most common animal exposure reported by

Aboriginal (n=28/32, 87.5%) and non-Indigenous (n=187/203, 92.1%) people. Living or working on a farm was the most reported occupational exposure for both Aboriginal (n=28/32, 87.5%) and non-Indigenous people (179/203, 88.2%). Risk ratio (RR) calculations showed that shearing exposures in Aboriginal people (n=18, 56.3%) were 4.2 times higher than those reported in non-Indigenous people (n=37, 18.2%), (RR 4.2 95% CI 2.2-7.9, p value=<0.01). Aboriginal people were 2.6 times more likely to have no high-risk occupation compared to non-Indigenous people, which was likely attributed to age (RR 2.6 95%CI:1.4-5.0, p value 0.01). Aboriginal people were 5 times more likely to be too young for vaccination when compared with non-Indigenous people (RR 5.1 95%CI: 2.8-9.1, p=<0.01). Aboriginal community consultation identified target groups and strategic actions for people living in rural NSW, hunters and shooters, job seekers, and primary industries workers and students which included the development of information, education and communications material.

Conclusion

Q fever is the most common vaccine-preventable zoonotic disease in Australia, which can cause debilitating and long term illness. Aboriginal people in Western NSW are disproportionately affected by Q fever. Aboriginal community consultation identified messaging channels to reach at-risk groups with a particular focus on young Aboriginal people in Western NSW. On-going engagement with the Aboriginal community in understanding the problem and finding culturally appropriate solutions is crucial to address Q fever in communities of Western NSW.

Introduction

On 31 October 1935, a man named Edward Holbrook Derrick hastily filled a page of his laboratory notebook, leaving just enough room at the bottom to sketch some unusual things he observed on an impression smear from a guinea pig. Derrick had been undertaking a tireless investigation into a strange flu-like illness affecting abattoir workers in South-East Queensland. He coined the condition Q (for Query) fever.

On that October day he was probably unaware of the great things his laboratory journal would come to detail, and that his sketch was likely the first depiction of the causative agent of the disease. (5) He forwarded his research to Frank Macfarlane Burnett, along with his suspicions that this may not be a virus as the majority believed, but a rickettsia. By 1937, Burnett and his colleague Mavis Freeman had isolated the pathogen; and at almost the same time on the other side of the world, another man, Herald Cox, had done the very same. (5) The causative agent was named Coxiella *Burnetii*, after the men who had isolated the pathogen. (6)

Though much has changed in the eighty-four years since those humble notes on paper, one thing has not: that both Derrick and Q fever have probably not received the recognition they deserve. For starters, the public health impact of Q fever is profound. With the exception of New Zealand and Antarctica, C. *burnetii* has been found all across the world. (7) Outbreaks have occurred overseas, the largest in the Netherlands between 2007-2010 (8) with over 3500 cases in the first two years. (9) In Australia, Q fever is the most common notifiable zoonotic disease that can be prevented in humans by vaccination. (10, 11) Outbreaks of Q fever have occurred in Australia on small scales including veterinary staff becoming infected by a single animal (12) to larger scale outbreaks at high-risk workplaces such as abattoirs (13) or high animal density areas

including the saleyards. (14) Attempts to mitigate the risks for disease are further weakened by gaps in knowledge on best practice to detect, promote awareness and prevent the disease.

In 2016 the Health Protection NSW Communicable Diseases Branch published the NSW Zoonoses Annual Surveillance Report: 2016. (1) The report stated that although the number of confirmed cases in 2016 (225 cases, 2.8 cases per 100,000) had decreased from 2015 (15), they were still higher than the five year annual mean (180 cases, 2.41 cases per 100,000). The most significant increases for 2016 were observed in remote regional areas of Western NSW and Far West NSW local health districts. Of the 225 cases, 89% (n=200) had data indicating the cases Indigenous status. Of these, a disproportionate rate of Q fever infections among Indigenous Australians living in NSW were observed (n=13, 5.60 cases per 100,000) compared to NSW residents who were listed as not Indigenous (n=187, 2.47 cases per 100,000). (1) The annual incidence of Q fever in Australia during this time period has hovered around 2.2 per 100,000 with up to 85% of the burden shared by Queensland and NSW, respectively. (16)

Transmission pathways

Q fever has a complex range of transmission pathways and risk factors. The primary reservoir are ruminants, particularly cattle, goats and sheep. (17) Other carriers include feral animals including rabbits (7), camels (18) and wild dogs (19); native animals including kangaroos and wallabies (20); and domestic animals including cats and dogs (20, 21). A number of tick species carry C. *burnetii* although there is more to learn about the role they play in the transmission cycle of the disease. (22) Animals shed C. *burnetii* through their tissues (flesh and blood), products (wool and milk) and discharges (vaginal excretions and faeces). Birthing products are one of the most significant sources of Q fever. (23) These tissues, products and discharges are easily desiccated into the soil, aerosolized and carried large distances via the wind. (17, 24-26) Increased herd density and movement is shown to enhance the risk of Q fever. (18, 24) While dry and dusty weather increases the risk of transmission, rainfall is shown to be a protective factor for Q fever infection (17, 24). Q fever appears to follow a seasonal pattern worldwide that aligns with birthing seasons of ruminants and when people are more likely to be outdoors. (6) The introduction of an animal or animals that have the disease (shedder animals) is a clear pathway to introduce C. *burnetii* into a previously uninfected population. (17, 24) Ruminants have been found to continually shed C. *burnetii* in urine or faeces after the acute phase of their infection. (23) While animals that are infected with C. *burnetii* are mostly asymptomatic they can suffer spontaneous abortion or give birth to animals with low weight. (23) Humans are infected by Q fever though infected animal tissues, products and discharges, particularly placentas and birthing products that are either splashed or sprayed onto them. However, the most efficient pathway for human infection is through inhalation of contaminated dust or droplets contaminated

with C. *burnetii.* (14) People have also been exposed to Q fever through cuts in their skin or by ingesting contaminated dairy products. (24) There have been rare accounts of sexual transmission (27, 28), transmission following human childbirth (29) and infection following bone marrow transplantation. (30)

Symptoms

The incubation period is around 2-3 weeks, with many asymptomatic of disease. Those with symptoms may have pneumonia, hepatitis (usually without jaundice), arthritis or (rarely) meningitis. (31) Symptoms of Q fever in the acute phase may include debilitating headaches and severe, prolonged fever which can last well over a month. (23) This fever may be characterised by 'drenching' sweats. (32) The most common co-morbidity to C. *burnetii* infection in humans is hepatitis which can elicit fever, abdominal pain, lack of appetite, diarrhoea, nausea and vomiting. Cases may present without jaundice or asymptomatically. (23) The most common symptom after the acute phase is a type of extreme fatigue known as Q fever fatigue syndrome (QFS). (33) A study in the Netherlands showed that although most will recover after an acute Q fever infection, a third will continue to have poor health including severe fatigue and reduced quality of life for over two years post-infection. (34) Q fever can result in severe illness which may be compounded if there is delay in the disease to be diagnosed and treated. (35) Additionally longer term, more severe illnesses known as persistent focal infections, which have also been described as 'chronic Q fever' can arise. Persistent focal infections mostly present as endocarditis or a vascular infection. Cases with hepatitis in the acute phase may end up with granulomas on the liver. The proportion of those with persistent focal infections in NSW is not known as this data is not collected.

Laboratory confirmation

Polymerase chain reaction (PCR) is the most acceptable testing method of Q fever, particularly if the case is positive, however the more recent qPCR is potentially more useful despite being less sensitive. (25) A serological immunoglobulin class G (IgG) result or an immunoglobulin class M (IgM) result against phase I and II antigens describes an acute infection. An IgG >= either 1/800 or 1/1600 against phase I antigens, often with an immunoglobulin class A (IgA) against phase I and II antigens may characterise a persistent focal infection. (25, 31) Doxycycline is a highly effective baseline treatment for Q fever (25, 31).

Risk factors

Q fever is more commonly reported in men than women. This is most likely due to differential exposure with traditional male roles being more likely to be exposed to animal/environmental sources. However animal models indicate that there may also be a differential immune response to C. *burnetii* between males and females, which may contribute to the predominance of persistent focal infections amongst males.(36) Notifications are generally highest individuals aged 45-69, perhaps due to this being an appropriate working age group for people in high-risk, animal related industries. (25) People at the highest risk of long-term health impacts are those who are immunosuppressed or have pre-existing conditions (particularly cardiac co-morbidities and pregnant women in the first trimester of pregnancy), children and young adults. (31, 34) Due to the great distances that C. *burnetii* can travel after being aerosolised and carried by the wind, infection can occur in people that do not appear to have any risk factors. (26) Generally, those in rural settings are at greater risk of getting Q fever due to the animal and occupational risk exposures common to the rural lifestyle. (14, 35)

Vaccination

Globally, Q fever vaccination is manufactured for veterinary use only. Australia is the only country where a human Q fever vaccine, 'Q-VAX®'(37) has been developed and made available to people over the age of 15. (38) The vaccine has a high estimated efficacy of 83-100%. (39) The reason Q fever vaccination is directed at humans in Australia rather than animals is largely due to the fact that the disease is considered endemic in many parts of the country and as such, an animal control approach may not be useful in Australian primary industries. (25)

Public health significance

Due to the severity and broad range of short and long-term health issues that may be associated with the disease, Q fever has a high public health significance. (32) It is therefore crucial to understand the epidemiology of the disease particularly when anomalies are detected among populations.

Gaps in existing knowledge

Q fever is found across non-traditional occupations and age groups, and in areas where people would not have been previously considered to be at risk. As knowledge increases, so does the complexity of building appropriate prevention strategies. There is no uniform approach to controlling Q fever, and more work is to be done to understand the aetiology the disease, particularly in non-traditional areas. (40) The development of preventative measures is dependent on many factors including animal density and movement, land characteristics, precipitation, temperature and industry type. (17, 24) It is important to gain a clearer understanding about the context of Q fever in NSW, and whether any risk groups are missing public health messages about the disease.

Objective

The aim of this study was to:

- Describe the epidemiology of Q fever in people living in Western NSW
- Determine if Aboriginal people are disproportionately affected by Q fever in Western NSW and examine exposure data to identify factors and other explanatory variables that may have driven this.
- Provide a community perspective of the data and understanding of the relevance of Q fever to the community.

Research Question

Are Aboriginal people disproportionately affected by Q fever in Western NSW compared to non-Indigenous people in the same area, and if so, are there any explanatory factors contributing to this?

Specific hypothesis under study

Aboriginal people are not disproportionately affected by Q fever in Western NSW.

Methodology

Context

As the data focused on Aboriginal people, decision-making and control by Aboriginal people over implementation and interpretation of findings through input, advice and oversight over the outcome of data was essential. To ensure elements of community control were upheld, an Aboriginal Research Advisory group was formed to provide a community perspective from the organizations that they represented and the communities they were from. Public health resource mobilisation may be ineffective if based on data alone without understanding if these approaches are relevant for community. The group reviewed and endorsed the results from the study and identified appropriate pathways to report and use the findings. This was done through a series of formal teleconferences and ad hoc communications. This approach allowed us to gain meaningful representation from the community and identify the most relevant matters to address which may not have been the key findings in the data.

Ethics

Ethics approval was granted from Australian National University (ANU), HREC number: 2018/030 and the AH&MRC, HREC number: 1367/18.

Study design

The study design followed a two-step process. The first was a secondary data analysis and the second was a community consultation to understand and interpret the findings, and to provide guidance to the government on potential strategies.

1) A secondary, descriptive data analysis was undertaken using Q fever notification data between 1 January 2012 to 31 December 2017 extracted from the NSW Notifiable Conditions Information Management System (NCIMS).
2) A community consultation was undertaken with Aboriginal people who represented organisations and communities affected by Q fever, and an Aboriginal Research Advisory group was formed to strengthen decision making.

Section 1: Retrospective data analysis

Study population

A case was defined as any NSW resident meeting the NSW Health control guideline case definition for confirmed Q fever from 1 January 2012 to 31 December 2017. A confirmed case requires laboratory definitive evidence, or the combination of laboratory suggestive evidence and clinical evidence: (41)

Laboratory definitive evidence

- Detection of *C. burnetii* by nucleic acid testing, OR
- Seroconversion or significant increase in antibody level to Phase II antigen in paired sera tested in parallel in the absence of recent Q fever vaccination, OR
- Detection of *C. burnetii* by culture (this practice should be strongly discouraged except where appropriate facilities and training exist) (41)

Laboratory suggestive evidence

- Detection of specific IgM in the absence of recent Q fever vaccination (41)

Clinical evidence

- Clinically compatible disease (41)

Extraction of notification data

Q fever is a notifiable condition under the NSW Public Health Act 2010. (11) This investigation used retrospective NSW Q fever notification data as a .CSV file extracted from NCIMS for the period 1 January 2012 to 31 December 2017 based on notification date. Data was drawn from NCIMS in January 2018, and again in December 2018. The Q fever data extract downloaded from NCIMS had 380 variables. Of these, approximately 95 variables included animal, environmental, or occupational exposure information. The remaining variables included demographic, hospital and laboratory data.

Geographical location

NCIMS automatically generates multiple options for geographical location based on the address of the person at the time of notification. If the address was inadequate, the geographical location was assigned to the provider's address. Local health district borders (defined in 2010) were chosen as the unit for geographical analysis.

Indigenous status

In the database there were initially five options for Aboriginal status: "Aboriginal", "Both Aboriginal and Torres Strait Islander", "Not Aboriginal or Torres Strait Islander", "Not stated or unknown", and "Missing". For clarity and in line with accepted NSW Health terminology these were condensed into three variables as follows:

- Aboriginal includes "Aboriginal," (as there were no Torres Strait Islanders or Aboriginal and Torres Strait Islanders identified in the dataset)
- Non-Indigenous - includes "Not Aboriginal or Torres Strait Islander"
- Missing - includes "Not stated or unknown" and "Missing"

Fifty-seven people from Western NSW did not have their Indigenous status recorded on NCIMS. Their NCIMS ID was sent by secure server to the Western NSW Public Health

Unit. Staff checked the NCIMS record against their hospital electronic medical records system 'PowerChart' to determine whether they had identified as Aboriginal, resulting in 100% completeness of Aboriginal status data. This was only done in Western NSW as the scope of the investigation was focused on that area. Aboriginal status was classified using the 'ever-Indigenous' algorithm, described by the Australian Institute of Health and Welfare as defining a person as Aboriginal and/or Torres Strait Islander if they are recorded as such on any data set. (42) This approach is an acceptable method for determining Indigenous status because of its simplicity and minimal data requirements, particularly where there are only two data sets to link. (42) It is also appropriate for health research as there may be complex reasons why a person will identify in one health setting and not another. (43)

Age distribution

The data was aggregated into <20, 20-29, 30-39, 40-49, 50-59, 60-69 and 70+ year age groups.

Animal and occupational exposures

Occupational, animal and environmental exposure variables were aggregated from 95 variables into four main exposure variables:

1. Animal contact: Contact with birthing products; tissues, products and discharges; farm animals; native animals; feral animals and vectors (ticks)*
2. Species: Contact with cattle, sheep, goats, pigs, wild pigs, wild deer camels, alpacas/llamas, bandicoots, birds, kangaroos/wallabies, possums, rats and

* The variable 'vector (ticks) would also be included when reviewing species categories

domestic animals

3. Occupational exposure: All reported occupational exposures including abattoir, animal related, dairy farm, living or working on a farm, living or working near a farm or abattoir, grazier, shearing, hunting for work or recreation, attending saleyards, livestock carrier, veterinary, other or no risk occupation
4. Environmental exposure: Any report of dry, dusty and windy weather, lawn mowing including visiting or mowing at a golf course, contact with faeces and laundering contaminated or dirty work clothing

Missing data was cross checked with case notes, interview summaries, questionnaires and discharge summaries.

Vaccination History

The nine vaccination status variables were aggregated into five, including having awareness of Q fever; not having awareness of Q fever; accessibility issues; medical contraindications preventing vaccination; and a not stated category (Table 1).

Table 1 Vaccination status information aggregated into categories of Q fever in New South Wales between 1 January 2012 to 31 December 2017

Category	**Variables that were aggregated into this category**
Accessibility issues	Accessibility issues Employer delay or refusal
Aware of Q fever but not vaccinated	Aware of vaccine but forgot Chose not to have vaccine
Medical contraindications	Hx infection or medically unable Too young
Unaware of Q fever	Not considered a risk for Q fever Unaware of disease or vaccination
Not stated	Not stated

Data analysis

We used STATA 15 (4) and Microsoft Excel (44) to summarise and interpret the data. It is important to note as a caution in interpreting results that the local health district of residence does not necessarily reflect place of acquisition of exposure. Q fever is underreported across all jurisdictions. Q fever notifications are reflective of testing data and undercounts are likely.

1) NSW data

Frequencies and proportions were produced for the descriptive analyses of all NSW Q fever data by occupational and animal exposures, sex, age group, Aboriginal and Torres Strait Islander status and geographic location. Denominator data to calculate rates by age, sex, jurisdiction and year were obtained from the SAPHaRI portal and exported as a Microsoft Excel (44) worksheet. These data were generated by the Centre for Epidemiology and Evidence within the NSW Ministry of Health. Age- and sex-specific estimated resident populations (ERPs) for NSW local health districts at 30 June were obtained from the Australian Bureau of Statistics (ABS) for use with calendar year data.

2) Western NSW data

Frequencies and proportions were produced for the Western NSW data stratified by Aboriginal and Torres Strait Islander status for all of the following variables: occupational and animal exposures, sex, age group, geographic location. Population data by Aboriginal and Torres Strait Islander status was obtained from the ABS and utilised to produce rates and age-specific rates. Because of the differences in size between Aboriginal and non-Indigenous populations, indirect standardization was an appropriate tool to determine whether there was a higher incidence of Q fever in Aboriginal people compared to non-Indigenous people of similar age and location using

the ABS dataset. (45, 46) To determine whether there was an association between the exposure and vaccination status variables of Aboriginal and non-Indigenous people, ratio risks were calculated for occupational and animal exposures and vaccination status.

Section 2: Qualitative community consultation

For an effective and appropriate public health outcome, it was crucially important to engage with communities to identify the most appropriate method for transmitting information, education and communication; and have meaningful participation in the co-development of those materials. (47) A community-led approach benefits NSW Health through the appropriate utility of public health resources, and benefits communities through the development of culturally appropriate and relevant public health action strategies. Community priorities may differ from what may appear to be priorities in the data and can only be identified by those with intrinsic knowledge of these areas. This was conducted in six stages.

i. Establishment of an Aboriginal Advisory Group

Ensuring Aboriginal governance

The purpose of the advisory group was to strengthen decision-making and control by Aboriginal people over implementation and interpretation of findings, by providing input, advice and oversight over the outcome of data produced from the investigation. Membership included Aboriginal Community Controlled Health Services (ACCHSs) representatives, NSW Health representatives, a tertiary institution representative, and ex-officio who did not participate in decision making. Members were Aboriginal and had links to Western NSW. Members had professional experience in health and knowledge

on activities having the risk of Q fever including hunting, shearing and abattoir work; and knowledge of the schools and job agencies in the region. Table 2 details information about the advisory group members, their affiliations and other skills and knowledge relevant to the investigation.

Table 2 Details of the Aboriginal Research Advisory Group for Q fever in Western New South Wales at 30 March 2019 showing meaningful representation through affiliations, other vocational skills and knowledge relevant to the Q fever investigation

Members	**Sex**	**Affiliation**	**Other vocational skills or knowledge relevant to Q fever investigation**
Member 1	Female	Aboriginal Medical Service	Shearing schools and shearing industry/ employment agency network
Member 2	Female	Aboriginal Immunisation Health Worker	School children in agricultural schools of NSW, barriers and enablers to vaccination
Member 3	Female	Aboriginal Environmental Health (NSW Health)	Q fever in rural communities of NSW/ Q fever and animal health
Member 4	Male	Aboriginal Medical Service	Meat works/ abattoir industry, employment agency network
Member 5	Male	Aboriginal Public Health Training Program Initiative (NSW Health)	Hunting/ recreational shooting/ employment agency network
Member 6	Male	Epidemiologist (Australian National University)	Investigation design/ health perspectives in community

ii. Reflection and interpretation of data by health and community

Is this a problem?

The advisory group contributed to the interpretation of data around reported risk factors for Q fever by providing community perspectives from the organisations they represented and communities to which they were affiliated. Three formal teleconferences were held where a mutual understanding of the investigation was

gained. Members used this time to reflect and identify questions, issues and priority groups in the data.

iii. Collaborative planning

What can be done about the problem?

The advisory group identified appropriate messaging channels to report and use the findings and pathways to reach these channels. Barriers and enablers were discussed around Q fever prevention and vaccination.

iv. Review mainstream Q fever campaign

Are current strategies adequate? Who do we need to link in with?

We reviewed the organisations NSW Health were currently working with, as well as the target groups identified in the mainstream Q fever campaign. Strategies were developed by the advisory group to either broaden Q fever actions with existing organisational partnerships or create new links and strategies with relevant organisations who were not currently involved in the NSW Q fever campaign.

v. Acceptable strategies

Keeping things on track.

The final strategies and draft Information, Education and Communication (IEC) materials were sent to the advisory group and a wider group of ACCHS representatives in an email list provided by the Chief Executive Officer of the Walgett AMS for endorsement or amendment.

vi. Monitoring and evaluation

Updates on progress were communicated to the group as they were actioned, and a sustainability plan was set to communicate findings after the MAE role ended.

Results

Q fever notifications in New South Wales

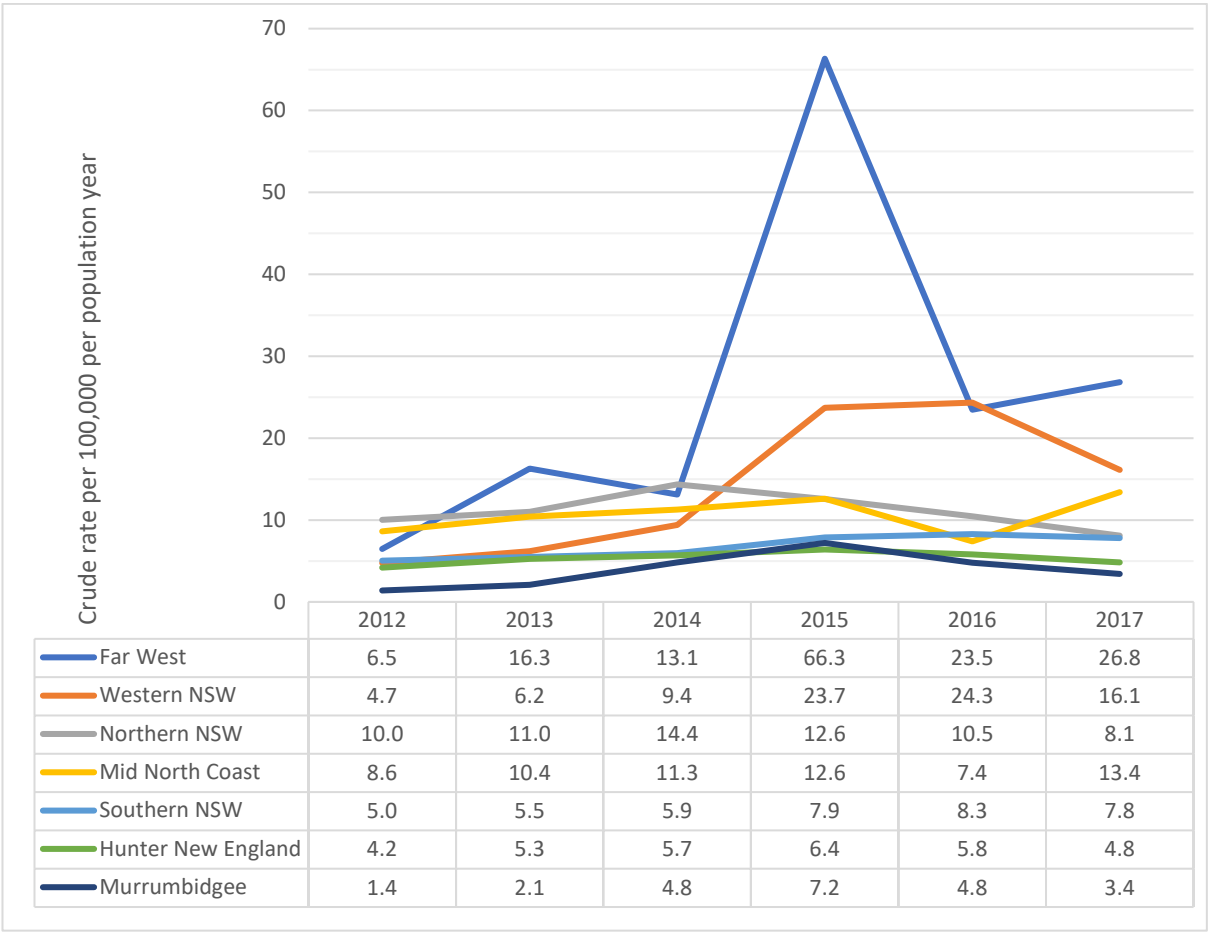
There were 1648 notifications for Q fever recorded in NCIMS across NSW from 1 January 2012 to 31 December 2017. Of these, 1178 met the case definition for confirmed Q fever as per NSW Health control guidelines. (32) The remaining 470 were excluded from analysis. There were 50 confirmed cases of Q fever in Indigenous Australians, 982 in non-Indigenous people, and a further 146 cases had unknown Indigenous status (Table 3). The rate was 3.7 per 100,000 for Indigenous Australians and 2.6 per 100,000 for non-Indigenous people. Males were most affected with 79% (n=933) of all notifications. The median age at the time of notification was 49 years with a 95% confidence interval (CI) 48.1-49.9% and a standard deviation of 16.5 years (Table 4). The local health districts with highest average rates per 100,000 population per year were Far West NSW (25.4 per 100,000), Western NSW (14.08 per 100,000), Northern NSW (11.08 per 100,000) and Mid North Coast (10.61 per 100,000). These local health districts all saw an upward trend into 2014 and 2015, when rates began to decline in most districts. However, Western NSW rates continued to climb until mid-2016, exhibiting the highest rates in NSW (Figure 1). In 2015 Far West had an elevated case count and rate due to an outbreak in Lightening Ridge where 14 confirmed cases were identified between 1 December 2014 and 31 May 2015. (48)

Table 3 Summary of Q fever notifications in New South Wales by selected demographic factors between 1 January 2012 and 31 December 2017.

Demographic characteristics	Number of notifications N (%)	Average rate per 100,000 population
Total cases	1178	2.6
Sex:		
Male	933 (79%)	111.5
Female	245 (21%)	29.6
Indigenous status:		
Indigenous	50	3.7
Non-Indigenous	982	2.6
Unknown	146	
Mean age	49 years (95% CI 48.1-49.9, standard deviation 16.5 years)	
<20 years	82	NA
20-29	140	NA
30-39	134	NA
40-49	242	NA
50-59	308	NA
60-69	196	NA
70+	74	NA
Local Health District		
Hunter New England	290	5.36
Western NSW	235	14.08
Northern NSW	195	11.08
Mid North Coast	136	10.61
Southern NSW	82	6.74
Murrumbidgee	69	3.95
Illawarra Shoalhaven	56	2.35
Far West	46	25.42
South Western Sydney	23	0.41
Northern Sydney	20	0.37
South Eastern Sydney	11	0.21
Central Coast	6	0.30
Nepean Blue Mountains	6	0.28
Western Sydney	2	0.04
Sydney	1	0.03

Demographic characteristics	Number of notifications N (%)	Average rate per 100,000 population
Vaccination status		
Not considered a risk for Q fever	305 (25.9%)	NA
Not stated	286 (24.3%)	NA
Chose not to have vaccine	223 (18.9%)	NA
Unaware of disease or vaccination	192 (16.3%)	NA
History of infection or medical contraindication	54 (4.6%)	NA
Employer delay or refusal	36 (3.1%)	NA
Too young	34 (2.9%)	NA
Aware of vaccine but forgot	26 (2.2%)	NA
Vaccinated	12 (1.0%)	NA
Accessibility issues	10 (0.8%)	NA

Figure 1 Rates* of Q fever notifications for NSW local health districts that exceed the state average of 2.7 per 100,000, by year and, 1 January 2012 to 31 December 2017



	2012	2013	2014	2015	2016	2017
Far West	6.5	16.3	13.1	66.3	23.5	26.8
Western NSW	4.7	6.2	9.4	23.7	24.3	16.1
Northern NSW	10.0	11.0	14.4	12.6	10.5	8.1
Mid North Coast	8.6	10.4	11.3	12.6	7.4	13.4
Southern NSW	5.0	5.5	5.9	7.9	8.3	7.8
Hunter New England	4.2	5.3	5.7	6.4	5.8	4.8
Murrumbidgee	1.4	2.1	4.8	7.2	4.8	3.4

*Rates were calculated using Indigenous Australian and non-Indigenous population data from SAPHaRI.

Indigenous status

Over half of Q fever cases in Aboriginal people were in Western NSW (26/50, 52%). Other local health districts where substantial proportions of Aboriginal cases lived were Hunter New England (5/50, 10%), Far West NSW (5/50, 10%) and Northern NSW (4/50, 8%). The most common local health districts of residence for non-Indigenous cases were Hunter New England (270/982, 27%), Northern NSW (175/982, 18%) and Western NSW (155/982, 16%). The highest rates of Q fever notifications for Aboriginal people in NSW were in Far West NSW (21.8 per 100,000), Western NSW (13.6 per 100,000) and Northern NSW (4.5 per 100,000) (Table 4). Similarly, the highest rates per 100,000 for non-Indigenous people and those who did not state their Indigenous status were in Far West NSW (25.2 per 100,000), Western NSW (14.02 per 100,000) and Northern NSW (11.03 per 100,000) (Table 4).

Table 4 Notifications and crude rates[a] per 100,000 population of Q fever notifications in New South Wales by Indigenous status, local health district, 1 January 2012 to 31 December 2017

Local health district	Indigenous Australian		Not identified as Indigenous Australian		
	Indigenous (n)	Crude rate per 100,000	Not Indigenous (n)	Not Stated	Crude rate per 100,000[b]
Hunter New England	5	1.6	270	15	5.6
Western NSW	26	13.6	155	54	14.2
Northern NSW	4	4.5	175	16	11.3
Mid North Coast	3	3.8	122	11	11.1
Southern NSW	1	2.3	68	13	6.9
Murrumbidgee	3	3.7	60	6	4
Illawarra Shoalhaven	3	3.7	43	10	2.3
Far West[c]	5	21.8	27	14	25.2
South Western Sydney	0	0	21	2	0.4
Northern Sydney	0	0	19	1	0.4
South Eastern Sydney	0	0	9	2	0.2
Central Coast	0	0	4	2	0.3
Nepean Blue Mountains	0	0	6	0	0.3
Western Sydney	0	0	2	0	0
Sydney	0	0	1	0	0
Grand Total	50	3.7	982	146	2.6

a) Rates were calculated using Indigenous Australian and non-Indigenous population data from SAPHaRI.

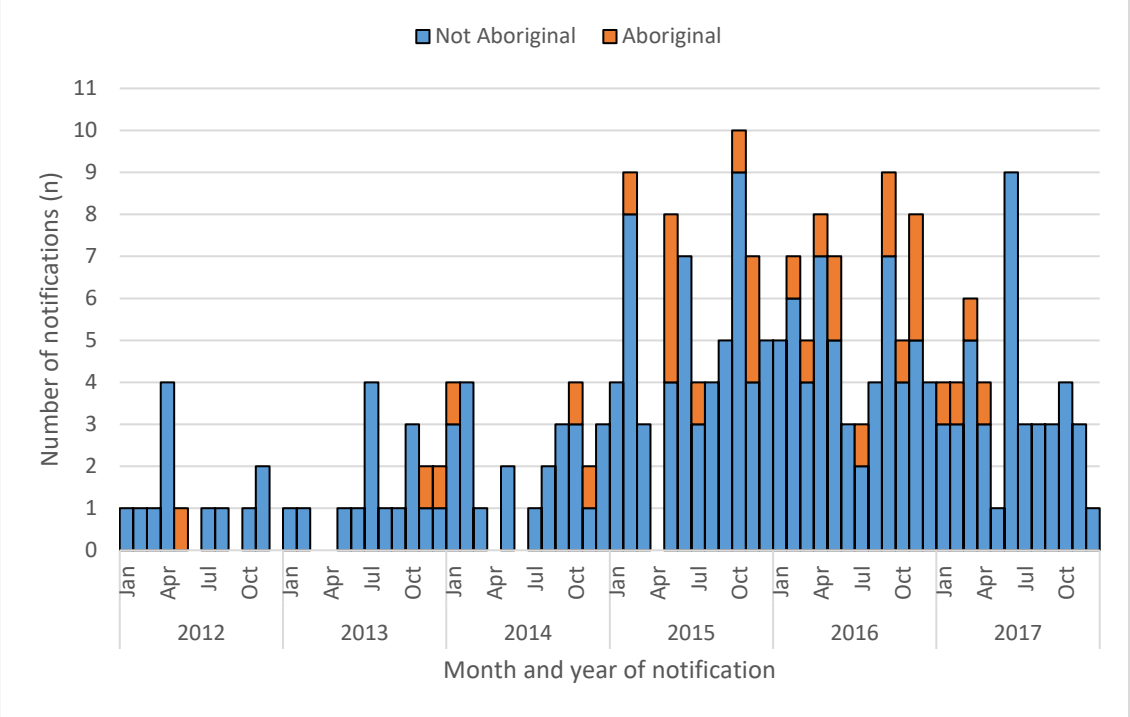
b) Where Indigenous status was not stated were included in the rate for non-Indigenous category.

c) Results in Far West NSW are shown to be statistically high however this is due to an outbreak between 2014-2015

Western New South Wales

An average of 39 cases of Q fever were notified annually in Western NSW between 2012 and 2017 (range 13-68 cases). The year with the highest notifications was 2016, with a peak of 9 cases in the month of September (Figure 2). An epidemiological curve of Q fever notifications is presented by month and year in Figure 2.

Figure 2 Epidemiological curve of Q fever notifications in Western New South Wales Local Health District, by notification month and year, 1 January 2012 to 31 December 2017 by Indigenous status.



Data cleaning to improve Indigenous status completeness

There were 54 cases in Western NSW that did not have Indigenous status information. After linking the data to PowerChart, six people were identified as Aboriginal and forty-eight as non-Indigenous. The differences in counts and rates before and after completeness of Indigenous status data is presented in Table 5. Prior to data cleaning the rate in the non-Indigenous population was slightly higher than the rate in the Aboriginal population, however after measures to ascertain Indigenous status the rate

was found to be higher in the Aboriginal population then the non-Indigenous population.

Table 5 Counts and crude rates[a] per 100,000 population per year of Q fever in Western New South Wales before and after data completeness of Indigenous status, 1 January 2012 to 31 December 2017

Aboriginal status	Western NSW		Western NSW after data completeness	
	Number of cases	Crude rate per 100,000	Number of cases (n)	Crude rate per 100,000
Aboriginal	26	13.6	32	16.7
Not Indigenous	155	14.2[b]	203	13.8
Not Stated	54		0	NA
Total cases	235	14.1	235	14.1

a) Crude rates were calculated using Indigenous Australian and non-Indigenous population data from SAPHaRI.
b) Notifications where Indigenous status was not stated were included in the rate for non-Indigenous category.

Indigenous status

Rates of Q fever in Western NSW for Aboriginal people were 16.7 per 100,000 and 13.8 per 100,000 non-Indigenous people. The indirectly standardised rate for Aboriginal people living in Western NSW was 19 per 100,000 (95%CI 12.8-26.3) and a reference rate of 14 per 100,000 for non-Indigenous people living in Western NSW. The standardised morbidity ratio was 135.4 (95% CI 92.6-191.1,) which indicated that Aboriginal people in Western NSW were notified with Q fever almost 35% more often as would be expected in non-Indigenous people living in the same area.

Comparison between Aboriginal and non-Indigenous notifications

Age distribution

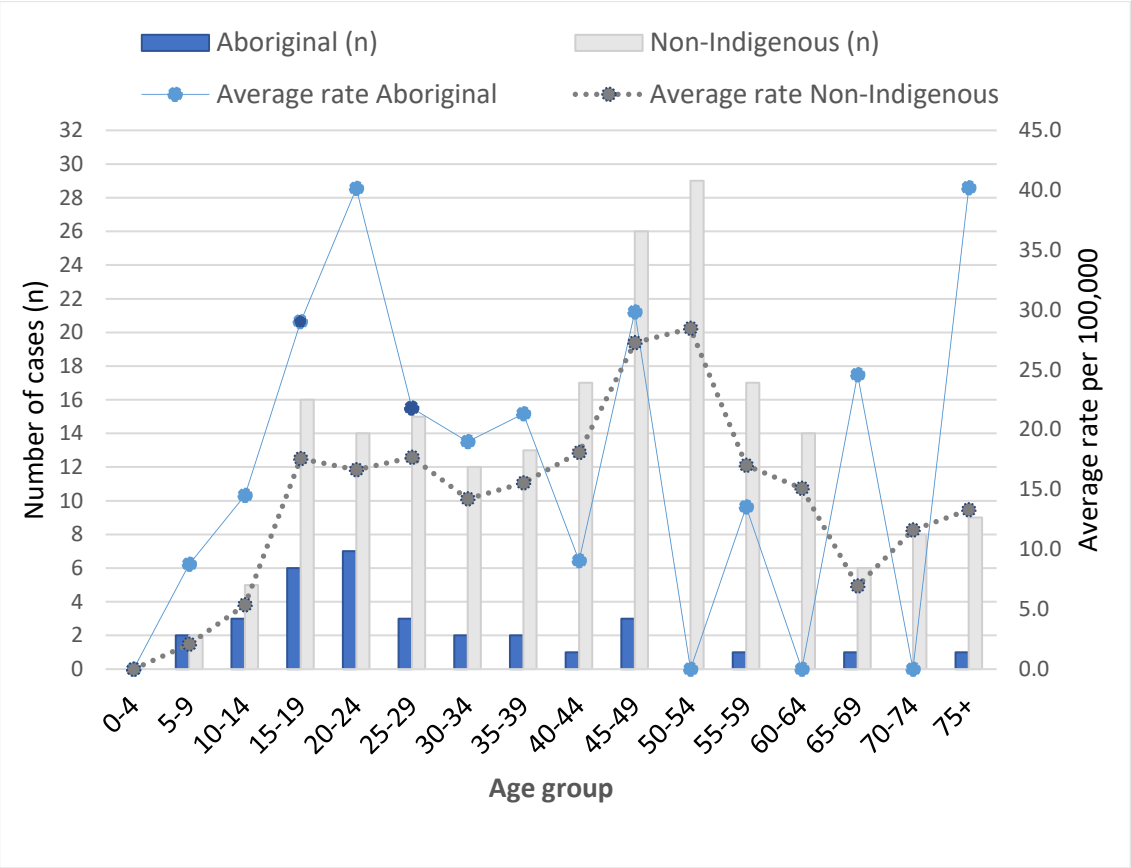
A difference was observed in the age distribution of Aboriginal and non-Indigenous people (Table 6). Aboriginal cases were positively skewed toward younger age groups

relative to the more symmetrical distribution of age among non-Indigenous people living in the same area (Figure 3). Half of all Aboriginal cases were under 30.

Table 6 Comparison between selected age and sex demographics of people in Western New South Wales notified with Q fever between 1 January 2012 and 31 December 2017.

Demographics		Number of Notifications		Population data		Crude rate per 100,000	
		Aboriginal (n)	Non-Aboriginal (n)	Aboriginal (n)	Non-Aboriginal (n)	Aboriginal	Non-Aboriginal
Sex	Male	28	163	96368	740464	29.1	22
	Female	4	40	95255	733475	4.2	5.5
Age group	<15	5	7	67957	279814	7.4	2.5
	15-29	16	45	51884	259907	30.8	17.3
	30-39	4	25	19907	168001	20.1	14.9
	40-49	4	43	21108	189367	19.0	22.7
	50-59	1	46	16135	201800	6.2	22.8
	60-69	1	20	9634	179335	10.4	11.2
	70+	1	17	4997	195713	20.0	8.7
Totals		32	203	191622	1473937	16.7	13.8

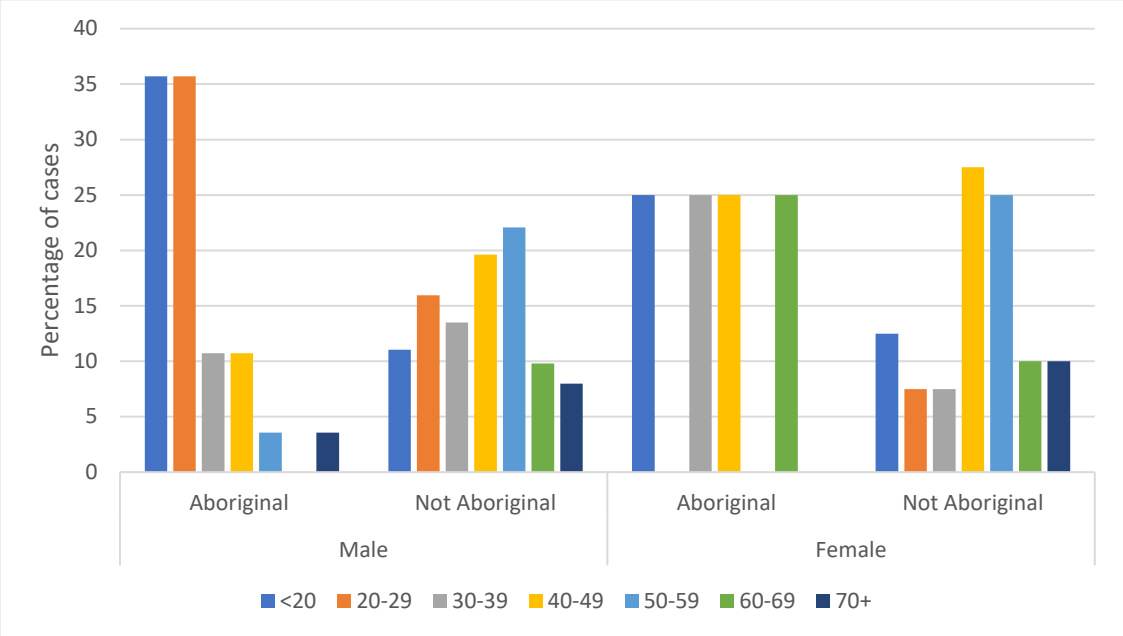
Figure 3 Age group distribution of Q fever notifications in Western NSW local health district between 1 January 2012 and 31 December 2017 by age group and Indigenous status



Sex

The burden of disease by sex was similar for both Aboriginal and non-Indigenous populations (Figure 4). When stratifying sex by age group, the age groups with the highest Q fever notifications appear to be different for Aboriginal men in Western NSW (Figure 4). Q fever notifications in women are quite small. It appears that similar age groups of Aboriginal and non-Indigenous women are affected by Q fever (Figure 4).

Figure 4 Percentages of notified cases of Q fever in Western New South Wales by sex, age group and Indigenous status, between 1 January 2012 and 31 December 2017



<u>Animal exposures</u>

The animal exposures reported in Western NSW were similar for both Aboriginal and non-Indigenous people (Table 7). Cases may have reported more than one animal exposure. Farm animals were the most common animal risk exposure reported by Aboriginal (n=28/32, 87.5%) and non-Indigenous (n=187/203, 92.1%) people. Exposure to tissues, products and discharges was the second highest reported exposure reported by Aboriginal (n=24/32, 75%) and non-Indigenous (n=119/203, 58.6%) people. Contact with native and feral animals was equally the third highest reported animal exposure in

Aboriginal people (n=5/32. 15.6% each). Exposure to birthing products was the third highest exposure for non-Indigenous people (n=66/203, 32.5%). Risk ratio calculations in Table 7 demonstrate there was no statistically significant different exposure between the Aboriginal and non-Indigenous people who reported animal exposures.

Table 7 Risk ratio of animal and occupational exposures, and vaccination status of people with Q fever in Western New South Wales, by Indigenous status, 1 January 2012 and 31 December 2017

Exposure		Aboriginal N (%)	Non-Indigenous N (%)	Risk Ratio (95%CI)	P-value
Animal exposure	Farm animals	28 (87.5)	187 (92.1)	0.65 (0.25-1.67)	0.38
	Tissues, products	24 (75.0)	119 (58.6)	1.9 (0.9-4.1)	0.08
	Feral animals	5 (15.6)	37 (18.2)	0.9 (0.4-2.1)	1
	Native animals	5 (15.6)	34 (16.7)	0.9 (0.4 – 2.3)	1
	Vectors (ticks)	2 (6.3)	5 (2.5)	2.17 (0.6 – 7.3)	0.24
	Birthing practices	4 (12.5)	66 (32.5)	0.3 (0.1 – 0.9)	0.02
Occupational exposure	Lives or works on farm	28 (87.5)	179 (88.2)	1.0 (0.4-2.5)	1
	Shearing	18 (56.3)	37 (18.2)	4.2 (2.2-7.9)	<0.01
	No risk occupation	10 (31.3)	25 (12.3)	2.6 (1.4-5.0)	0.01
	Hunting	4 (12.5)	22 (10.8)	1.14 (0.4 – 3.0)	0.76
	Wool classing	2 (6.3)	9 (4.4)	1.4 (0.4 – 5.0)	0.65
	Sales yard	2 (6.3)	17 (8.4)	0.8 (0.2-2.9)	1
	Lives near farm	2 (6.3)	8 (3.9)	1.5 (0.4 – 5.4)	0.63
	Abattoir	2 (6.3)	9 (4.4)	1.4 (0.1-0.4)	0.65
	Veterinary	0 (0.0)	2 (1.0)	NA	NA
Vaccinated	Yes	0 (0.0)	0 (0.0)	NA	NA
Reason for no vaccination	Choose not to	9 (28.1)	76 (37.4)	0.7 (0.3 – 1.4)	0.3
	Too young	9 (28.1)	8 (3.9)	5.1 (2.8-9.1)	<0.01
	Unaware of disease	5 (15.6)	47 (23.2)	0.6 (0.3-1.6)	0.37
	Not stated	3 (9.4)	30 (14.8)	0.6 (0.2 – 2.0)	0.6
	Not considered at risk	3 (9.4)	7 (3.4)	2.3 (0.9-6.4)	0.1
	Employer refusal	2 (6.3)	6 (3.0)	1.9 (0.5-6.6)	0.3
	Accessibility issues	1 (3.1)	4 (2.0)	1.4 (0.2 – 8.6)	0.5
	History of infection	0 (0.0)	20 (9.9)	NA	NA
	Aware but forgot	0 (0.0)	5 (2.5)	NA	NA

Occupational exposures

Reported farm exposures were similar between Aboriginal people and non-Indigenous people in Western NSW. Notably, the number of shearing exposures reported in Aboriginal people (n=18, 56.3%) was 4.2 times higher than the number observed in non-Indigenous people (n=37, 18.2%) and this was statistically significant (RR 4.2 95% CI: 2.2-7.9, p value=<0.01) (Table 7). The majority of Aboriginal people with Q fever in Western NSW either lived or worked on a farm (n=28, 87.5%). A further ten cases (31.3%) reported having no high-risk occupation, statistically significantly higher when compared to non-Indigenous people (RR 2.6 95%CI:1.4-5.0, p value 0.01) (Table 7). Hunting native or feral animals was reported by four Aboriginal people (12.5%).

Vaccination

Aboriginal people living in Western NSW primarily were too young to receive the vaccine (n=9, 28.1%) or knew about Q fever but chose not to have the vaccine (n=9, 28.1%) (Table 7). Of all nine people too young to receive the vaccine, four were siblings who had been exposed to a relative's contaminated shearing gear, three lived on a farm, one had been to the saleyards and the other had a parent who was a professional kangaroo shooter. One of the children living on a farm had direct hunting exposures shooting native and feral animals. Aboriginal people were 5 times more likely to be too young for vaccination when compared with non-Indigenous people (RR 5.1 95%CI: 2.8-9.1, p=<0.01) (Table 7). There were accounts across both groups of employers delaying or refusing to vaccinate, and other barriers accessing the vaccine.

Qualitative results

The main concern of the community representatives involved was the fact that Aboriginal people, particularly youths, in Western NSW were being notified with Q fever, and the level of community awareness about the disease was low to non-existent. This was a disconnect with how the government health authority interpreted the notification data, where concern was raised around comparisons between Western NSW and the rest of NSW (i.e. trying to determine if those being infected in Western NSW were somehow different to the those being infected in the rest of NSW). The strong and recurring themes from the group were the need to protect those community members most at risk and provide culturally appropriate education material to improve awareness especially among young people.

<u>High risk groups identified within the community</u>

The advisory group identified five risk groups and discussed the barriers and opportunities around these. The risk groups included people in rural NSW, hunters and shooters, high-risk workers, rural job seekers; and students and teachers:

1. People in rural NSW: the advisory group recognised that people do not need to have a high-risk occupation or animal exposure to get Q fever.

2. Hunters and shooters: include people who hunt game or feral animals professionally or recreationally. Educational modules must be completed to obtain firearms licensing through the DPI Game Licensing department. The advisory group discussed the importance of Q fever education, particularly in relation to safe handling of animals and preparation of meat.

3. High-risk workers: Discussion about the barriers around Q fever prevention related to the nature of transient employment in the area. Many people in the area undertake work such as shearing as an independent contractor, or an individual knowing where to turn up for the day. As such, there are often no formal employee/employer arrangements which potentially leaves workers (regardless of whether they work under a business or not) at a greater chance of not receiving information about Q fever prevention and vaccination. Group members shared stories about the reluctance of workers to disclose injuries or illnesses, and most (if not all) will not report their illness to Safe Work NSW as they are concerned this would minimize their chance for more work in the future.
4. Rural job seekers: A major barrier was the limited support to jobseekers in having no awareness about Q fever risks in the jobs they are seeking. Employment agencies often cover personal protective equipment costs for job seekers. While SafeWork NSW is able to provide rebates to small businesses and self-employed workers to equip them against hazards in the workplace, vaccines for occupationally prescribed conditions are not covered. In addition, this rebate is not available to jobseekers because their legislation relates to people who are already employed. There appears to be a gap in reaching information to people before they engage in Q fever risk occupations. As people in our dataset had experienced delays or refusals for vaccination by their employers, it is important that people know about their rights and responsibilities before they engage in risk occupations. Education about Q fever before entering the industry was identified as an important way to minimise risks for the disease.

5. Students and teachers: The largest barrier discussed was the lack of Q fever disease and vaccination awareness in high risk vocations and institutions including high schools, TAFE or other high school vocational courses. The group advised that there are many agricultural high schools across the region, as well as schools that raise and present animals at shows (e.g. the Sydney Royal Easter Show). Discussion was raised about shearing schools not having Q fever vaccination as a requirement for students and teachers.

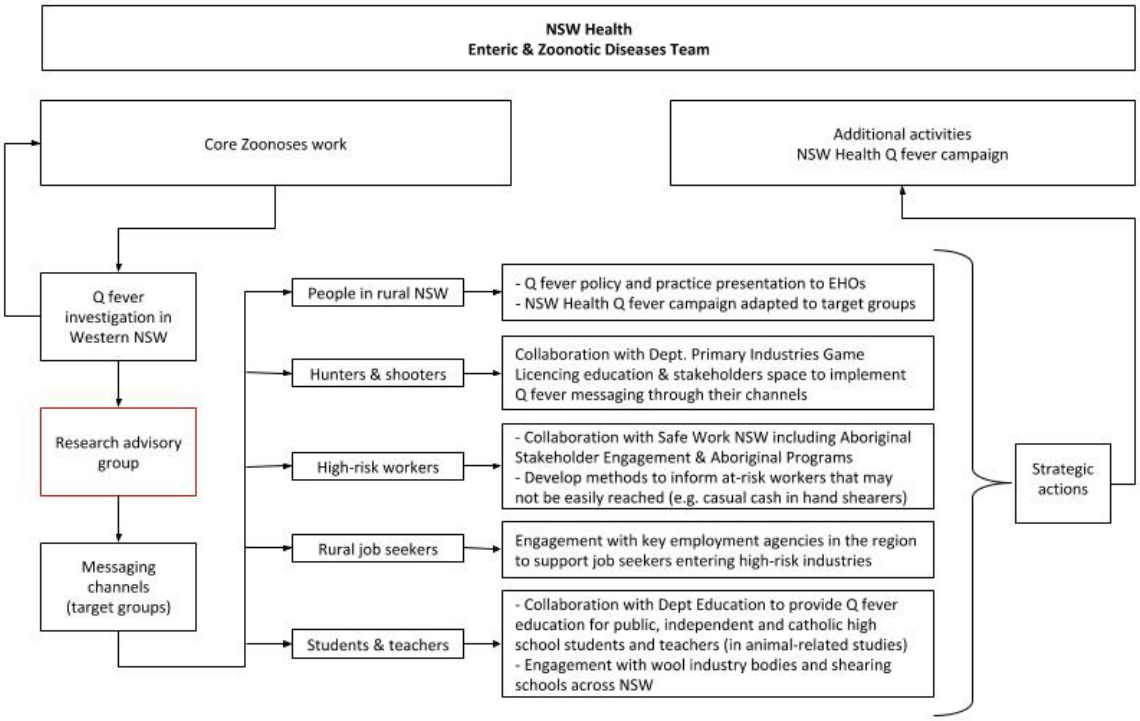
Acceptable messaging channels

Pathways were identified to reach these groups and strategic actions were developed that were designed to feed into the overall NSW Health Q fever campaign for 2019-2022.

Actions speak louder than words

Appendix B summaries the actions taken for each identified high risk group to build Q fever awareness, identified by the advisory group at 30 March 2019. This large body of work involved a commitment by the NSW Health Enteric and Zoonotic Diseases team to ensure these actions are carried out over the next few years. An email list was provided to the team who will update this group on progress on a 6-12 month basis. Figure 5 illustrates where the Q fever investigation arose from core work of the Enteric and Zoonotic Diseases Team (1, 10, 15); outlines response actions from the control guidelines that were fed back into core work activities (32); and advisory group recommendations to address the overrepresentation of Aboriginal people in the data.

Figure 5 Accountabilities of the Enteric and Zoonotic Diseases Team including information flow of messaging channels and actions recommended by the Aboriginal Research Advisory Group for Q fever in Western New South Wales at 30 March 2019.



<u>Appropriate material for distribution through messaging channels</u>

The mainstream Q fever campaign materials were not considered relevant to people that the community perceive as having an obligation to protect, such as school children and young people about to enter the workforce.

"I can't see myself in these (sic)"

"This is too wordy, and probably better suited for a veterinarian"

The group co-developed and approved a lay sheet to inform people in the community about Q fever, particularly those who were looking for work (Appendix A).

Discussion

This secondary data analysis described the epidemiology of Q fever in Western NSW; determined that Aboriginal people had been disproportionately affected by the disease; and identified explanatory factors that may have driven this. Using indirect standardisation, we discovered there were 35% more cases of Q fever in Indigenous Australians compared to non-Indigenous populations. Western NSW had the highest notification rates of Q fever, with over half of all Aboriginal cases living in the region. It should be noted that Western NSW accounts for only a third of the NSW Indigenous Australian population. Despite this disproportion, a series of community consultations indicated that the community was not concerned about comparing itself to the non-Indigenous population, but were more alarmed that Aboriginal people, particularly youths, were getting Q fever in settings where community awareness was low. While a mainstream Government-led Q fever awareness campaign had recently been released, the community consultation showed that the content was not fitting for their community and specific target material was required to have a broader and more meaningful impact in Western NSW.

<u>Why were notifications higher in Western NSW compared to rest of NSW?</u>

A possible explanation is related to the geographical and meteorological features of Western NSW. Wind speed and windy areas increase the risk of Q fever infection in humans and animals (14, 26), and generally occurs in open, flat landscapes, characteristic of Western NSW . The risk is further enhanced by climatic factors including lowered precipitation and high temperatures. (17, 18, 24) Western NSW region has been in a prolonged period of drought for many years, with some areas being in an intense drought phase, defined by the Bureau of Meteorology as a combination of no soil

moisture, very low plant growth and low rainfall across the preceding 6-12 months. Droughts in this region are expected to increase in severity and intensity, which enhance the risk of Q fever through increased dust and hand-feeding of animals. (49) Consistent with other research, (6, 36) there were more notifications of Q fever in males than females. Due to the variance or absence of symptoms, Q fever is an underreported disease. (6) Past research has aimed to quantify the burden of disease, including a national study in the United States that analysed Q fever testing data between 2012-2016. The study conservatively estimated that acute Q fever cases were underreported annually by an average of 63%. (6)

High Q fever rates in young Aboriginal people

Our study showed young Aboriginal people specifically are at risk of developing Q fever. Five (16%) Aboriginal children with Q fever were under age 15 and half (n=16, 50%) were aged 15-29. All had direct or indirect shearing or hunting exposures; a family member who was in a high-risk occupation, or had contact with contaminated work gear. Australian research on pediatric Q fever found that symptomatic children may visit a health service numerous times before Q fever is investigated. (6, 39, 40) Evidence from a two-year cohort study by van Loenhout et al. found that children are particularly vulnerable to lower quality of life and long-term reduced health outcomes, including severe fatigue lasting years, or severe persistent focal infections. (34) As rural children grow their exposure risks increase and diversify, particularly if their responsibilities increase on a farm. (50) This places rural children as a particularly vulnerable group for Q fever due to the current unavailability of a vaccine. (38) The safety and efficacy of administering Q fever vaccination under 15 years of age is currently being explored (38) including clinical trials in the 10-15 year age group. (51) Between 2006-2017 twelve

children across Australia at severe risk of Q fever infection were administered the vaccine off-label with no serious side effects. (38) Q fever education for children and their parents is crucially important to minimise the risk of Q fever for this group.

Higher proportion of Aboriginal people with Q fever had exposure to shearing

Q fever in the workplace is a notifiable incident under the *NSW Work Health and Safety Act 2011.* (52) Employers must ensure employees are not vulnerable to infection in high-risk areas. (52) There were reports from Aboriginal and non-Indigenous who had made a genuine attempt to be vaccinated and their employer acted as a barrier to their vaccination.

There were 18 (56.3%) Aboriginal people working as shearers which was significantly higher (4.2 times higher) than non-Indigenous people (n=37, 18.2%). Five Aboriginal shearers had not heard about Q fever at all, so never had the chance to ask the employer about vaccination. The Commonwealth Government's National Q fever Management Program (NQFMP) was launched in late 2000, heavily subsidizing vaccines for abattoir, meat industry workers and transient work such as shearing. (37, 39)

A community perspective

Appropriate community representation and perspectives were vital to this investigation, as the data analysis alone did not reflect what was considered to be most important for the community. While government found interest in comparisons between the phenomenon in Western NSW compared to the rest of NSW, the community consultation identified higher priorities relating to the health of specific groups at risk in Western NSW. Aboriginal governance and consultation were essential to produce meaningful, worthwhile and impactful public health action that is not only culturally

appropriate but also builds resilience capacity for the community to minimise the risk of Q fever, long after the investigation has ended.

Raising community awareness

Raising awareness is best achieved through the lenses of people who have intrinsic knowledge of the community. Community-led methodology has been advantageous in other settings to deliver impactful messages to people that may not be reached easily. An example of successful co-development of information, education and communications (IEC) material development was an initiative to provide HIV/AIDS education in remote communities of Nepal. Despite high illiteracy levels, the initiative was successful, mostly due to engaging local outreach workers from the community to oversee the development, testing and launch of the materials. The consultants intrinsic knowledge of culture, social norms and literacy levels of the communities allowed crucial messages to reach people in a meaningful way. (47)

Recommendations: NSW Government

Update Q fever terminology

This research recommends the term 'chronic Q fever' be amended to 'persistent focal infections'. An extensive clinical review by Eldin et al in 2017 puts forward reasonable argument for the change in terminology. (2) As we have a better understanding of the different diagnostic pathways, morbidities and treatments associated with the disease it no longer makes sense to group all of the persistent focal infections sequel to acute Q fever under the umbrella term 'chronic Q fever'. In the review the authors highlighted the issues in combining different illnesses that require different approaches to treatment and clinical management into the same group. (2)

Advocate to reinstate the National Q fever Management Program

Review the health economics of the National Q fever Management Program (NQFMP), which offered heavily subsidised vaccines for people working in high-risk occupations. This program coincided with a 50% reduction of Q fever notifications and outweighed the overall health cost of a person that gets Q fever. (37)

Reduce barriers to Q fever vaccination

It is acknowledged that more work is required to determine the minimum dose recommendation, efficacy and overall safety of the vaccine, as well as ways to ensure adequate surveillance through a potential register. Current research suggests that the Q fever vaccine may be safe and beneficial for children under 15 years of age who live in high-risk areas. (38) Reducing barriers to the availability and accessibility of the vaccine is highly important to protect those at risk. (39) We consulted with SafeWork NSW to find ways to improve vaccination of people in risk industries. Although the NQFMP is no longer operational (37) other financial assistance is available. The

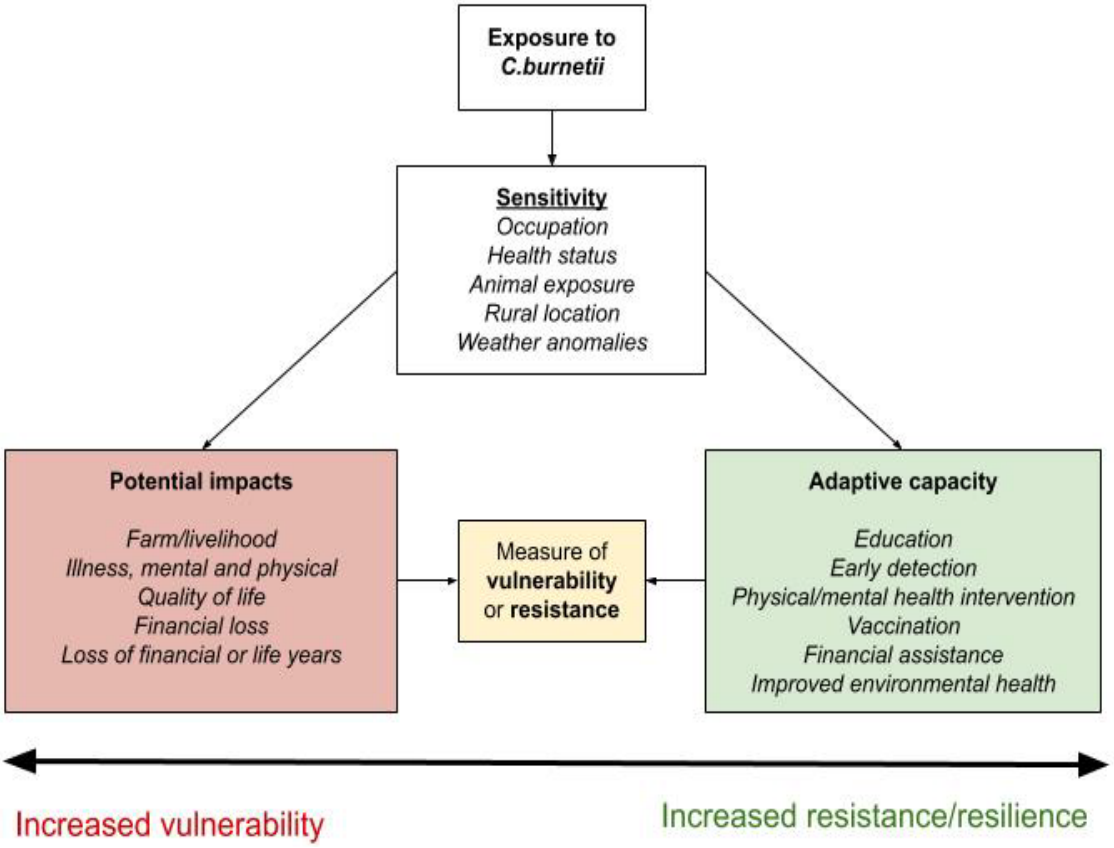
Australian Taxation Office ruled that Q fever vaccine is tax-deductible for people engaging in relevant employment, but this information is not widely known and is one of the points highlighted in the NSW Health Q fever awareness campaign. (53)

Prioritise community consultation

Community collaboration is essential to developing appropriate public health responses to Q fever in Western NSW. While there is no 'one size fits all' approach to Q fever, Figure 6 provides a model to assist government in any future Q fever community consultation. The model was largely based on my interpretation of how the advisory group developed and prioritised risk groups; as individuals/families with similar sensitivities but suffering different impacts from Q fever infection, with different resilience/resistance factors to manage or prevent Q fever. Consultation can identify risk groups through discussion about:

a) Factors that may increase vulnerability to Q fever (sensitivity)
b) How these factors may negatively impact people/community (potential impacts)
c) What current capacity is available or can be introduced to build resistance and ultimately resilience against Q fever (adaptive capacity)

Figure 6 Proposed Q fever vulnerability and resilience response model to assist consultation groups to understand the context and potential responses to Q fever across New South Wales



Recommendations: Western NSW

Implement targeted education and awareness material

The advisory group recommended the development of practical information towards hunters, primary industries job seekers and workers, students and people living in rural parts of NSW. We liaised with NSW Department of Education administrators for Catholic, Public and Independent schools to incorporate Q fever messaging into the agricultural studies curriculum. These focal points agreed for us to target messaging toward these groups (Appendix B). For hunters and shooters, we consulted with the Game Licencing Department of the Department of Primary Industries who will be sending our Q fever messaging through their education and licencing channels (Appendix B). For primary industries job seekers, we contacted major Aboriginal

employment agencies in Western NSW, and developed information for job seekers about Q fever. We attempted to contact shearing schools across NSW with mixed success, as a number of these schools were closed down due to the severe drought in NSW at the time of the analysis (Appendix B). (49)

Improve the Q fever surveillance system (NCIMS)

An evaluation of the current Q fever surveillance system (NCIMS) would be an appropriate start to improve the quality of data on the system. There were significant differences in interview formats, questionnaires and data input across the state. Many cases did not have exposure data until PDF attachments of questionnaires, clinical notes and discharge summaries were downloaded, read and entered manually into the extracted dataset. A high concern was that most reported shearing exposures were found in these notes and not in the dataset. The question should be asked, "who is using Q fever data on NCIMS, what are they using the data for, and what data do they need?" Exposure information recorded onto NCIMS should be collapsed into clearer categories and more exclusive variables. The addition of a variable that records persistent focal infections, and if present, the type of infection would be useful to further understand the epidemiology of Q fever.

Limitations

There were a number of limitations. Cases were not looked at by season as data was analysed by notification date, not calculated onset date (consistent with other NSW Health reporting). The four local health districts with the highest Q fever counts had awareness programs, which potentially increased testing in these areas and drove notifications. The study strived to have Aboriginal and/or Torres Strait Islander status data as complete as possible as to minimize bias on final estimates. As there was no

2017 Aboriginal population data available, 2016 data was used as the denominator for 2016 and 2017. It is estimated that the NSW Aboriginal and Torres Strait Islander population grows between 1.8% and 2.1% annually. It is likely that the 2017 contribution to the indirectly standardised rates and ratios were counted with a denominator that is slightly smaller than it should be. A sensitivity analysis was not conducted on these rates to determine whether this influenced the data. As reported exposures were drawn from case interviews, NCIMS and clinical notes, recall bias may have occurred for people remembering exposures (particularly if diagnosed in later stages of disease).

Before a standard national Q fever questionnaire was released across Australia in 2019, varied questionnaires were used across NSW, causing complexities in interactions of the data (which was already weakened by low numbers). There were difficulties selecting the correct method to standardise ages between the two groups and choosing appropriate tests to compare variables. The limitations began when the data was pulled from NCIMS, due to the extensive data cleaning and number of variables that had to be collapsed to find meaning within the data. After careful consideration by biostatisticians in NSW Health and the ANU, it was recommended that tests such as a multivariate analysis should not be performed.

The consideration of testing bias was discussed extensively among the Aboriginal Research Advisory group. It was agreed by consensus among the group that any testing bias would have the opposite effect, in that Aboriginal people are less likely to present for medical care and identify as Aboriginal for infectious diseases generally. This was supported by two methods:

1. Discussion with and comparison of rates against other Australian jurisdictional health departments, which had not detected a discrepancy between Q fever

notification rates in Aboriginal and non-Aboriginal people; and

2. Data-completeness activities, as described on from pp.105, in which the 'ever-Indigenous' algorithm was applied to determine if cases investigated for Q fever who were not reported as Aboriginal (or not Aboriginal) had either presented to a medical facility as Aboriginal. This activity led to a reclassification for 6 people from 57 with unknown status to Aboriginal, which further increased the rate of Aboriginal people notified with Q fever. In context of the discussions with the Aboriginal Research Advisory group and other Health Department, this providing provided sufficient evidence to exclude to impact of any testing bias towards Aboriginal people as a major factor contributing to the higher crude rates of reported disease.

Conclusion

Aboriginal people in Western NSW are disproportionately affected by Q fever. While NSW Health was interested in comparing the factors leading to this disproportion with the rest of NSW, the main concern highlighted during Aboriginal Advisory Group consultations was that young Aboriginal people in Western NSW were getting Q fever in an area where community awareness was low. On-going engagement with the Aboriginal community in understanding the problem and finding culturally appropriate solutions was vital and should occur wherever an investigation has a focus on Aboriginal people. The advisory group identified meaningful messaging pathways toward groups where there would be value in targeted awareness. Actions were taken with key focal points in hunting and shooting; education; primary industries job seekers and workers; and other areas of rural NSW. Overall, best practice for prevention and mitigation strategies are required, as is the improvement of surveillance and notification data on

NCIMS. This may be facilitated by considering the sensitivities of an individual or community against the potential impacts they may face versus the adaptive capacities that they already have or could benefit from having.

Q fever is an important zoonotic disease that can lead to debilitating illness and significant decrease in quality of life. (34) Although the ubiquitous nature of *C. burnetii* means that Q fever may never be eliminated or fully prevented, the risk of disease can be minimised through increased public and clinical awareness, vaccination of high risk groups and environmental regulation.

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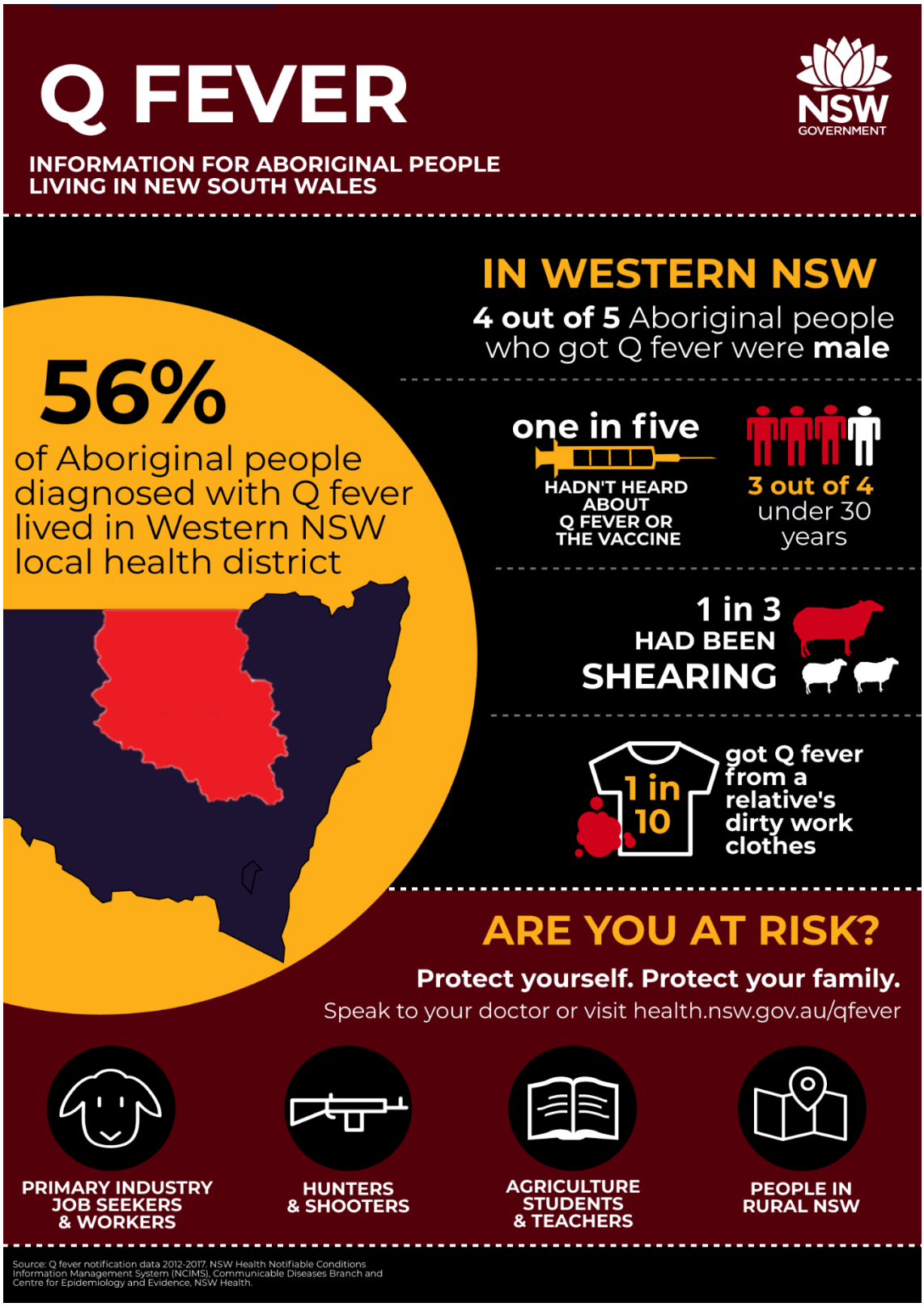
Appendices

Appendix A. Q fever infographic for job seekers



Appendix B. Target groups to build Q fever awareness

Identified by the Aboriginal Research Advisory Group for Q fever in Western New South Wales at 30 March 2019.

Target groups	Advisory group discussion	Messaging channels	Objective	Action
People in rural NSW	People do not need to have a high-risk occupation or animal exposure to get Q fever	NSW Environmental Health Officers (EHOs)	Environmental health can strengthen resilience against Q fever. Ensure EHOs are aware of Q fever prevention, legislative scope and health promotion	In April 2019 at the NSW Environmental Health Policy & Practice Day a presentation was given to Environmental Health Officers (EHOs) across NSW. The presentation provided information about Q fever, the Western NSW study, types of initiatives they can do in response to Q fever in non-risk groups and the recommendations made by the advisory group.
		NSW health Q fever campaign adapted to target groups	General awareness raising for those not in high risk groups	As part of the Q fever mainstream campaign NSW Health commissioned a Q fever artwork to be made into a poster by Mr. Garry Purchase, an Australian award winning Aboriginal artist. This was endorsed post development by the advisory group. A lay sheet for community was co-developed through the advisory group
Hunters & shooters	Hunting and shooting, and preparing meat is spontaneous and transient	Collaboration with department primary industries Game Licencing Education & Stakeholder Space to implement Q fever messaging through their channels	Raise awareness among hunter and shooters through the licensing process.	NSW Health met with NSW DPI Game Licensing on 1 April 2019. The department had a large social media reach (10-50,000), plus a monthly newsletter with a subscriber list not exclusive to license holders. Education models must be completed before a license is issued. The trainer notes for the "Safe Game Meat Harvest" section could be amended, and they were also willing to spread Q fever and Brucellosis messaging through their networks.
Hunters & shooters	Additional strategies need to be developed for those	To reach those exempt, Local	Raise awareness among hunter and	Unfortunately, this process was not within the time scope of the MAE however this recommendation has been added to the overall action plan of

Target groups	Advisory group discussion	Messaging channels	Objective	Action
(continued)	exempt from hunting licenses.	Aboriginal Land Councils (LALCs) should be engaged.	shooters.	the Q fever campaign.
High risk workers	Transient workers, particularly shearers are groups for concern due to many of these roles undertaken via word of mouth and cash in hand.	Collaboration with Safe Work NSW including Aboriginal Stakeholder Engagement & Aboriginal Programs	To build interagency collaboration around fever awareness, including for target groups	The manager of Aboriginal Stakeholder Engagement & Aboriginal Programs met with NSW to assist with the Q fever investigation. This builds upon pre-established relationships between agencies for Q fever. The nature of employment was described from a programs perspective and guidance was given on how to reach specific groups.
		Advisory group discussion	Develop methods to inform at-risk workers that may not be easily reached (e.g. casual cash in hand shearers)	Strategies put forward included products like magnets for fridge, washing machine, carry bags for work cloths. However, this was not actioned during MAE involvement.
Rural job seekers	Job seekers are a critical group to contact before entering a high risk workforce which does not always guarantee that an employer will abide by WHS legislation	Engagement with key employment agencies in the region to support job seekers entering high-risk industries	Develop culturally appropriate information sheet to advise those seeking work in high risk areas.	Agencies contacted and poster information distributed. Most employment agencies are independent, so we approached them one by one. We contacted the largest Aboriginal employment agency in the region who were willing to distribute materials sent from NSW Health.
Students and teachers	There are many agricultural high schools across the region, as well as schools that raise and present animals at shows	Collaboration with dept education to provide Q fever education for public, independent and	Development and distribution of flyers and information that is appropriate for school age children	NSW Health met with education representatives from catholic, independent and public schools at the Annual meeting on the School Vaccination Program. Representatives were unaware of Q fever as an issue but indicated that they were the correct liaison point. NSW Health provided further information about Q fever and arranged a follow up meeting. Ongoing collaboration was

Target groups	Advisory group discussion	Messaging channels	Objective	Action
	(e.g. the Royal Easter Show).	catholic high school students and teachers (in animal-related studies)	and their teachers	continuing in this space around prevention and vaccination messaging for students and teachers at the time of writing this chapter. We could not find an appropriate contact at TAFE for students undertaking rural skills subjects at the time of this analysis, however this contact has now been identified.
		Engagement with wool industry bodies and shearing schools across NSW	Face to face presentations with the wool industry. Link-in with shearing schools to provide similar messaging as in the schools.	A presentation was delivered to the Australian Wool Innovation as a “train the trainer” session. During the analysis Western NSW was in a period of prolonged drought which meant that all of the targeted shearing schools were closed. Engagement will recommence as they open

Chapter 4

Outbreak investigation

Multi-state outbreak of *Salmonella* Typhimurium caused by a novel multi-locus variable number tandem repeat analysis type, 2018-2019

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Chapter 4 Table of Contents

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List of tables and figures

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Acronyms

ACF	Aged-care facility
ANU	Australian National University
CIDMLS	Centre for Infectious Diseases & Microbiology Laboratory Services
DALYs	Disability adjusted life years
DNA	Deoxyribonucleic acid
DPI-BFS	New South Wales Department of Primary Industry Biosecurity & Food Safety
ERL	Enteric Reference Laboratory
FDA	United States Food and Drug Administration
FSANZ	Food Standards Australia New Zealand
ICPMR	Institute of Clinical Pathology and Medical Research
LHD	Local Health Districts
MAE	Master of Applied Epidemiology Scholar
MLVA	Multi-locus variable number tandem repeat analysis
MLST	Multi-locus sequence typing
N	Number
NA	Not available
NCIMS	Notifiable Conditions Information Management System
NSW	New South Wales
PHU	Public health unit
SNP	Single Nucleotide Polymorphism
WGS	Whole genome sequencing
Yr	Year

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Prologue

This chapter describes the overall picture of the largest novel *Salmonella* Typhimurium outbreak that occurred in Australia between 10 October 2018 and 30 May 2019. I will talk about the epidemiological, environmental and laboratory investigation, actions and outcomes. I will also discuss the egg industry in Australia, and recommendations to improve egg safety along the food supply chain. I demonstrate the power of multi-locus variable number tandem repeat analysis (MLVA) and whole genome sequencing (WGS) in the identification of outbreaks.

MAE role

The outbreak occurred over a holiday period where many public health units (PHUs) had skeleton staff so I interviewed cases across many jurisdictions while coordinating the follow up of PHUs. As lead investigator on the outbreak, my key roles were to:

- Coordinate and record the epidemiological and environmental investigation
- Interview cases using the OzFoodNet *Salmonella* Hypothesis Generating Questionnaire (1)
- Add and collate interview data into a Microsoft Excel (2) line list
- Analyse data and report findings through Situation Reports (SitReps), evidence summaries and the OzFoodNet quarterly report.

Lessons learnt

Interviewing

The most significant skill I learned from this opportunity was to apply theoretical skills into a real situation, and to interview well. Everyone has their own interview style and during this outbreak I found my own. I realised you need to be realistic with your expectations and learned that there is a bit of an art to prompting a case for information without leading them to an answer. I used this opportunity to focus on asking the right questions, actively listening and helping the case feel encouraged to respond honestly about their food history. For example, I spoke to a parent with a toddler who had mainly eaten tomato sauce (on its own) or chicken nuggets during the incubation period of their illness. The parent became anxious when I got to the questionnaire section relating to fresh and healthy produce. At the time my infant son had been insisting on water crackers over almost everything I cooked for him, so I paused the interview for a short time to share a laugh about the struggles of feeding fussy children, then resumed the questionnaire.

Working across jurisdictions

Although the outbreak began in Hunter New England, it quickly spread across the state. Many of the implicated PHUs had skeleton staff operating over the Christmas and New Year period. Hunter New England rapidly drew on resources to interview cases in other jurisdictions, and as measles cases began to emerge, I watched other districts offering to assist with outbreak cases to alleviate the pressures of inundated jurisdictions. This was a wonderful example about how even though we work in our own jurisdictions, we all have a common goal to serve the public in the fastest way possible, even if that means resourcing past our boundaries.

Hand-over and the roles and expectations of the host location

This was a large protracted multijurisdictional outbreak with multiple point sources, and at the time I was the only one working on the investigation. In hindsight it would have been useful to clarify the roles, responsibilities and expectations in the outbreak at the beginning and put in a support structure to assist if required. I do feel the extended time on the outbreak was where I became an epidemiologist. I learned to lead an outbreak, prepare SitReps, evidence summaries, and surveillance reports. I know where to locate guidelines and have a better understanding of the aetiology of *Salmonella*. I learned to work under pressure, completing multiple tasks with little to no support or guidance. All attributes which will benefit me in the future.

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Abstract

Background

A multijurisdictional outbreak of *Salmonella* Typhimurium (*S*. Typhimurium) with a unique multi-locus variable number tandem repeat analysis type (MLVA) profile was identified on 14 December 2018 by NSW Health after a cluster of cases with the same profile was identified in two aged-care facilities (ACFs) owned by the same company. The outbreak quickly spread into the community, resulting in a large protracted multijurisdictional outbreak. The MLVA profile for this outbreak (5-17-9-13-490) had not been identified in humans since MLVA typing was introduced in NSW in 2008. On 14 December 2018, investigation commenced between NSW Health and the NSW Department of Primary Industries Biosecurity and Food Safety (DPI-BFS).

Methods

Descriptive case series between 10 October 2018 and 30 May 2019. Cases were identified by routine surveillance and interviewed by trained public health staff using the OzFoodNet *Salmonella* Hypothesis Generating Questionnaire. (1) DPI-BFS conducted food premise inspections and egg trace-back. Environmental samples were taken from the implicated egg farm. Whole genome sequencing (WGS) of a sample of human and environmental isolates was used to assist in the investigation.

Results

During the outbreak period *S*. Typhimurium MLVA profile 5-17-9-13-490 was responsible for 235 cases across the Australian Capital Territory (7), New South Wales (215), and Queensland (13). Eighty per cent (n=188) of cases were interviewed. Twenty-six per cent were children <10 years of age, and 33% (n=77) of cases were linked to 11 point source clusters. Five deaths occurred. Egg consumption was reported by 91% (n=171) of cases,

including 71% (n=133) who ate eggs, and the remaining 29% (n=38) who ate egg-related products. A sample of 81 isolates (78 human, 3 environmental/food) underwent WGS and were found to be highly related, indicating a single originating source for all infections.

Conclusion

This was a large protracted multi-jurisdictional outbreak of *S. Typhimurium* linked to eggs through MLVA and WGS. Point source outbreaks were linked to one egg farm through complex distribution channels.

Public Health Impact

Salmonella is synonymous with eggs and can make its way into the egg supply despite high and active compliance at the industry level. Continued interagency and multi-organisational collaboration and communication is necessary to strengthen the egg supply chain, particularly in relation to efficient trace-back of eggs in an outbreak situation. Further, more emphasis is required on improving egg safety and awareness throughout the entire egg supply chain, including food produced in centralised kitchens and in the home.

Introduction

From the Enterobacteriaceae family, non-typhoidal *Salmonella* is characterised as a gram-negative, non-spore-forming, facultative anaerobic bacilli, that generally manifests as the self-limiting gastroenteritis salmonellosis. (3) The two species of *Salmonella* are *Salmonella enterica* and *Salmonella bongori*. (4) *S. enterica* has six subspecies and approximately 2557 known serovars. Warm-blooded animals are more likely to have *S. enterica.* (4, 5) *S. bongori* has 22 known serovars and is found in cold-blooded animals. (5)

Due to the ubiquitous distribution of *Salmonella*, the mode of transmission can be found in both food and the environment. Most people become infected with *Salmonella* by eating food contaminated with animal faeces, or made from infected animals and their products. (6) The mode of transmission for some serovars (particularly environmental) is yet to be fully understood. Another less common mode of infection occurs after direct contact with another person that has been infected with *Salmonella*.

Infected persons usually develop symptoms 6-72 hours after exposure and may experience fever, headache, stomach cramps, joint and muscle pain, diarrhoea, nausea and vomiting, for approximately 4-7 days. More severe cases may present with tachycardia, high white blood cell count, confusion or coma. (6) Children, the elderly and immunocompromised persons can be at higher risk of severe illness including infections to the bloodstream, which can result in a loss of disability adjusted life years (DALYs) and lead to further co-morbidities throughout the life course. (6-9)

Public health impact

The estimated global burden of *Salmonella* is high, however cannot be accurately quantified due to the varied presence and quality of national surveillance systems. (3) In 2010, an extensive global study measured the burden of non-typhoidal *Salmonella* worldwide. (3) The researchers estimated that globally there are 93.8 million non-typhoidal *Salmonella* illnesses per year, with 80.3 million of these related to food. The research also suggested that annually 155,000 people die from their infection. (3) *Salmonella* testing is reliant on both health-seeking behaviour and the clinician to take a specimen from the case. (3) Due to the self-limiting nature of the disease there is a good chance that the person infected may not attend a health facility at all. (10)

Salmonella Typhimurium (*S.* Typhimurium), identified by antigenic formula 1,4,[5],12:i:1,2 as described by the White Kauffmann-Le Minor Scheme for *Salmonella* subtyping (5), is one of the most common serovars of all *Salmonella* enterica species worldwide. (6, 11) It is the primary serovar in Australia, followed by *Salmonella* Enteritidis. Like most *Salmonella* species, *S.* Typhimurium follows a seasonal pattern, with outbreaks more frequent between December and May (the summer to autumn seasons). (6, 12) This serovar was the causative serotype in 84% of all *Salmonella* foodborne outbreaks in Australia between 2001 and 2016 and was implicated in 61% of all foodborne outbreaks linked to food premises. (9)

The most common source for infection is though the consumption of eggs and egg products. This includes raw egg sauces and butter, and desserts that involve raw or undercooked eggs. (13, 14) *S.* Typhimurium is primarily found on the outer shell of the egg. The bacterium is motile and can enter the egg through cracks or damage on the outer shell, or by direct contact such as using eggshells to separate yolk from albumen.

S. Typhimurium is highly attracted to egg yolk, and has been shown to travel through albumen despite its purpose as a chemical barrier to bacteria. (15, 16)

Context

Between November and December 2018, 17 people fell ill with gastroenteritis across two aged-care facilities (ACFs) that were geographically distinct (340 km apart) but operated by the same company. Of those who fell ill, 14 cases were residents and three were staff. Symptom onsets occurred between 12 November 2018 and 2 December 2018. Of the 17 unwell, 13 were *Salmonella* positive, of which 12 were confirmed as *Salmonella* Typhimurium characterised as multi-locus variable number tandem repeat analysis (MLVA) 5-17-9-13-490. This MLVA profile had not previously been identified in humans in NSW since the introduction of routine MLVA in 2008. (17) The remaining four suspected cases who were unwell did not have a specimen collected. Seven cases presented to hospital and four cases were admitted. Three resident deaths occurred during the outbreak in persons who had acquired a *Salmonella* infection.

The NSW Department of Primary Industries Biosecurity and Food Safety (DPI-BFS) conducted site inspections and collected environmental samples from both ACFs. The dishwashers at both facilities were not operating at an adequate sanitising temperature. One boot swab specimen in an entrance hallway was positive for *S.* Typhimurium 5-17-9-13-490. Trace-back of the eggs used at each ACF identified a common egg grading facility. *S.* Typhimurium cases with the novel MLVA were subsequently identified in the community and were not able to be linked to the ACF. On 14 December 2018, NSW Health commenced a wider outbreak investigation. This chapter details the process of the investigation, the epidemiology of the outbreak and control measures that were taken during the period 14 December 2018 to 30 May 2019.

Methodology

Epidemiological investigation

Hypothesis generation

A descriptive case-series investigation was conducted between 10 October 2018 and 30 May 2019.

Case definition

A working case definition was created on 14 December 2018 and last amended on 10 January 2019 to include and investigate epi-linked cases. The final case definition included any person with *S.* Typhimurium MLVA 5-17-9-13-490 (or related[†]) infection with illness onset since 10 October 2018 with at least some of their exposure period in Australia;

OR

Salmonella infection with illness onset since 10 October 2018 with an epidemiological link to a confirmed MLVA case or point source cluster, with at least some of their exposure period in Australia.

Case finding and data gathering

In Australia, *Salmonella* infections are laboratory notified under the relevant jurisdiction's legislation. Cases who met the case definition were interviewed by trained public health officers using the standardised OzFoodNet *Salmonella* Hypothesis

[†] Related MLVAs were those that were close enough to be deemed as likely from the same source. This was determined by ICPMR and epidemiological data. The MLVAs that were related to this outbreak were: 5-17-8-13-490, 5-17-9-0/1-490, 5-17-9-13/14/15-490, 5-17-10-13-490 and 5-18-9-13-490

Generating Questionnaire (Appendix A). Questionnaire data was manually added to the line list maintained by the lead investigator. Cases who met the case definition were followed up by their jurisdictional health department. The exposure rate of cases to foods were calculated and cases were analysed on an epi curve that was filtered by location and point source.

Environmental investigation and trace-back

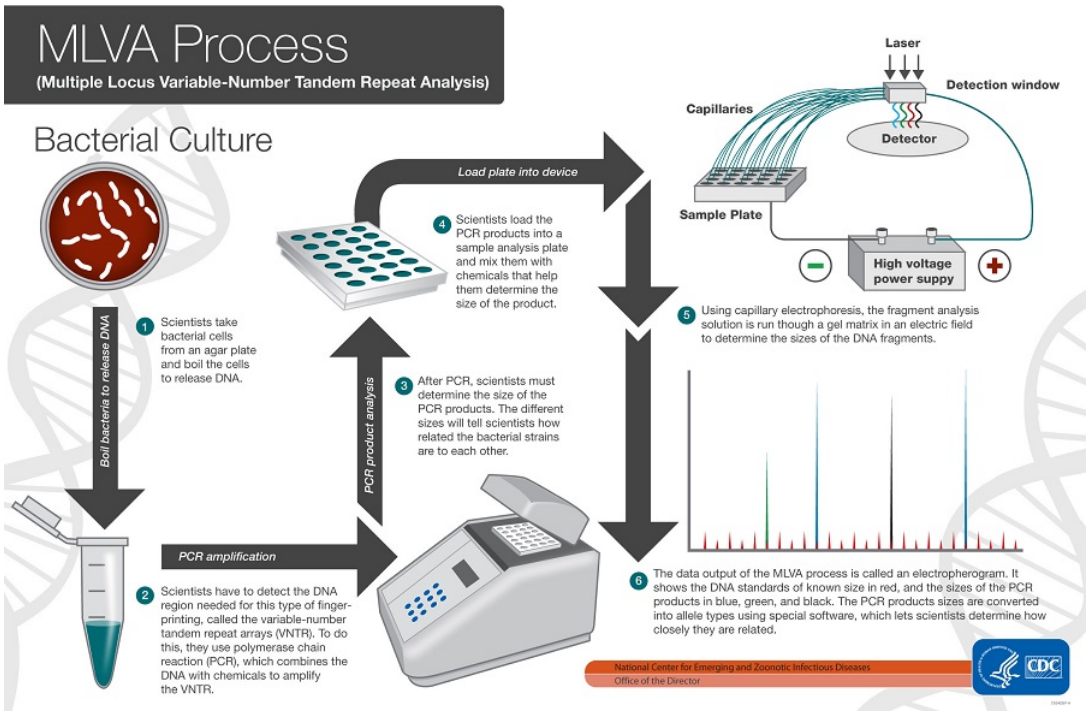
The coordination of the environmental investigation was performed by the DPI-BFS who inspected implicated food premises with assistance from local councils if necessary. Staff in the food premises were interviewed in regard to preparation techniques and storage of foods. The names of food suppliers were obtained for specific ingredients identified through hypothesis generation interviews. Food and environmental samples were taken, as appropriate. An egg trace-back was conducted, which involved taking details of the eggs used on site and following the chain of purchase back to the farm, grading and distribution centres, which were subsequently investigated. Environmental and food samples were taken at these sites.

Laboratory investigation

Serotyping and MLVA

Individuals with *S.* Typhimurium were identified by public health reference laboratories in NSW (Institute of Clinical Pathology and Medical Research [ICPMR]) and QLD (Queensland Forensic and Scientific Services [FSS]) using the Kauffmann White Le Minor scheme. (5) All isolates were further characterised using the MLVA typing method. The process of MLVA is described in Figure 1.

Figure 1 Infographic from PulseNet, Centers for Disease Control and Prevention (online), describing the laboratory process of multiple locus variable-number tandem repeat analysis that would be used to characterise strain specific profiles of *Salmonella* Typhimurium (18)



MLVAs were classified as closely related and could be considered part of this outbreak if they shared the same outer two loci and if there was only a variation of 1-2 digits in one of the three inner loci. MLVAs that did not meet this requirement but had strong epidemiological evidence to suggest a relationship were also investigated.

<u>Whole genome sequencing</u>

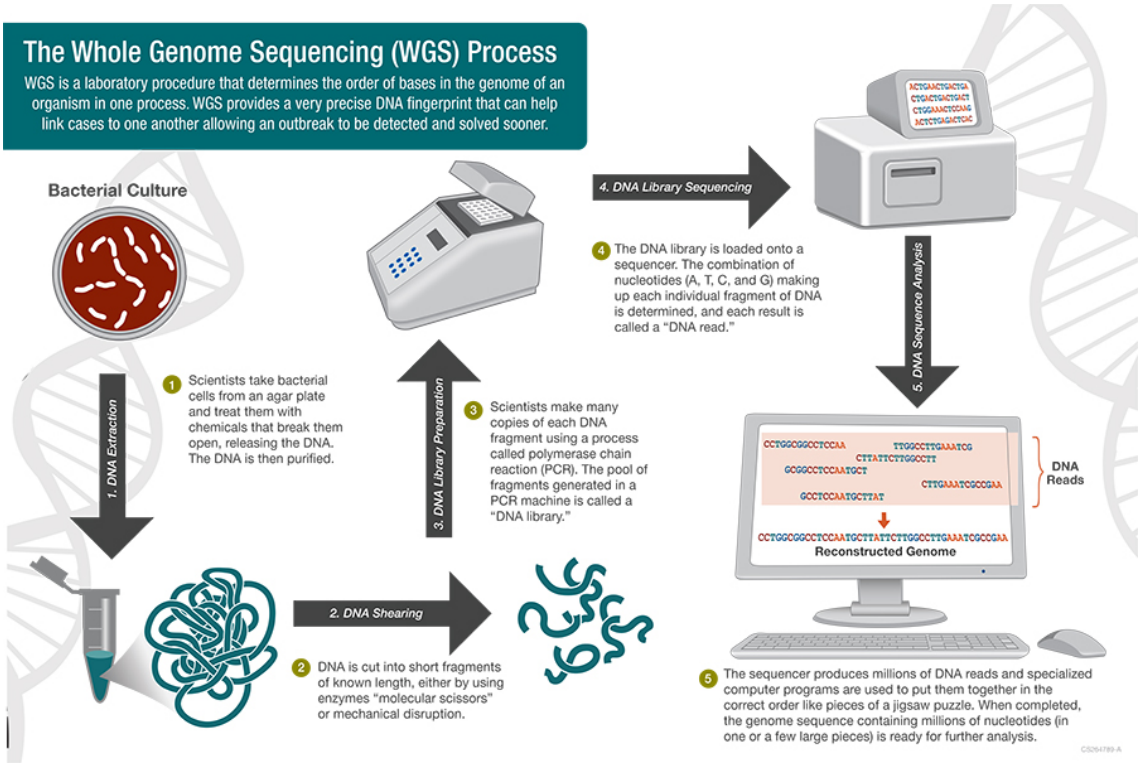
The objectives for WGS was:

1. To determine whether a genomic relationship existed between MLVA profile 5-17-9-13-490 and the seven suspect MLVA profiles.
2. Confirm link between human and environmental isolates.
3. Determine if QLD cases were genetically related to the NSW cases

Process for WGS at ICPMR NSW

WGS was performed at the Centre for Infectious Disease Laboratory Services (CIDMLS), ICPMR, NSW Health Pathology and CIDM-Public Health, Westmead Hospital. The process of WGS is described in Figure 2.

Figure 2 Infographic from PulseNet, Centers for Disease Control and Prevention (online) describing the laboratory process of whole genome sequencing that would be used to characterise strain specific profiles of *Salmonella* Typhimurium (19)



NSW Health submitted the accession numbers and the NSW Notifiable Conditions Information Management System (NCIMS) patient identification number of 44 MLVA cases for WGS. This included 41 MLVA 5-17-9-13-490 isolates that were either linked to point source outbreaks, or representative of the local health districts (LHDs) that were still being affected by the outbreak at the time of submission, three environmental isolates from the implicated farm.

ICPMR reported that the Geneaid™ Bacterial DNA Isolation Kit (GeneAid) was used to extract genomic deoxyribonucleic acid (DNA). The sequencing libraries were prepared

using Nextera XT DNA Library Prep Kit (Illumina) and sequenced on NextSeq 500 instrument using NextSeq 500/550 v2 mid output Kits (Illumina). The sequenced raw reads were subjected to in–house quality control procedures prior to further analysis and the data was analysed using Nullarbor pipeline (v1.3). The raw reads were mapped to a *S*. Typhimurium complete genome strain LT2 (NCBI GenBank Accession NC_003197). The relationship between genomes was examined using single nucleotide polymorphisms (SNPs) analysis where SNPs were defined as substitutions present in at least 90% of reads with minimum depth coverage of 30. Core genome SNPs from each sequence were aligned using Snippy-core. The SNP cluster was called based on the phylogenetic tree and the SNP distance, from which <5 SNPs was regarded as likely linked. The WGS-based multi-locus sequence type (MLST) was inferred from sequencing data using MLST 2.8 from the pipeline. The maximum likelihood tree was generated using FastTree 2.1.10. Antibiotic resistance genes were searched from the sequencing data by Abricate (v0.7) using ResFinder as the default database.

A phylogenetic tree of the isolates was generated using Microreact, a visual online phylogenetic mapping tool developed by the Centre of Genomic Pathogen Surveillance. (20) A metadata file (.newick file) was uploaded to Microreact which contained all *S*. Typhimurium notified to NSW Health in the time period. A Microsoft Excel (2) file containing information about the isolates submitted to ICPMR for WGS was also uploaded into the system. Together this generated a phylogenetic tree which was adjusted to clearly show that the isolates were novel compared to all other strains in the tree.

Comparison with food/environmental isolates

A subset of environmental *S.* Typhimurium isolates with matching MLVA to human cases were selected for inclusion in the WGS process described above. At least one person from each cluster had an isolate run through WGS to ensure all clusters were linked to the outbreak.

Genomic comparisons with QLD

NSW Health requested the QLD Public Health Microbiology Reference Laboratory run WGS analysis on eight QLD cases that were known at the time to have the MLVA 5-17-9-13-490. ICPMR electronically sent a copy of the outbreak WGS strain to QLD Public Health Microbiology Reference Laboratory for comparison with QLD cases.

Ethics

This investigation of a multi-jurisdictional outbreak of *Salmonella* Typhimurium was carried out under routine state and territory public health legislation. Public health units in NSW had an obligation to participate in the investigation as required by the NSW *Salmonella* Control Guidelines. (21) Participation in the investigation was voluntary for cases or their guardians, who were asked for verbal consent to interview using the OzFoodNet *Salmonella* Hypothesis Generating Questionnaire. As this was an issue of acute public health importance, clearance from a human research ethics committee (HREC) was not required, however approval was sought and granted by the Australian National University HREC under protocol number 2017/909.

Results

Epidemiological results

Case finding and demographics

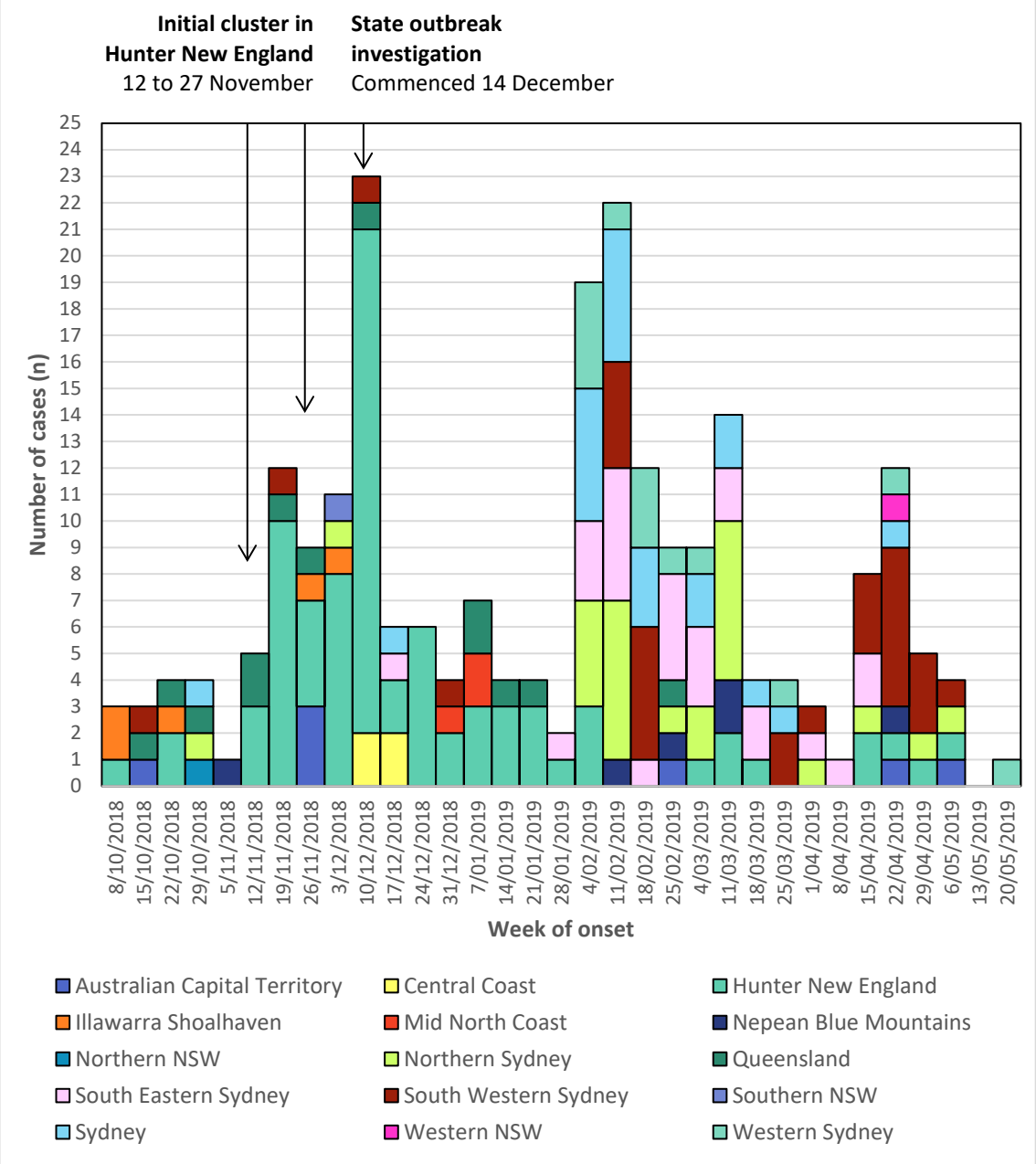
Between 10 October and 30 May 2019, 235 people met the definition for this outbreak of *S.* Typhimurium with MLVA 5-17-9-13-490 or similar. Notifications occurred in multiple Australian jurisdictions: Australian Capital Territory (7), New South Wales (215), and Queensland (13). A breakdown by state and territory is shown in Table , with NSW further divided into LHDs affected. The highest burden was in NSW with 92% of all cases.

Table 1 Jurisdictions affected by *Salmonella* Typhimurium with multi-locus variable tandem repeat analysis profile 5-17-9-13-490 or similar, by location, from 8 October 2018 to 27 May 2019.

Australian Jurisdiction	NSW Local Health District	Number of confirmed cases	Percent of total cases
New South Wales (NSW)	All districts (NSW)	215	91.5
Regional	Hunter New England	79	33.6
	Mid North Coast	3	1.3
	Northern NSW	1	0.4
	Southern NSW	1	0.4
	Western NSW	1	0.4
	Murrumbidgee	0	0
	Far West	0	0
Metropolitan	South Western Sydney	29	12.3
	Southern Eastern Sydney	26	11.1
	Northern Sydney	25	10.6
	Sydney	22	9.4
	Western Sydney	13	5.5
	Nepean Blue Mountains	6	2.6
	Illawarra Shoalhaven	5	2.1
	Central Coast	4	1.7
Australian Capital Territory		7	3.0
Queensland		13	5.5
Grand Total		235	100

The epi curve is presented in Figure 3 which describes cases by jurisdiction of residence (NSW is divided by local health districts) and week of symptom onset date between 8 October 2018 and 20 May 2019.

Figure 3 Epidemiological curve of Salmonella Typhimurium cases with multi-locus variable tandem repeat analysis profile 5-17-9-13-490 or similar, by local health district or state (ACT, QLD) and week of symptom onset date from 8 October 2018 to 27 May 2019.



Case series

Of the 235 cases, 188 (80%) were interviewed, 47 cases were not interviewed, 30 could not be reached, ten were not attempted to be interviewed, two declined and five had died. Three cases were secondary infections, epidemiologically linked other cases. Table 2 describes the demographic age, sex, clinical onset and severity data of the cases.

Table 2 Demographic and epidemiological characteristics of *Salmonella* Typhimurium cases with multi-locus variable tandem repeat analysis type 5-17-9-13-490 or similar notified in NSW between 8 October 2018 and 30 May 2019

Characteristic	Details	Result
Age (n=235)	Average	32 years
	Median	25 years
	Range	0 - 95 years
	Youngest affected age group Oldest affected age group	<10 years (n=62, 26%) 21-30 years (n=42, 18%)
Sex (n=235)	Male	105 (45%)
	Female	130 (55%)
	Male/Female sex ratio	81:100
Onset period (n=235)	First notified case	10 October 2018
	Last notified case	24 May 2019
Severity (n=188)	Hospital admissions	64 (34%)
	Emergency department presentation (no admission)	38 (20%)
	Deaths Aged Care Facility (n=3) and Community residents (n=2)	5 (2%)

For all notifications, the age range of cases were between 0-95 years, with a median age of 25. Children under 10 years of age were the most affected age group, carrying a quarter of the overall burden. Adults aged 21-30 was the next highest age group affected with 18% of the burden. The sex distribution of cases was higher in females (n=130, 55%), with 81 males for every 100 females. Of those cases interviewed (n=188), over half of cases required acute care, including 64 hospital admissions (34%) with an average of 4.7 days spent in hospital (median 3 days), and 38 emergency department presentations (20%) and five were deceased.

Food Consumption

The most common food item consumed in the likely exposure period was eggs. The overall reported rate of exposure to eggs or egg products was 91% (n=171) (Table 3). Of these, 71% (n=133) reported eating eggs, and the remaining 38 of the 171 consumed foods that can be categorised as potentially containing eggs. Of the 133 who reported eating eggs, 53% (n=101) ate eggs at home and 42% (n=80) ate eggs away from home. Exposure to common sources drawn from case interviews is illustrated in Table 3.

Table 3 Food exposure list of interviewed *Salmonella* Typhimurium cases with multi-locus variable tandem repeat analysis type 5-17-9-13-490 or similar notified in NSW between 8 October 2018 and 30 May 2019

Item	Food exposures	Number reporting exposure (N=188)	Percentage reporting exposure (%) N=188
Eggs	Total consumed eggs and/or egg-related products	171	91
	Total consumed eggs (general)	133	71
	• Ate eggs at home	101	54
	• Ate eggs away from home	79	42
	Possibly ate eggs	17	9
	Did not eat eggs	17	9
	• No consumption of eggs or egg products	5	3
	No information provided	24	13
	• No information on eggs, ate egg products	53	28
Chicken	Total consumed chicken (general)	118	63
	• Cooked chicken	90	36
	• Raw chicken	67	48
	Possibly ate chicken	12	5
	Did not eat chicken	16	7
	Does not know if ate chicken	3	1
	No information provided	86	37
Beef	Total consumed beef	73	39
	• Ate beef mince	46	24
	• Ate sausages	36	19
Pork	Total consumed pork	55	29
	• Ate any pig meat	46	24
	• Ate bacon	34	18
	• Ate ham	31	16

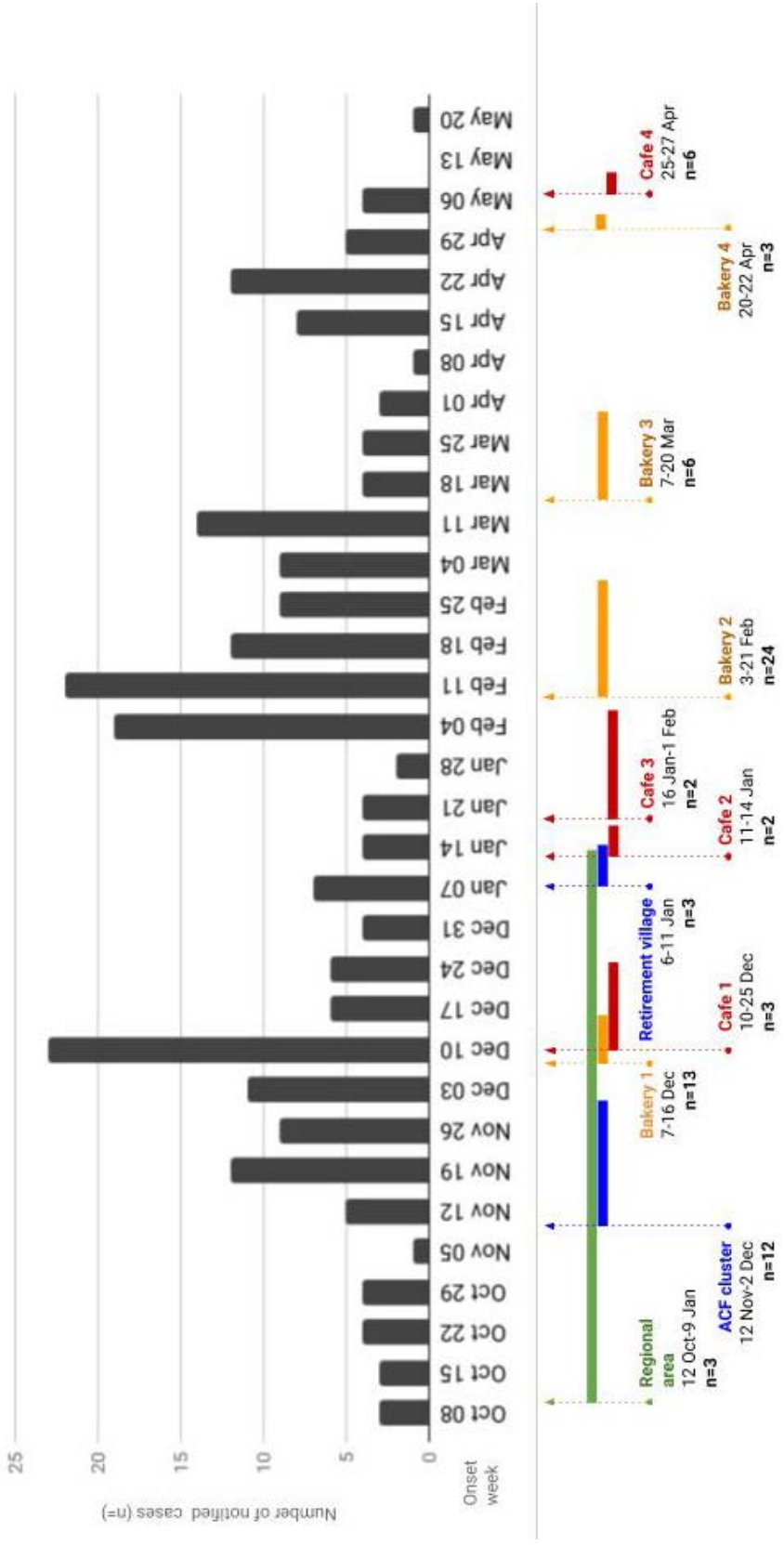
Point source investigation

Eleven point source clusters were identified from 10 October 2018 through case interviews, representing 77 cases (41%). Table 4 provides a summary of each point source cluster. No meal was common, however most meals contained eggs. Figure 4 is an epi curve illustrating eleven point source clusters identified during the outbreak.

Table 4 Summary of each point source cluster of *Salmonella* Typhimurium with multi-locus variable tandem repeat analysis type 5-17-9-13-490 or similar notified in the ACT, NSW and QLD between 8 October 2018 and 30 May 2019

Cluster	Cases (n)	Dates of purchase	Foods consumed	Ingredients if relevant
ACF (2 sites)	12	12 Nov-2Dec	Multiple foods consumed. Two affected staff members consumed scrambled eggs	Multiple ingredients. Food contained eggs
Bakery 1	13	7-16 Dec	Vietnamese pork rolls containing egg butter spread	Pork, salad and egg butter spread
Egg Farm B (Retail Stall)	3	12 Oct- 9 Jan	Fresh eggs	Eggs
Cafe 1	3	10-25 Dec	Poached eggs, scrambled eggs Egg and mayo sandwich	Food contains eggs
Retirement Village	3	6-11 Jan	Take away cooked dinners and desserts	Food contains eggs
Cafe 2	2	11-14 Jan	Eggs, beef nachos	Eggs, potential cross contamination
Cafe 3	2	16 Jan - 1 Feb	Beef salad from display cabinet	Food contains eggs. Potential cross-contamination
Bakery 2	24	3-21 Feb	White cream cake, tiramisu and matcha cream cake	Food contains eggs
Bakery 3	6	7-20 Mar	Cakes and custard buns	Food contains eggs
Bakery 4	3	20-22 Apr	Potato pie, cheese and bacon pie. Cream bun, bread	Multiple ingredients.
Cafe 4	6	25-27 Apr	Fried eggs, French toast	Foods containing eggs

Figure 4 Epi curve of *Salmonella* Typhimurium with multi-locus variable tandem repeat analysis type 5-17-9-13-490 or similar notified in the ACT, NSW and QLD between 8 October 2018 and 30 May 2019, including eleven point source clusters identified during the outbreak.



Environmental results

All eleven point source clusters were identified and inspected by either the NSWFA or council as summarised in Table 5. All point source clusters were able to be linked to the one egg producer through various complex distribution channels (Table 6). The egg producer maintained one egg farm, “Egg Farm A”. Egg Farm A was inspected multiple times, with the first inspection conducted on 16 January 2019. Inspection of the farm found no issues on site and the farm was highly compliant with directions made by the DPI-BFS. These directions included thorough cleaning and additional sanitation steps were introduced, however people continued to be infected with this strain regardless of the control measures introduced on farm. No eggs were withheld from sale.

Environmental specimen results

Twenty-seven environmental samples collected during food premises and farm inspections were positive for the MLVA. One isolate was from a boot swab collected during the initial ACF outbreak, and 26 were taken from Egg Farm A.

Table 5 Details of 27 environmental samples collected during food premises and farm inspections that were positive for *Salmonella* Typhimurium with multi-locus variable tandem repeat analysis type 5-17-9-13-490.

Premises	Date Inspected	Food Vehicle Suspected*	Root Cause	Samples	Outbreak Strain Identified	Control Action
ACF (2 Sites)	25 Nov 2018	Unknown. Possible eggs	Improper sanitising	Yes	Yes. 1 boot swab	Restricted use of third party ready to eat high risk foods until investigation complete
Bakery 1	9 Jan 2019	Eggs	Raw egg use	Yes	No	Previous prohibition notice for raw eggs on 18 Dec 2018
Egg Farm B (Retail Stall)	11 Feb	Eggs	Eggs sourced from Egg Farm A	Yes	No	None
Cafe 1	Council inspection around 23 Jan	Egg	Improper cleaning and sanitising	Yes	No	Council Improvement Notice
Retirement Village	4 & 7 Feb	Eggs	No obvious issues	Yes	No	None
Cafe 2	Council	Egg	Incorrect sanitiser and low dishwasher operating temp	Yes	No	None
Cafe 3	Council	Eggs	Dishwasher temperature low	Yes	No	Issues addressed on the day
Bakery 2	22 Feb 2019	Eggs	Improper gg use	Yes	No	None
Bakery 3	12 April 2019	Eggs	Pest, improper sanitiser, inadequate cleaning	Yes	No	None
Bakery 4	21 May 2019	Eggs	Inadequate temps in dishwasher	Yes	No	None
Cafe 4	30 May 2019	Eggs	No issues identified	Yes	No	None

Table 6 Summary of point source clusters of outbreak strain of *Salmonella* Typhimurium with multi-locus variable tandem repeat analysis type 5-17-9-13-490 or similar, notified in NSW between 8 October 2018 and 30 May 2019, in order of notification to NSW Health.

Cluster name	**Egg supplier to business**	**Egg Trace-back**
ACF (2 sites)	Producer B, through grading facility A	Egg Producer A- Egg Farm A
Bakery 1	Producer A	Producer A - Egg farm A
Regional Area	Producer C, side of road stall	Rebranded eggs from producer A - Egg farm A
Cafe 1	Distributor 1 and Distributor 2	Supply from Producer A- Egg Farm A
Retirement village	Producer C	Rebranded eggs from Egg Farm
Cafe 2	Producer A direct	Supply from implicated farm
Cafe 3	Producer A direct	Supply from implicated farm
Bakery 2	Producer B	Rebranded eggs from Egg Farm A
Bakery 3	Producer B, through grading facility A	Rebranded eggs from Egg Farm A
Bakery 4	Producer A direct	Supply from implicated farm
Cafe 4	Producer B, through grading facility A	Rebranded eggs from Egg Farm A

Laboratory results

Genomic comparisons with QLD

The QLD Public Health Microbiology Reference Laboratory confirmed that the eight QLD isolates tested were highly related and clustered together within 0-3 SNP differences of the NSW outbreak strain.

Genomic analysis with NSW cases

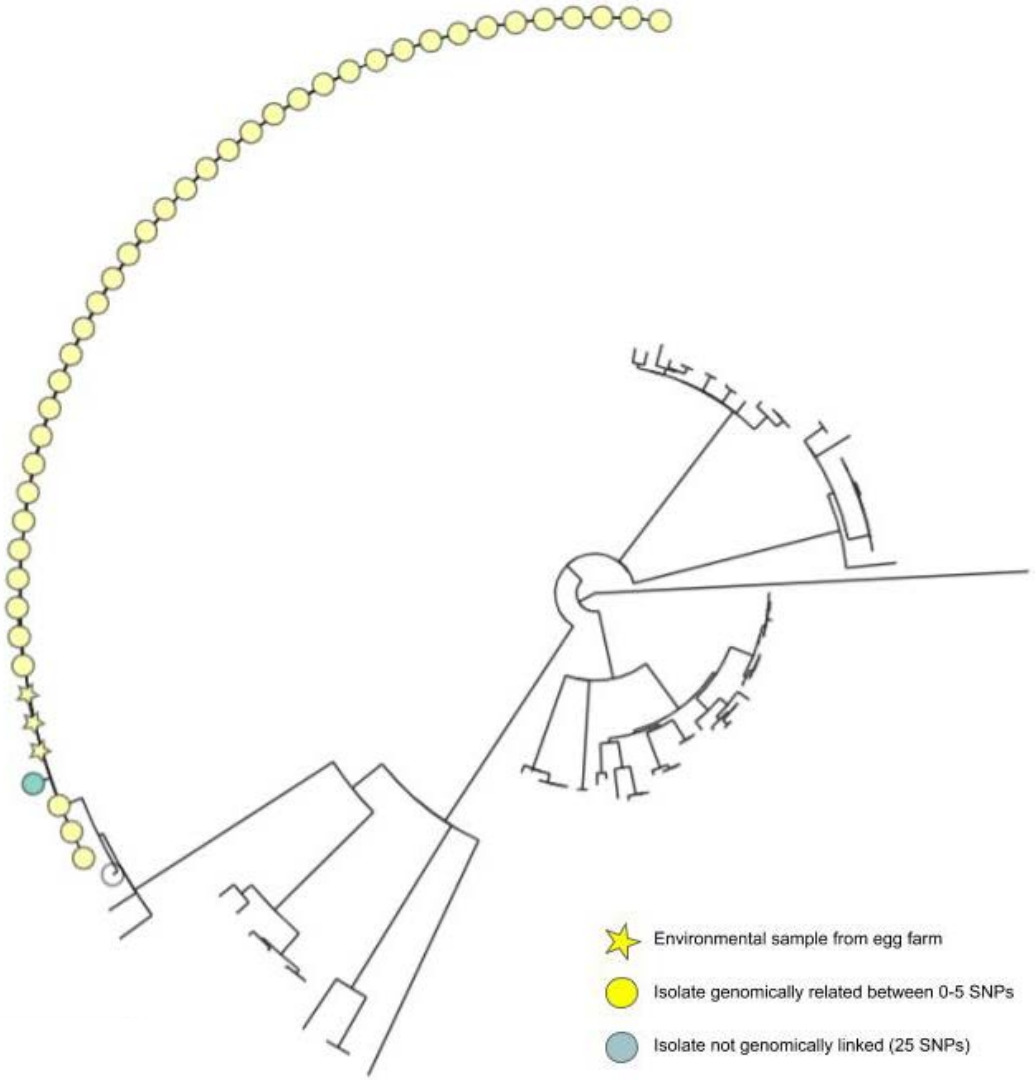
Of the 44 isolates that were sequenced, 43 were highly related within 0-5 single SNPs. This included 41 human isolates and 3 environmental isolates from the implicated farm). Table 7 indicates the cluster was made up of 7 MLVA patterns, 3 where considered closely related to primary MLVA pattern.

Table 7 Whole genome sequencing results showing genomic relationship between isolates of *Salmonella* Typhimurium with multi-locus variable tandem repeat analysis type 5-17-9-13-490 or similar, notified in NSW between 8 October 2018 and 30 May 2019

Source	MLVA type	Isolates submitted (n)	Genomic relationship	Actions (if required)
Human isolate	5-17-8-13-490	1	Not related (25 SNPs)	MLVA sent for reanalysis. Dropped from line list pending confirmation
	5-17-9-13-490	33	Highly related (between 0-5 SNPs)	NA
	5-17-9-14-490	2		
	5-17-9-0-490	1		
	5-17-9-1-490	1		
	5-17-9-15-490	1		
	5-17-10-13-490	1		
	5-18-9-13-490	1		
Environmental isolate	5-17-9-13-490	3	Highly related (0-5 SNPs)	NA
Total		44		

The phylogenetic tree presented in Figure 5 demonstrated that this novel MLVA is not closely genomically related to other *S.* Typhimurium isolates in the sequencing library. The star symbols represent environmental samples and the circles represent human isolates in the outbreak cluster. The yellow colour represents genomic relatedness between 0-5 SNPs, and the green colour represents the isolate that was not shown to be related (25 SNPs).

Figure 5 Phylogenetic tree generated by Microreact (20) illustrating the genomic relationship between the 40 isolates submitted for whole genome sequencing of outbreak strain of Salmonella Typhimurium with multi-locus variable tandem repeat analysis type 5-17-9-13-490 or similar, notified in NSW between 8 October 2018 and 30 May 2019



Discussion

This was a large protracted multi-jurisdictional outbreak of *Salmonella* Typhimurium with a novel MLVA of 5-17-9-13-490 (or related) linked to eggs. Although there were 235 cases notified as part of this outbreak the actual number of people infected is likely to be in excess of 1900 cases, for research indicates every *Salmonella* infection notified represents seven additional infections in the community. (22) The egg trace-back process was complex and implicated a single farm in NSW as the source of the outbreak. Environmental samples from the farm matched human cases via WGS. Eleven point source outbreaks were identified, indicating while it is important to address contamination at the farm the safe handling of eggs at both retail and consumer level is crucial to avoid egg related illnesses.

In Australia, MLVA is used to improve the detection, monitoring and prediction of *S.* Typhimurium clusters, trends and patterns. (12) WGS is an emerging technology that can be performed on *Salmonella* bacteria isolated from specimens to obtain a DNA fingerprint, which is the most definitive and detailed typing method available for this organism. (19) WGS characterised the bacteria isolated from a sample of ill people with this MLVA outbreak over the course of the outbreak (earliest to latest) and included a range of neighbouring MLVA profiles to determine the scope of the outbreak. WGS showed that all but one[‡] of these isolates were closely related genetically. This shows WGS is able to provide a higher power of discrimination than MLVA and that ill people in this outbreak were more likely to share a common source of infection.

[‡] MLVA isolate sent for reanalysis

Improving the capacity of food regulators to better manage food supply chain

While the MLVA type was novel, outbreaks of this nature in NSW are not. Outbreaks such as these highlight the difficulties in trace-back when eggs from different farms are graded at one facility and/or rebranded under another company name. This was demonstrated in an Australian study published by Ford et al in 2018, who described seven outbreaks of *S*. Typhimurium across the country. (13) Five of the outbreaks were linked to a single egg grading facility. Similar to this outbreak, the outbreaks studied were across three states, and the grading facility was compliant with food safety requirements. The eggs stamped at the facility could not be traced as they were from a number of farms, and no egg packaging with the farm establishment number was identified during the investigation (13).

While outside of the scope of this outbreak, this raises the question about whether the practice of sending surplus eggs to other farms to rebrand as their own is misleading the consumer. A consumer may have specific reasons for their purchasing choices of eggs. They may wish to buy locally, or from the region they believe the eggs are from, or by the number of chickens per hectare. On the other hand, selling surplus eggs to other companies may have economic and environmental benefits including minimising food waste, saving resources and ensuring supply meets demand for larger companies without placing additional burden on their farms. However, with the absence of stronger trace-back methods, this is not an ideal practice in an outbreak setting.

Supply chain – retail industry level

The outbreak showed that it is possible for a carton of eggs from one company to include one or more eggs sourced from other companies. At the retail level, if an egg farm was subject to a recall, that recall would not extend to the farm that they distributed surplus eggs to, unless this was detected by the DPI-BFS. If there was only one egg in a carton from the implicated egg farm, and a person became unwell, we would not be able to determine where the egg came from. The eggshell and its identifying stamp would be long disposed of before the case was identified and interviewed. Given the complexities of the egg supply chain, had the point source clusters not occurred in this protracted outbreak, it is unlikely that a link would have been found between MLVA 5-17-9-13-490 and Egg Farm A. This raises the need for improved trace-back methods, particularly for eggs that are sold and rebranded to other companies.

This idea is not impossible and could potentially be factored into the Australian Eggs food safety portfolio. Australian Eggs is a voluntary governing body of the Australian egg industry that has made food safety and biosecurity a key portfolio priority. (23) In the July 2017 to June 2018 fiscal year, Australian Eggs reported that 515.7 million dozen eggs were produced in Australia. Around 32% of Australia's poultry flock was located in NSW and the ACT. It was estimated that 245 eggs were consumed per capita, and both the sale and consumption of eggs overall is on an increasing trend. (23) *Salmonella* in Australia has a heavy impact on this industry. Multiagency and multidisciplinary consultations with the Australian egg industry and regulatory bodies acknowledged that the safety of eggs is a key priority for commercial egg farms. (24) During the consultation a survey found that many believed the spread of the pathogen is less likely to occur in an egg grading facility or during egg and poultry transport, and more likely to occur with the use of dirty or cracked eggs in food service outlets. There was a level of uncertainty

regarding the strength of the industry to successfully control *Salmonella* at the farm and industry level. (24) Egg related outbreaks and subsequent recalls contribute to decreased consumer trust which can negatively impact the entire industry long after the risk has been mitigated. The 2017/2018 Australian Eggs Annual Report detailed allocated funding toward measures that improve systems that build trust, safety and strengthen the entire industry. (23) This has been demonstrated through consultations between regulators and the Australian egg industry, who support MLVA and WGS as effective measures to detect and trace-back *Salmonella* clusters in the community. (24) During this outbreak, the DPI-BFS found that the farm had a good compliance history and a willingness to improve processes on site to reduce the occurrence of MLVA 5-17-9-13-490. The farm complied with all directions from DPI-BFS, but cases continued to be linked to the farm. Despite their compliance efforts it is unlikely that the farm will ever be free of *Salmonella*. *Salmonella enterica* serovars will almost always be present in egg farms due to the high likelihood of intestinal colonization of serovars in chickens via their feed, environment or other animals. (25) Although the mechanism of infection is not fully understood, chickens have the ability to persistently shed these serovars without any indication that they are infected, leading to carcass and egg contamination which subsequently enters the food supply chain. (25). Being a novel MLVA, there is potential that more people could have been immunologically naïve to this strain. (12) There is however a knowledge gap in what constitutes the minimum acceptable level of *S.* Typhimurium and other *S. enterica* serovars at the primary production level.

Post supply – consumer awareness

Food Standards Australia New Zealand (FSANZ) is an independent statutory agency established by the Food Standards Australia New Zealand Act 1991 (FSANZ Act) which develops food standards for both countries. (26) FSANZ acknowledge that the majority of egg related illnesses are due to undercooked or raw contaminated egg products (at the retail level and in the home). If handled and prepared correctly, the chance of contracting a *Salmonella* infection is quite low. (15) Over half of those interviewed reported eating eggs at home. Of these, over a third of people reported eating eggs at home only. Regulatory authorities provide egg safety information on their websites for those who seek it, however this type of messaging is not readily available at the point of purchase. Since 2000, it has been a requirement of the United States Food and Drug Administration (FDA) to ensure that warning labels are provided on cartons of eggs that have not gone through processing steps to destroy *Salmonella*. (27) The statement on the egg carton must be written as follows and displayed on the main display panel to ensure it is noticed by the consumer. (27)

SAFE HANDLING INSTRUCTIONS:
To prevent illness from bacteria: keep eggs refrigerated, cook eggs until yolks are firm, and cook foods containing eggs thoroughly.

In Australia, eggs must be listed as an ingredient on food labels due to its role as an allergen, and any product containing unpasteurised eggs must state this on the packaging. This is the only warning requirement relating to egg labelling in the Australia New Zealand Food Standards Code. (28) The reason there is no requirement for safe handling instructions on eggs in Australia is likely due to the absence of *Salmonella* species in egg laying flocks that can contaminate the inside of the egg, such as *Salmonella* Enteritidis, which is generally overseas acquired. (28)

The primary barrier in this investigation was through the trace-back of eggs. The Food Standards Code requires businesses to have traceability of their eggs, however, a gap exists for an acceptable trace-back method for eggs purchased by the consumer. During the outbreak, interviewed cases had difficulty recalling the brands of eggs they used. Many respondents thought they had purchased a particular brand, but when they checked their fridge or grocery purchase history a different brand would be listed altogether.

Consumers have the right to purchase safe food, but also have responsibility to safely handle and prepare potentially hazardous food to minimise food safety risks. Increasing public awareness about food safety is a final protective step to minimise the impact of foodborne illness. Although information is readily available by regulatory and health authorities on egg safety and high risk foods, the consumer has to a) demonstrate health seeking behaviour; b) be aware that egg and food safety information exists and c) know where and how to access this information. To give the public more control over their decisions when selecting and preparing risk foods, particularly eggs, the introduction of a warning label similar to that issued by the FDA, or at very least a link to egg safety information may increase food safety awareness and fill the gap left by inadequate trace-back measures at the consumer level.

Limitations

Recall bias and interviewer bias was a risk in interviewing cases. However, jurisdictions were trained to use the OzFoodNet *Salmonella* Hypothesis Generating Questionnaire which guided the respondent to describe their food history in several ways. Another limitation was that we did not run every case through WGS however, there is no standard requirement to do this, and the human isolates that were run represented each MLVA type identified and point source cluster during the outbreak period. (13)

Recommendations

It is recommended that trace-back methods for eggs that are passed through a number of distribution channels or rebranded are improved. Both the egg industry and regulators have a high investment and commitment to strengthening the biosecurity and food safety of eggs in Australia. (23, 24) It is recognised that to achieve this requires ongoing communication, collaboration and education of all involved in the egg supply chain. This also extends to the consumer who can greatly minimise the risk of foodborne illness through awareness about safe preparation of high-risk food in retail settings and in the home. NSW Health will continue to improve surveillance and methods to control foodborne disease outbreaks, and it is recommended that more resources are invested to collaborate with the DPI-BFS in increasing awareness for businesses and the public.

Recommendations specific to the MAE program

Based on the experiences of my role as lead investigator, I would recommend the development of a model that designates any MAE on an outbreak as (1) lead, (2) co-lead or (3) team member. The designation should be based on who is accountable in an outbreak investigation and responsible for decisions made, as well as outline the level of participation and responsibility of the MAE in high level conversations, public health

decision making and the aspects of the outbreak they are required to monitor or manage. When I started on this outbreak, I learned much from a public health trainee who was already involved with another outbreak. Many lessons about how to do things were passed from trainee to trainee. The development of a consolidated model describing delegations including templates or procedures would improve the overall management and timeliness of outbreak response for the MAE.

Conclusion

Epidemiological, laboratory and environmental evidence suggest that a single egg farm was the source of an outbreak of *S.* Typhimurium with a novel MLVA 5-17-9-13-490. The identification of clusters through MLVA and WGS was essential in identifying the source of the protracted outbreak. Enhanced controls throughout the food chain are required, particularly for consumers at the point of sale as eggs will never be completely free of *S. enterica* serovars. The minimum acceptable level of contamination at the primary production level needs to be explored.

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Appendices

Appendix C. OzFoodNet *Salmonella* hypothesis generating questionnaire

ozfoodnet

***Salmonella* Hypothesis Generating Questionnaire**
(Nov16)

Case Initials:	
State ID:	
☐ sporadic case ☐ outbreak case	
Outbreak ref:	

Incubation	Duration	Prognosis	Shedding	Reservoir
6-72 hours (av. 12-36 hours) Longer possible, especially with low dose exposure	Diarrhoea, 1-20 days (5 days av.)	Most people completely recover within 1-2 weeks A small number develop complications such as reactive arthritis.	50% of adults >5 weeks 10% for >9 weeks Prolonged shedding more common in children	Colonised intestinal tract of many animals, including chickens, ducks, pigs, cows, reptiles, amphibians, native animals, dogs and cats

CASE DETAILS

First Name:	Last Name:	Parent's Name (if applicable):
DOB: __ / ___ / ___ Age:	Gender: ☐M ☐F	
Address:		
Home Phone:	Mobile Phone:	
Email:		
Physician name:	Physician Phone:	
Born in Australia ☐Y ☐N *If no*, specify where:		
Are [you/the case] of Aboriginal or Torres Strait Islander origin? (check all that apply) ☐No ☐Yes, Aboriginal ☐ Yes, Torres Strait Islander ☐ Not stated		

Interviewer Initials:

Date/time	Interviewed
1	☐
2	☐
3	☐
4	☐
5	☐
6	☐

Person interviewed (if not case):

Call back notes:

Interpreter used ☐
Case lost to follow up ☐

OCCUPATION (Include part-time/casual/volunteer work) and/or INSTITUTION CONTACT

What is [your/the case's] occupation? Specify

Name of work place:

Address of workplace:

Contact details for work place:

Does the case's occupation involve:

Handling food/drink? ☐Y ☐N

Close contact with sick people? (e.g. health care worker) ☐Y ☐N

Close contact with the children/elderly? (e.g. child care worker?) ☐Y ☐N

If yes, please provided relevant public health advise for exclusion period to the case

Do [you/the case] attend childcare / preschool / school /prison/ aged care facility? ☐Y ☐N
If yes, provide details

Name :

Address :

Contact details :

Please provided relevant public health advise for exclusion period to the case

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LABORATORY			
Serotype:	Sub-type:	Specimen collection date: ____/____/____	Specimen type: ☐Stool ☐Blood ☐Urine ☐Other

CLINICAL

I'm now going to ask you about some symptoms that are associated with your illness.

Did you experience any diarrhoea : ☐Y ☐N ☐DK (3 or more loose stools in a 24 hour period)

Diarrhoea onset date: Onset time: ☐am ☐pm Duration : ☐hrs /☐days ☐ ongoing diarrhoea

____/____/____

Blood in stool? ☐Y ☐N ☐DK

Did [you/case] experience any of these following symptoms associated with the illness?

Fever: ☐Y ☐N ☐DK *If case reported fever:* Temperature recorded °C ☐DK / temp not taken

Abd Pain: ☐Y ☐N ☐DK Nausea: ☐Y ☐N ☐DK Vomiting: ☐Y ☐N ☐DK Headache: ☐Y ☐N ☐DK

Lethargy: ☐Y ☐N ☐DK J/M pain: ☐Y ☐N ☐DK Other: ☐Y ☐N ☐DK if yes *specify:*

What was the first symptom [you/case] experienced?

First symptom: First symptom onset date: ____/____/____ Onset time: ☐am ☐pm

Duration of illness ☐hrs /☐days ☐ still ill

Emerg. Dept visit for illness? ☐Y ☐N	Date of visit(s): ____/____/____	Hospital Name:
Admitted for illness? ☐Y ☐N	Date Admitted ____/____/____	Date Discharged: ____/____/____
Treated for illness? ☐Y ☐N	*If yes:* ☐ Rehydration ☐ Antibiotics ☐ other, *please describe:*	
Case deceased? ☐Y ☐N	*If yes:* Date of death:	

Underlying conditions or medications that suppress the immune system (e.g. pregnancy, diabetes, cancers, steroids, etc.) ☐Y ☐N ☐DK

If yes: specify:

EXPOSURE PERIOD

I'm going to ask some questions about what you did before [you/the case] got sick, including some questions that are specifically about the 7 days before the start of [your/the case's] illness.

The first day of illness was (day and date) ____/____/____

Seven days before this was (day and date) ____/____/____

It is often helpful to have a calendar or diary in front of you to help you remember what you did during this time.

CONTACT EXPOSURES

In the 7 days before your illness, did [you/the case] have contact with a:

- Family member with a similar illness? ☐Y ☐N ☐DK *if yes* complete below table
- Friend or work/school colleague with a similar illness? ☐Y ☐N ☐DK *if yes* complete below table

Name	Relationship	Illness onset	Illness description	Phone contact

TRAVEL EXPOSURES

In the 7 days prior to your illness, did [you/the case] travel?

Overseas?	☐Y ☐N ☐DK	If yes, provide travel details: Destination(s):
Interstate?	☐Y ☐N ☐DK	Date departure: ____/____/____ Date of return: ____/____/____
Within State?	☐Y ☐N ☐DK	Mode of travel: ☐air ☐car ☐train ☐ bus ☐ other, specify: Name of airline / tour company / travel numbers (if applicable):

Case classification for international travel

☐ Travel acquired salmonellosis (international travel for *entire* incubation) STOP interview
☐ Possibly travel acquired salmonellosis (international travel for *part* of incubation) CONTINUE interview
☐ Locally acquired salmonellosis (*no* international travel during incubation) CONTINUE interview

ENVIRONMENTAL EXPOSURES

In the 7 days prior to [your/the case's] illness, did [you/the case]		*Name/location/description/details of exposure:*
Live on or visit a rural property	☐Y ☐N ☐DK	
Have any contact with farm or zoo animals (petting zoos, farms, shows, etc)	☐Y ☐N ☐DK	
Have contact with of any the following pets		
Dogs	☐Y ☐N ☐DK	
Cats	☐Y ☐N ☐DK	
Pet fish	☐Y ☐N ☐DK	
Lizards, snakes, turtles, other reptiles	☐Y ☐N ☐DK	
Other pets, specify:	☐Y ☐N ☐DK	
If yes to any Pets, were they fed?		
Dry food, tinned food, raw meat	☐Y ☐N ☐DK	
Fish pellets, flakes, worms	☐Y ☐N ☐DK	
Mice, crickets, other reptile/snake food	☐Y ☐N ☐DK	
Hay, pellets, seed, other animal food/treats	☐Y ☐N ☐DK	
Other pets, specify:	☐Y ☐N ☐DK	
Have any contact with native animals	☐Y ☐N ☐DK	
Swim in / paddle in any pools, dams, or other water ways?	☐Y ☐N ☐DK	
Participate in any sports that include direct contact with water or mud?	☐Y ☐N ☐DK	
Drink any untreated water?	☐Y ☐N ☐DK	
Drink any bottled water?	☐Y ☐N ☐DK	

HOME FOOD PURCHASES

Where did you purchase the groceries consumed in the 7 days prior [your/the case's] illness?

Store	**Where** (location)	**Chicken**	**Eggs**	**Other meats**	**Fruit & Veg**	**Fish & seafood**	**Other groceries**
☐ Aldi		☐	☐	☐	☐	☐	☐
☐ Coles		☐	☐	☐	☐	☐	☐
☐ IGA		☐	☐	☐	☐	☐	☐
☐ Woolworths		☐	☐	☐	☐	☐	☐
☐ Butchery		☐	☐	☐	☐	☐	☐
☐ Local Markets		☐	☐	☐	☐	☐	☐
☐ Fruit & Veg shop		☐	☐	☐	☐	☐	☐
☐ Other		☐	☐	☐	☐	☐	☐
☐ Home Grown or Self-Slaughtered		☐	☐	☐	☐	☐	☐

FOOD EATEN OR PREPARED OUTSIDE THE HOME				
In the 7 days prior to [your/the case's] illness, did [you/the case] eat food from:				
Food Premise Type		**Where:** (Name and location of premises)	**When:** (date and time)	**What:** (did you eat)
Cafes, restaurants, bars	☐Y ☐N ☐DK			
Bakeries	☐Y ☐N ☐DK			
Takeaways, including from service stations, fast food outlets, etc.	☐Y ☐N ☐DK			
Continental deli or specialty grocer (e.g. Asian supermarkets)	☐Y ☐N ☐DK			
Farmers Markets or other market stalls	☐Y ☐N ☐DK			
Direct from farms	☐Y ☐N ☐DK			
Home delivered food e.g. Lite & Easy, Meals On Wheels	☐Y ☐N ☐DK			
Social gatherings, such as: festivals - weddings - parties - religious events - work conferences?	☐Y ☐N ☐DK			

SPECIAL DIETS		
Are [you/the case] on a special diet?	☐Y ☐N ☐DK	Details:
Are [you/the case] allergic to any foods?	☐Y ☐N ☐DK	Details:
Are there any foods or food groups that [you/ the case] *never* eat?	☐Y ☐N ☐DK	Details:

OPEN ENDED FOOD HISTORY			
Collect as much detail as possible including brands, place of purchase or name and location of restaurant/takeaway and everything that was eaten as part of a meal, others who shared the meal, side dishes, etc.			
Day of illness onset	☐M ☐T ☐W ☐T ☐F ☐S ☐S **Date:** ____/____/____	Type / brand / description	Where purchased or eaten
Breakfast:			
Lunch:			
Dinner:			
Other snacks and drinks:			
1 day before illness	☐M ☐T ☐W ☐T ☐F ☐S ☐S **Date:** ____/____/____	Type / brand / description	Where purchased or eaten
Breakfast:			
Lunch:			
Dinner:			
Other snacks and drinks:			

FOOD HISTORY CONT.			
2 days before illness	☐M ☐T ☐W ☐T ☐F ☐S ☐S **Date:** ____/____/____	Type / brand / description	Where purchased or eaten
Breakfast:			
Lunch:			
Dinner:			
Other snacks and drinks:			
3 days before illness	☐M ☐T ☐W ☐T ☐F ☐S ☐S **Date:** ____/____/____	Type / brand / description	Where purchased or eaten
Breakfast:			
Lunch:			
Dinner:			
Other snacks and drinks:			
4 days before illness	☐M ☐T ☐W ☐T ☐F ☐S ☐S **Date:** ____/____/____	Type / brand / description	Where purchased or eaten
Breakfast:			
Lunch:			
Dinner:			
Other snacks and drinks:			

FOOD HISTORY CONT.			
5 days before illness	☐M ☐T ☐W ☐T ☐F ☐S ☐S **Date:** ____/____/____	Type / brand / description	Where purchased or eaten
Breakfast:			
Lunch:			
Dinner:			
Other snacks and drinks:			
6 days before illness	☐M ☐T ☐W ☐T ☐F ☐S ☐S **Date:** ____/____/____	Type / brand / description	Where purchased or eaten
Breakfast:			
Lunch:			
Dinner:			
Other snacks and drinks:			
7 days before illness	☐M ☐T ☐W ☐T ☐F ☐S ☐S **Date:** ____/____/____	Type / brand / description	Where purchased or eaten
Breakfast:			
Lunch:			
Dinner:			
Other snacks and drinks:			

PRIORITY TRAWLER:				
In the 7 days prior to [your/the case's] illness, did [you/the case] eat any of the following POULTRY products PURCHASED RAW and prepared/cooked at home?				
RAW POULTRY	**Eaten during:**		**Type / brand / description**	**Where purchased**
	7 day period before illness?	**3 day period before illness?**		
Whole chicken	☐Y ☐N ☐DK	☐Y ☐N ☐DK	☐ *Free Range* ☐ *Organic* ☐ *Corn Fed* ☐ General *Other details:*	
Chicken pieces (e.g. thigh, wings)	☐Y ☐N ☐DK	☐Y ☐N ☐DK	☐ *Free Range* ☐ *Organic* ☐ *Corn Fed* ☐ General ☐ Pre-packaged[†] ☐ From deli[•] *Specify cuts:*	
Chicken skewer	☐Y ☐N ☐DK	☐Y ☐N ☐DK	☐ *Free Range* ☐ *Organic* ☐ *Corn Fed* ☐ General ☐ Pre-packaged[†] ☐ From deli[•] *Specify flavour:*	
Chicken mince	☐Y ☐N ☐DK	☐Y ☐N ☐DK	*Other details:*	
Chicken sausages	☐Y ☐N ☐DK	☐Y ☐N ☐DK	*Other details:*	
chicken purchased raw and cooked at home (e.g. schnitzel, kiev, chicken paddies)	☐Y ☐N ☐DK	☐Y ☐N ☐DK	☐ Pre-packaged[†] ☐ From deli[•] *Specify what:*	
Turkey	☐Y ☐N ☐DK	☐Y ☐N ☐DK	*Details:*	
Duck	☐Y ☐N ☐DK	☐Y ☐N ☐DK	*Details:*	
Other raw poultry	☐Y ☐N ☐DK	☐Y ☐N ☐DK	☐ Pre-packaged[†] ☐ From deli[•] *Specify what:*	

[†] pre-packaged: purchased in a seal package
[•] from deli: means served to you directly from a deli display or sliced for you at the time of purchase

PRIORITY TRAWLER:				
In the 7 days prior to [your/the case's] illness, did [you/the case] eat any of the following POULTRY products PURCHASED COOKED and eaten out or at home?				
COOKED POULTRY	**Eaten during:**		**Type / brand / description**	**Where purchased or eaten**
	7 day period before illness? →	**3 day period before illness?**		
Cooked BBQ or Charcoal chicken	☐Y ☐N ☐DK	☐Y ☐N ☐DK	*Specify type:*	
Shredded chicken	☐Y ☐N ☐DK	☐Y ☐N ☐DK	☐ Pre-packaged[#] ☐ From deli[*] *Other details:*	
Chicken burger	☐Y ☐N ☐DK	☐Y ☐N ☐DK	*Other details:*	
Other cooked chicken (e.g. chicken kebab, crumbed chicken pieces, stir-fry Schnitzel)	☐Y ☐N ☐DK	☐Y ☐N ☐DK	*Details:*	

PRIORITY TRAWLER:				
In the 7 days prior to [your/the case's] illness, did [you/the case] eat any EGGS or EGG CONTAINING foods eaten out or at home?				
EGGS or EGG CONTAINING foods	**Eaten during:**		**Type / brand / description**	**Where purchased or eaten**
	7 day period before illness? →	**3 day period before illness?**		
Eggs eaten at home (Including egg in salads, on burgers, etc.)	☐Y ☐N ☐DK	☐Y ☐N ☐DK	☐ Free range ☐ Barn Laid ☐ Caged ☐ Organic ☐ Backyard ☐ DK ☐ Runny ☐ Soft ☐ Hard ☐ DK *Brand:* *Other details: (e.g. stamp or best before date)*	
Eggs eaten away from home (Including egg in salads, on burgers, etc.)	☐Y ☒N ☐DK	☐Y ☐N ☐DK	☐ Boiled ☐ Poached ☐ Fried ☐ Scrambled ☐ Other Specify: ☐ Runny ☐ Soft ☐ Hard ☐ DK *Other details:*	

EGGS or EGG CONTAINING foods	Eaten during:		Type / brand / description	Where purchased or eaten
	7 day period before illness? →	3 day period before illness?		
Tiramisu	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Uncooked cake batter	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Homemade custard	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Chocolate mousse	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Homemade ice-cream	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Raw egg milkshake/egg nog	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Homemade Caesar salad dressing	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Homemade mayonnaise/aioli	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Homemade tartare sauce	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Homemade Hollandaise/ béarnaise sauce	☐Y ☐N ☐DK	☐Y ☐N ☐DK	Raw eggs used? ☐Y ☐N ☐DK *Other details:*	
Asian roll, including pork rolls, etc	☐Y ☐N ☐DK	☐Y ☐N ☐DK	*Details:*	
Any other food or drink containing raw eggs	☐Y ☐N ☐DK	☐Y ☐N ☐DK	*Details:*	

EXTENDED TRAWLER (OPTIONAL): Foods eaten in 7 days before illness?			
In the 7 days prior to [your/the case's] illness, did [you/the case] eat any			
MEAT PRODUCTS	**Eaten in 7 days prior to illness**	**Type / brand / description**	**Where purchased or eaten**
Beef mince *(Including lasagna, bolognaise, etc.)*	☐Y ☐N ☐DK		
Beef burger/hamburger from home	☐Y ☐N ☐DK		
Beef burger/hamburger from a food premises	☐Y ☐N ☐DK		
Other beef (e.g. roast, steak, etc.)	☐Y ☐N ☐DK		
Lamb	☐Y ☐N ☐DK		
Veal	☐Y ☐N ☐DK		
Pork	☐Y ☐N ☐DK		
Sausages (e.g. pork, beef, lamb)	☐Y ☐N ☐DK	*Type of sausages and if flavoured:*	
Kebab meat (e.g. meat skewers)	☐Y ☐N ☐DK	*Type of meat and flavour:*	
Game meat (e.g. venison, pheasant, kangaroo)	☐Y ☐N ☐DK	Specify:	
FRESH/FROZEN SEAFOOD	**Eaten in 7 days prior to illness**	**Type / brand / description (specify if self-caught)**	**Where purchased or eaten**
Fish	☐Y ☐N ☐DK		
Oysters	☐Y ☐N ☐DK		
Mussels	☐Y ☐N ☐DK		
Scallops	☐Y ☐N ☐DK		
Prawns	☐Y ☐N ☐DK		
Lobster	☐Y ☐N ☐DK		
Crab	☐Y ☐N ☐DK		
Squid/calamari	☐Y ☐N ☐DK		
DELI MEATS (pre-packaged or sliced at deli)	**Eaten in 7 days prior to illness**	**Type / brand / description**	**Where purchased or eaten**
Bacon	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	
Chicken	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	
Turkey	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	
Ham	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	
Corned beef (Silverside)	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	
Devon	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	
Roast beef	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	

DELI MEATS (pre-packaged or sliced at deli)	Eaten in 7 days prior to illness	Type / brand / description	Where purchased or eaten
Mortadella	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	
Strasburg	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	
Salami/Pepperoni	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli* ☐ **Salami** ☐ **Pepperoni**	
Pastrami	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli*	
Other e.g. (Prosciutto, Speck, Capocollo, Kabana)	☐Y ☐N ☐DK	☐ Pre-packaged ☐ From deli* Specify other:	
MILK AND DAIRY	**Eaten in 7 days prior to illness**	**Type / brand / description**	**Where purchased or eaten**
Unpasteurized (raw) milk	☐Y ☐N ☐DK		
Other milk (soy, almond, rice, etc.)	☐Y ☐N ☐DK		
Flavoured milk (e.g. chocolate)	☐Y ☐N ☐DK		
Powdered milk	☐Y ☐N ☐DK		
Butter (not margarine)	☐Y ☐N ☐DK		
Sour cream	☐Y ☐N ☐DK		
Fresh cream from a tub or carton	☐Y ☐N ☐DK		
Whipped cream from a spray can	☐Y ☐N ☐DK		
Yoghurt	☐Y ☐N ☐DK		
Frozen yoghurt	☐Y ☐N ☐DK		
Ice-cream – tub	☐Y ☐N ☐DK		
Ice-cream – soft serve	☐Y ☐N ☐DK		
Ice-cream bars or frozen desserts	☐Y ☐N ☐DK		
Custard	☐Y ☐N ☐DK		
Dairy desserts	☐Y ☐N ☐DK		
Chocolate	☐Y ☐N ☐DK		
Tasty/cheddar cheese	☐Y ☐N ☐DK	☐ Block ☐ Sliced ☐ Grated ☐ Other	
Parmesan cheese	☐Y ☐N ☐DK	☐ Block ☐ Grated ☐ Shaved ☐ Other	
Edam cheese	☐Y ☐N ☐DK		
Gouda cheese	☐Y ☐N ☐DK		
Cottage cheese	☐Y ☐N ☐DK		

MILK AND DAIRY	Eaten in 7 days prior to illness	Type / brand / description	Where purchased or eaten
Camembert	☐Y ☐N ☐DK		
Brie	☐Y ☐N ☐DK		
Ricotta	☐Y ☐N ☐DK		
Feta	☐Y ☐N ☐DK		
Cream cheese	☐Y ☐N ☐DK		
Processed cheese (e.g. cheese singles , stringers)	☐Y ☐N ☐DK	Specify type:	
Cheese made from goat or sheep milk	☐Y ☐N ☐DK		
Cheese made from unpasteurized milk	☐Y ☐N ☐DK		
Imported cheese	☐Y ☐N ☐DK		
VEGETABLES / SALAD	**Eaten in 7 days prior to illness**	**Type / brand / description specify if eaten (RAW)**	**Where purchased or eaten**
Celery	☐Y ☐N ☐DK	☐Cooked ☐ Raw	
Carrots	☐Y ☐N ☐DK	☐Bagged ☐ Loose ☐Cooked ☐ Raw	
Broccoli	☐Y ☐N ☐DK	☐Cooked ☐ Raw	
Cauliflower	☐Y ☐N ☐DK	☐Cooked ☐ Raw	
Capsicum	☐Y ☐N ☐DK	☐ Red ☐ Green ☐Mixed bag ☐ Other specify : ☐Cooked ☐ Raw	
Chilli	☐Y ☐N ☐DK	☐Cooked ☐ Raw	
Asparagus	☐Y ☐N ☐DK	☐Cooked ☐ Raw	
Fresh corn	☐Y ☐N ☐DK		
Snow peas	☐Y ☐N ☐DK	☐Cooked ☐ Raw	
Other fresh peas or beans	☐Y ☐N ☐DK	☐ Peas ☐Cooked ☐ Raw ☐ Beans ☐Cooked ☐ Raw	
Brussels sprouts	☐Y ☐N ☐DK		
Eggplant	☐Y ☐N ☐DK		
Zucchini	☐Y ☐N ☐DK		
Pumpkin	☐Y ☐N ☐DK	Specify:	
Onions	☐Y ☐N ☐DK	☐Bagged ☐ Loose ☐Cooked ☐ Raw Specify type:	
Spring onions	☐Y ☐N ☐DK		
Leeks	☐Y ☐N ☐DK		
Potatoes	☐Y ☐N ☐DK	☐Bagged ☐ Loose Specify:	

VEGETABLES / SALAD	Eaten in 7 days prior to illness	Type / brand / description specify if eaten (RAW)	Where purchased or eaten
Sweet potatoes	☐Y ☐N ☐DK		
Cabbage	☐Y ☐N ☐DK	☐Whole ☐ Pre-cut ☐Cooked ☐ Raw Specify type:	
Avocado	☐Y ☐N ☐DK		
Tomatoes	☐Y ☐N ☐DK	☐ Truss ☐ Hydro ☐ Roma ☐ Cherry ☐ Grape ☐ General ☐ Other Specify:	
Cucumbers	☐Y ☐N ☐DK	☐ Lebanese ☐ Continental/Telegraph ☐ Other Specify:	
Alfalfa sprouts	☐Y ☐N ☐DK		
Bean sprouts	☐Y ☐N ☐DK		
Salad mix in sealed bag (e.g. baby spinach, rocket ,4 leaf mix, Asian, Caesar)	☐Y ☐N ☐DK	☐ Baby Spinach ☐Rocket ☐ 4 leaf mix ☐ Asian ☐Caesar ☐ Other	
Loose salad mix (e.g. baby spinach, rocket ,4 leaf mix)	☐Y ☐N ☐DK	☐ Baby Spinach ☐ Rocket ☐ 4 leaf mix ☐ Other	
Lettuce (e.g. Cos, Iceberg, Butter, Oak)	☐Y ☐N ☐DK	☐Cos ☐ Iceberg ☐Butter ☐Oak☐ Other	
English Spinach /Silverbeet/Kale	☐Y ☐N ☐DK	☐Spinach ☐Silverbeet ☐ Kale	
Fresh garlic or ginger	☐Y ☐N ☐DK	☐ Garlic ☐ Ginger	
Mushrooms	☐Y ☐N ☐DK	Specify:	
Any other root vegetables	☐Y ☐N ☐DK	☐ Beetroot ☐ Turnip ☐ Radishes ☐ Other	
FRUIT	**Eaten in 7 days prior to illness**	**Type / brand / description**	**Where purchased or eaten**
Apples	☐Y ☐N ☐DK		
Pears	☐Y ☐N ☐DK		
Peaches	☐Y ☐N ☐DK		
Nectarines	☐Y ☐N ☐DK		
Apricots	☐Y ☐N ☐DK		
Oranges	☐Y ☐N ☐DK		
Mandarins	☐Y ☐N ☐DK		
Grapefruit	☐Y ☐N ☐DK		
Lemons	☐Y ☐N ☐DK		
Limes	☐Y ☐N ☐DK		
Cherries	☐Y ☐N ☐DK		
Plums	☐Y ☐N ☐DK		
Grapes	☐Y ☐N ☐DK		

FRUIT	Eaten in 7 days prior to illness	Type / brand / description	Where purchased or eaten
Bananas	☐Y ☐N ☐DK		
Rockmelon (Cantaloupe)	☐Y ☐N ☐DK	☐ Purchased whole ☐ Purchased sliced	
Honeydew melon	☐Y ☐N ☐DK	☐ Purchased whole ☐ Purchased sliced	
Watermelon	☐Y ☐N ☐DK	☐ Purchased whole ☐ Purchased sliced	
Pineapple	☐Y ☐N ☐DK	☐ Purchased whole ☐ Purchased sliced	
Kiwi fruit	☐Y ☐N ☐DK		
Mango	☐Y ☐N ☐DK		
Paw paw	☐Y ☐N ☐DK		
Blueberries	☐Y ☐N ☐DK		
Raspberries	☐Y ☐N ☐DK		
Strawberries	☐Y ☐N ☐DK		
Pre-cut fruit (purchased already cut into portions/pieces)	☐Y ☐N ☐DK		
Packaged fruit salad	☐Y ☐N ☐DK		
Exotic fruits (dragon fruit, star apple)	☐Y ☐N ☐DK		
Homegrown fruits/vegetables	☐Y ☐N ☐DK	Manure used? Type	
CONVENIENCE AND SNACK FOOD	**Eaten in 7 days prior to illness**	**Type / brand / description**	**Where purchased or eaten**
Packaged ready to eat pasta salad	☐Y ☐N ☐DK		
Packaged ready to eat potato salad	☐Y ☐N ☐DK		
Packaged ready to eat coleslaw/dry-slaw	☐Y ☐N ☐DK		
Peanuts	☐Y ☐N ☐DK	☐Loose ☐Packaged	
Almonds	☐Y ☐N ☐DK	☐Loose ☐Packaged	
Cashews	☐Y ☐N ☐DK	☐Loose ☐Packaged	
Walnuts	☐Y ☐N ☐DK	☐Loose ☐Packaged	
Pistachios	☐Y ☐N ☐DK	☐Loose ☐Packaged	
Macadamia nuts	☐Y ☐N ☐DK	☐Loose ☐Packaged	
Brazil nuts	☐Y ☐N ☐DK	☐Loose ☐Packaged	
Hazelnuts	☐Y ☐N ☐DK	☐Loose ☐Packaged	

CONVENIENCE AND SNACK FOOD	Eaten in 7 days prior to illness	Type / brand / description	Where purchased or eaten
Mixed Nuts	☐Y ☐N ☐DK	☐Loose ☐Packaged	
Peanut butter	☐Y ☐N ☐DK		
Other Nut spreads e.g. Nutella	☐Y ☐N ☐DK		
Sunflower seeds or Sesame seeds	☐Y ☐N ☐DK	☐ Sunflower seeds ☐ Sesame seeds	
Tahini	☐Y ☐N ☐DK		
Halva/Hummus	☐Y ☐N ☐DK	☐ Halva ☐ Hummus	
Sultanas/ Raisins	☐Y ☐N ☐DK	☐ Sultanas ☐ Raisins	
Dried apricots	☐Y ☐N ☐DK		
Dried dates	☐Y ☐N ☐DK		
Commercial dip e.g. French onion or similar items	☐Y ☐N ☐DK	☐ Fish based ☐ Vegetable based	
Pate	☐Y ☐N ☐DK		
Meat Paste	☐Y ☐N ☐DK		
Frozen meals (e.g. lasagna)	☐Y ☐N ☐DK		
Frozen Berries	☐Y ☐N ☐DK	☐ Blueberries ☐ Raspberries ☐ Mixed berries	
Frozen vegetarians products (e.g. vegie-burgers)	☐Y ☐N ☐DK		
Frozen chicken e.g. strips, nuggets, schnitzel, kiev	☐Y ☐N ☐DK		
Premade pizza	☐Y ☐N ☐DK		
Dried noodles	☐Y ☐N ☐DK		
Soft noodles	☐Y ☐N ☐DK		
Tofu	☐Y ☐N ☐DK		
Desiccated coconut	☐Y ☐N ☐DK		
Commercial baby food (in jars, cans, pouches)	☐Y ☐N ☐DK		
DRINKS	**Eaten in 7 days prior to illness**	**Type / brand / description**	**Where purchased or eaten**
Freshly squeezed fruit/vegetable juice – made at home	☐Y ☐N ☐DK		
Freshly squeezed fruit/vegetable juice from a juice bar/café	☐Y ☐N ☐DK		
Smoothie	☐Y ☐N ☐DK		

COMMERCIAL SALAD DRESSING & SAUCES	Eaten in 7 days prior to illness	Type / brand / description	Where purchased or eaten
Mayonnaise	☐Y ☐N ☐DK		
Sauces / chutneys e.g. Tomato, BBQ, fruit chutney	☐Y ☐N ☐DK		
Marinades	☐Y ☐N ☐DK		
Cooking sauces e.g. soy, oyster, simmer sauce	☐Y ☐N ☐DK		
HERBS & SPICES	**Eaten in 7 days prior to illness**	**Type / brand / description**	**Where purchased or eaten**
Any spices bought in bulk (from a tub or other container)	☐Y ☐N ☐DK		
Black pepper	☐Y ☐N ☐DK		
Paprika	☐Y ☐N ☐DK		
Dried chilli	☐Y ☐N ☐DK		
Ground coriander	☐Y ☐N ☐DK		
Other Spices	☐Y ☐N ☐DK	Specify:	
Fresh basil	☐Y ☐N ☐DK		
Fresh parsley	☐Y ☐N ☐DK		
Fresh mint	☐Y ☐N ☐DK		
Fresh coriander	☐Y ☐N ☐DK		
Other fresh herbs	☐Y ☐N ☐DK	Specify:	
TAKEAWAY FOOD	**Eaten in 7 days prior to illness**	**Specify further details if relevant** (e.g. chicken, lamb kebab with hummus)	**Where purchased or eaten**
Burger from takeaway/fast food shop	☐Y ☐N ☐DK		
Kebab on a stick	☐Y ☐N ☐DK		
Kebab (e.g. a doner with lamb, beef or chicken etc.)	☐Y ☐N ☐DK		
Takeaway pizza	☐Y ☐N ☐DK		
Sandwich or filled rolls	☐Y ☐N ☐DK		
Spring rolls/ Dim Sims	☐Y ☐N ☐DK	☐ Spring rolls ☐ Dim Sims	
Satay sticks	☐Y ☐N ☐DK		
Takeaway pasta	☐Y ☐N ☐DK		
Pies/pasties/sausage rolls	☐Y ☐N ☐DK		
Fresh pre-made meals to be reheated at home (not frozen)	☐Y ☐N ☐DK		
Consume any foods that are associated with a specific culture (e.g. Indian, Chinese, Italian, Lebanese, Thai	☐Y ☐N ☐DK	Specify	

EDUCATION: Preventing Salmonella and other foodborne diseases

Key tips

Wash your hands before handling food and often during food preparation especially when handling raw eggs and chicken.

Wash and clean all surfaces and equipment used for food preparation or serving especially when handling raw eggs and chicken.

Keep clean

Wash your hands after going to the toilet, changing the baby or being in contact with animals.

Protect kitchen areas and food from insects, pests and other animals.

Separate raw and cooked foods

Separate raw meat, poultry, fish and seafood from other foods.

Use separate equipment and utensils such as knives and cutting boards for handling raw foods.

Store foods in covered containers to avoid contact between raw and cooked foods.

Cook thoroughly

Cook food thoroughly, especially meat, poultry, eggs, fish and seafood.

For meat and poultry, make sure juices are clear, not pink.

Bring foods like soups and stews to boiling point.

Reheat cooked food thoroughly. Bring to the boil or heat until too hot to touch. Stir while re-heating.

Keep food at safe temperatures

Do not leave cooked food at room temperature for more than two hours.

Do not store food too long, even in a refrigerator.

Do not thaw frozen food at room temperature.

Food for infants and young children and other people with low immune systems should ideally be freshly prepared and not stored at all after cooking.

Use safe water and foods

Do not use food beyond its expiry date.

Wash fruits and vegetables in clean water, especially if eaten raw.

Hygiene and preventing transmission discussed	☐Y ☐N
Would you like us to send you a fact sheet with information about *Salmonella*?	☐Y ☐N

CONCLUSION

Thanks for your time today.
The information you provide in this questionnaire is for the purpose of trying to prevent further cases of illness.
We do this by trying to find out what is likely to have caused your illness and also by providing you with information to reduce the spread of illness to others.
The data collected is kept confidential and identifying information will not be disclosed for any other purpose without your consent

If we have any further questions, could we contact you again?	☐Y ☐N

FOLLOW-UP AND EXCLUSIONS	
Exclusion required?	☐Y ☐N
Exclusion discussed with case / parent / guardian	☐Y ☐N

JURISDICTIONAL EXCLUSION GUIDELINES

Jurisdiction to add guidelines…

INTERVIEW COMPLETED BY

Name of Interviewer:

How well did the case recall the information requested? ☐ very well ☐ well ☐ not well ☐ not at all

GENERAL NOTES:

Chapter 5

Evaluation of a public health surveillance system

Evaluation of the acute rheumatic fever and rheumatic heart disease surveillance system, including the rheumatic heart disease register

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Chapter 5 Table of Contents

Tables and figures

Tables

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Acronyms

ACCHSs	Aboriginal Community Controlled Health Services
AH&MRC	Aboriginal Health and Medical Research Council of NSW
AMS	Aboriginal Medical Service
ANU	Australian National University
BCC	Better Cardiac Care
CDNA	Communicable Diseases Network Australia
DPI	Department of Primary Industries
HREC	Human Research Ethics Committee
IgA	immunoglobulin class A
IgG	immunoglobulin class G
IgM	immunoglobulin class M
IT	Information Technology
LGA	Local Government Area
LHD	Local Health District
MAE	Master of Philosophy in Applied Epidemiology
NCIMS	Notifiable Conditions Information Management System
NSW	New South Wales
PCR	Polymerase chain reaction
PPE	Personal protective equipment
SAPHaRI	Secure Analytics for Population Health Research and Intelligence
US CDC	United States Centres for Disease Control and Prevention
Yr	Year

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“It’s terrible, you know.

These are young people, that won’t make old bones”

- In conversation with Priscilla Stanley, Western and Far Western NSW local health district

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Prologue

On 10 November 2018, I was engaged by NSW Health to evaluate the acute rheumatic fever (ARF) and rheumatic heart disease (RHD) surveillance system, including the RHD Register. ARF/RHD carry serious health implications throughout the life course, and I was very appreciative of being the first person to undertake this task for NSW. This chapter presents the background, methodology, evaluation and recommendations relating to surveillance activities in the NSW ARF/RHD Programme.

Public health impact

ARF and RHD became notifiable in NSW on 2 October 2015 and was added as an amendment to the list of notifiable diseases in Schedule 2 of the NSW Public Health Act 2010. (1) A surveillance system was launched in 2015, followed by a RHD Register in 2016, (1, 2) structured by former MAE, Dr Chaturangi Yapa. (3) An evaluation of the surveillance system and register was necessary to determine whether the system was useful and had met its objectives for surveillance. The evaluation found that the surveillance system had improved epidemiological knowledge of ARF/RHD in the context of NSW. It is likely that recurrences of ARF was prevented and the severity of RHD minimised for some individuals through enrolment onto the RHD Register. Service provision and delivery was improved by the evaluation through the feedback provided by stakeholders of the system, particularly in the way information is presented and reported. The outcomes of the evaluation encourage focus toward building relationships between primary and secondary health care services and to find new strategies to build clinician awareness about ARF/RHD as a notifiable disease.

MAE role

I coordinated the project proposal, questionnaire design, stakeholder consultation, qualitative and quantitative interviews, data collection and analysis. Working alongside the NSW RHD Network and the RHD Coordinator and Manager at Health Protection NSW I prepared recommendations based on these findings against attributes detailed in the *Updated Guidelines for Evaluating Public Health Surveillance Systems* by the United States (US) Centers for Disease Control and Prevention (CDC). (1) I conducted a stakeholder session at a NSW RHD Network workshop on 4 April 2019, undertook qualitative semi-structured interviews and sent an electronic survey around the network. I provided a report to outline the evaluation findings and recommendations.

Lessons learnt

Community-based approaches

Through semi-structured interviews I learnt about the initiative of one local health district, who held Town Hall meetings in communities with cases. Community members, General Practitioners (GPs) and Aboriginal Community Controlled Health Services (ACCHS) attended and were provided with information, education and opportunity for discourse. After these events, more cases were identified by clinicians and community members, demonstrating the benefit of meaningful community partnerships and prioritising resources toward building these relationships.

Technical knowledge

I learnt how to utilise appropriate guidelines such as the US CDC *Updated Guidelines to Evaluate Surveillance Systems* to evaluate the surveillance system by measuring attributes including simplicity, stability, flexibility, acceptability, data quality, sensitivity, predictive value positive (PVP), representativeness and timeliness. (4)

Abstract

Background

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) became notifiable in NSW on 2 October 2015. At this time the ARF/RHD surveillance system was launched, followed by a voluntary consent-based RHD Register in 2016 to help patients follow their long-term health plan, including secondary prophylaxis and clinical reviews. An evaluation was conducted to determine whether the system had met their objectives to monitor the epidemiology of ARF/RHD in NSW and enrol cases onto the RHD Register.

Methods

Microsoft Excel and STATA 15 (5) was used to calculate indirect age standardised rates and conduct a descriptive analysis of ARF/RHD notification data in NSW. Face to face network consultation, online open and closed questions survey and semi-structured interviews were undertaken to assess attributes of the surveillance system and register against an evaluation framework by the United States Centers for Disease Control and Prevention *Updated Guidelines for Evaluating Public Health Surveillance Systems.* Attributes were evaluated for flexibility, simplicity, data quality, sensitivity, predictive value positive, acceptability, representativeness, timeliness and stability.

Results

The surveillance system has been useful in monitoring the epidemiology of ARF/RHD in NSW. Eighty-three cases of ARF and 81 cases of RHD met the case definition on the surveillance system, of which 36% consented to the RHD Register. The surveillance system is simple, flexible and stable from a systems perspective. Small improvements are required to enhance data quality and ensure sustainability of the program at the central level. Active surveillance is highly sensitive which results in many non-cases

although without a baseline it is unknown whether it has been effective in capturing all cases. Low clinician awareness affects the acceptability, sensitivity and timeliness of the system. The system is not likely to be representative of the true burden of disease due to unknown prevalence and people over 35 years of age excluded from the register.

Conclusion

The surveillance system is useful and should continue to monitor the epidemiology of the disease in NSW, and work toward understanding the prevalence of ARF/RHD to measure the true burden of disease. While the secondary objective to enrol cases onto the RHD Register have partially been met, eligible cases remain off the register.

Introduction

Over a third of all throat infections are thought to be associated with Group A Streptococcus (GAS) which can cause an autoimmune response of the heart, brain, joints or skin. This response is described as acute rheumatic fever (ARF), which can reoccur in 'episodes' which can cause severe and permanent damage of the heart valves. This is known as rheumatic heart disease (RHD), the leading cause of cardiovascular deaths in people under 40 years of age. (6) For the individual, this means long term heart problems including scarring and hardening of the valves, obstruction (stenosis), or reverse flow of blood into the heart (mitral regurgitation). It also means a higher chance of further illness and premature death, particularly for young children. (7)

In 2005 there were an estimated 15.6-19.6 million cases of ARF worldwide. There are an estimated 471,000 ARF annually of which 336,000 were in children 5-14 years of age. Sixty per cent of all ARF cases are thought to develop into RHD. (8) At least 2.4 million cases of RHD are in children aged 5-14 years worldwide, illustrated by a prevalence map in Figure 1. (8) The global prevalence of RHD is estimated at 33 million, which contributes to 275,000 deaths annually. (9, 10) The number of reported cases of RHD in 2013 by country, and the change in age-standardized RHD prevalence from 1990 to 2013 is described in Figure 2. (10) It should be noted that global prevalence data is primarily calculated from schools, and as such, the burden is thought to be substantially underestimated for children as they may not have access to education. (8)

Figure 1 Global prevalence of rheumatic heart disease in children aged 5–14 years. (8)

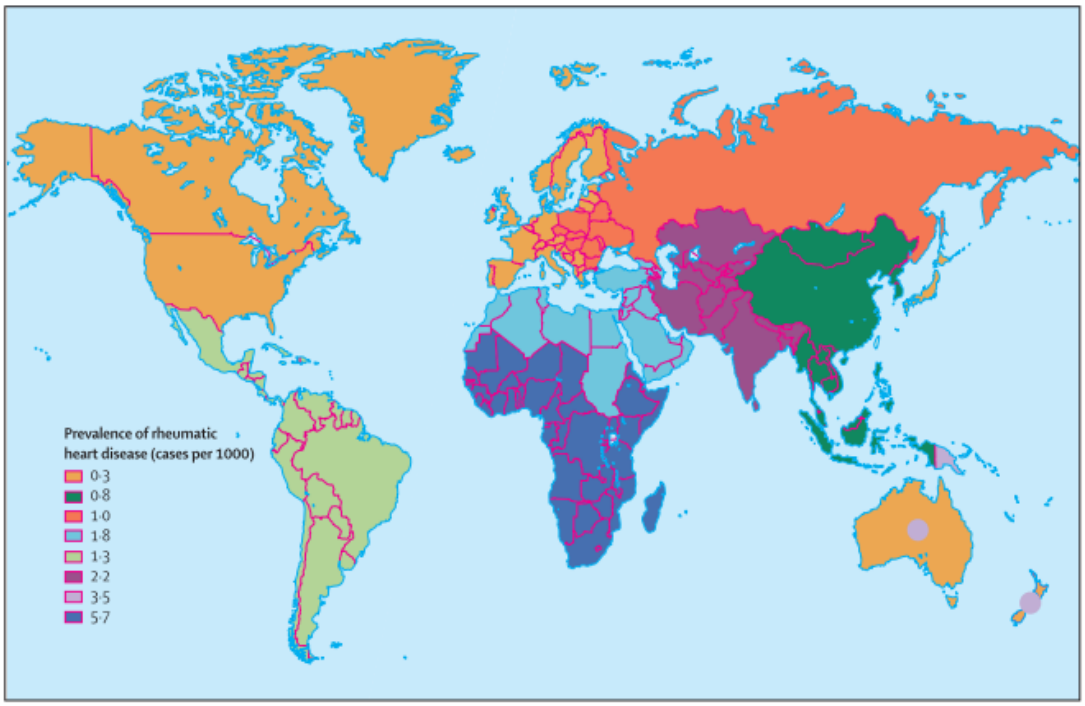
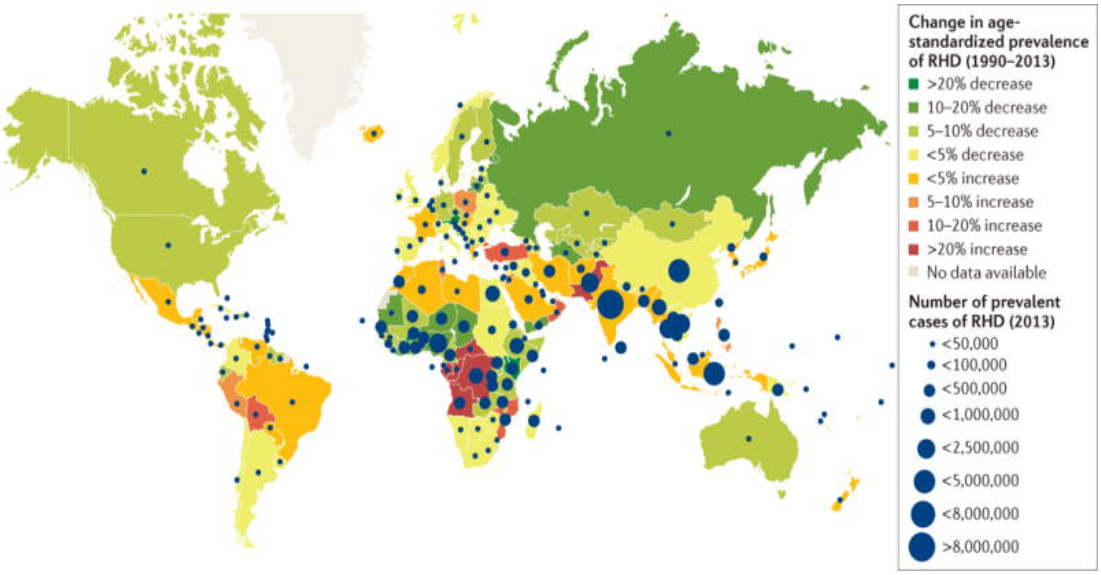


Figure 1: Prevalence of rheumatic heart disease in children aged 5–14 years
The circles within Australia and New Zealand represent indigenous populations (and also Pacific Islanders in New Zealand).

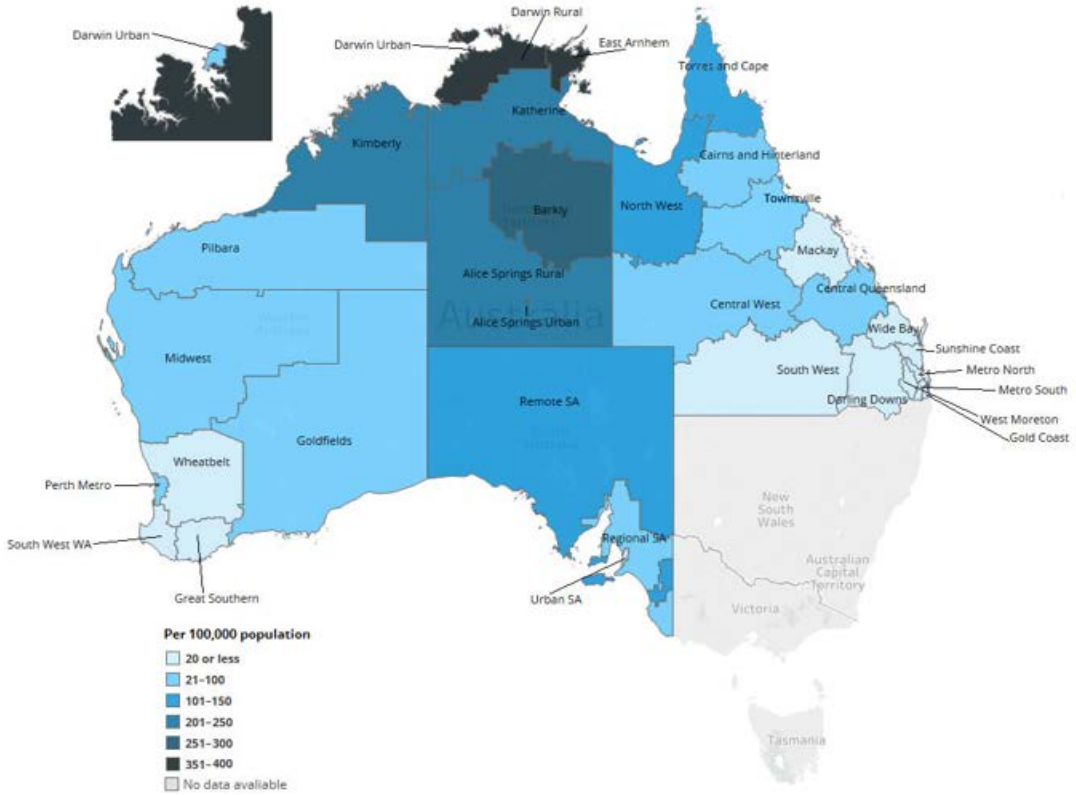
Figure 2 The global burden of rheumatic heart disease (RHD): Number of prevalent cases of RHD in 2013 by country, as well as the change in age-standardized RHD prevalence from 1990 to 2013. Image courtesy of R. Seth, Telethon Kids Institute, Perth, Australia. (10)



Acute rheumatic fever in Australia

Indigenous Australians have some of the highest rates of ARF in the world (85 per 100,000), more than 250 times the rate than non-Indigenous Australians (4 per 100,000). (7) The Australian Institute of Health and Welfare reported that from 2013 to 2017 there were 1,897 people diagnosed with ARF in Australia, of which 94% (n=1,776, 85 per 100,000) were Indigenous Australians. Of these, females were most affected with 1006 cases (96 per 100,000). (7) Consistent with global research, children aged 5-14 years were most affected with a rate of 195 per 100,000 (n=602) (Figure 3). (7)

Figure 3 Rate of acute rheumatic fever diagnoses per 100,000 among Indigenous Australians by region of management, 2013–2017. Source: AIHW analysis of National Rheumatic Heart Disease data collection (7)



Notes:

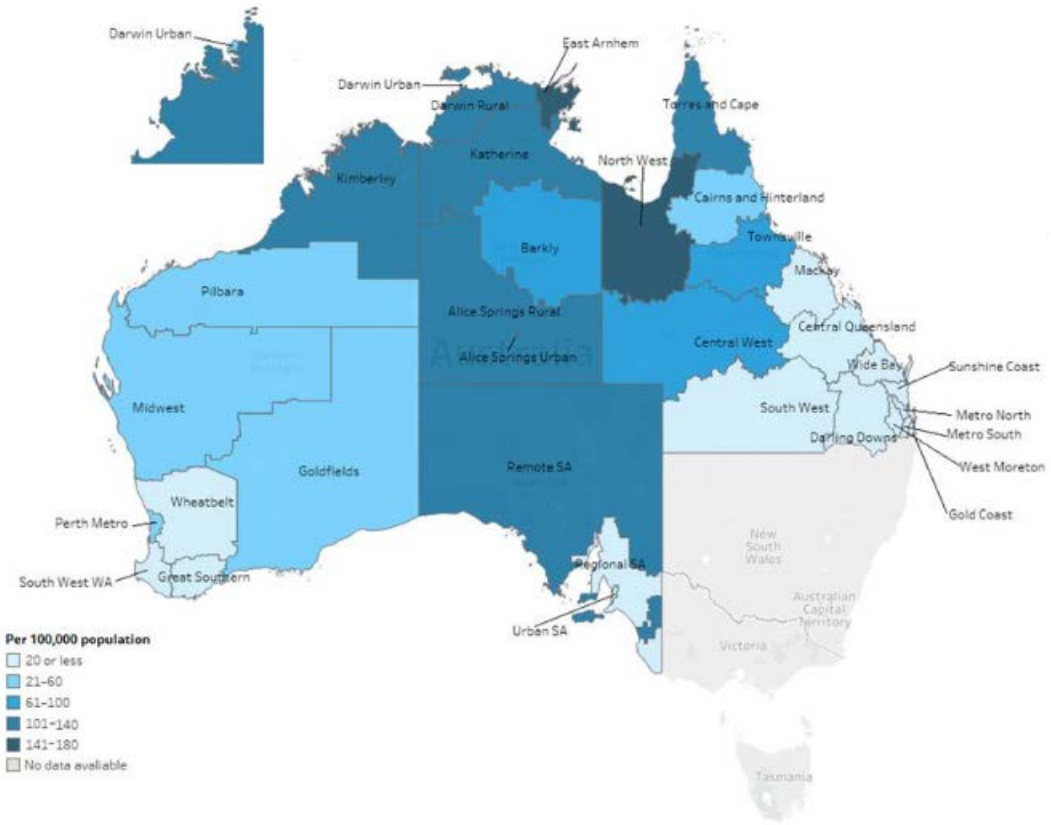
1. There are 33 regions across the 4 states and territories. Each state and territory define regions uniquely, based on their own specific health services boundaries.
2. Rates are crude rates per 100,000 population.
3. ARF diagnoses include all episode types and confirmation statuses. Refer to box 2 and 3 for more information.
4. No data are available for jurisdictions not included in the National Rheumatic Heart Disease data collection.
5. For Queensland regions, the 2016 population estimates were used to calculate rates for 2016 and 2017.

Source: AIHW analysis of National Rheumatic Heart Disease data collection.

Rheumatic heart disease in Australia

Between 2013 and 2017 there were 4259 people alive in Australia with RHD recorded on a jurisdictional register. Eighty-seven per cent (n=3690) were Indigenous Australians, and of these, 65% were female (n=2787). Approximately 60% of all individuals diagnosed with RHD were under the age of 25. The national crude rate for RHD is around 0.4 per 100,000 compared to 48 per 100,000 for Indigenous Australians (Figure 4). (7)

Figure 4 Rate of rheumatic heart disease (RHD) cases among Indigenous Australians per 100,000 by region of management, as at 31 Dec 2017. Source: AIHW analysis of National RHD data collection (7)



Notes:

1. There are 33 regions across the 4 states and territories. Each state and territory define regions uniquely, based on their own specific health services boundaries.
2. Rates are crude rates per 100,000 population
3. No data are available for jurisdictions not included in the National Rheumatic Heart Disease data collection.
4. For Queensland regions, the 2016 population estimates were used to calculate rates for 2016 and 2017.

Source: AIHW analysis of National Rheumatic Heart Disease data collection.

Acute rheumatic fever and rheumatic heart disease in NSW

Although the burden of ARF/RHD is unknown in NSW, internal surveillance reports have found the majority of cases are Aboriginal, Maori and Pacific Islander children. (11) The over-representation of Aboriginal people with ARF/RHD is consistent with other states and territories in Australia, as is the overrepresentation in Maori and Pacific islander children in New Zealand, where the incidence of ARF/RHD is believed to be 20 to 40 times higher than non-Indigenous children. (12)

Risk factors and inequities

The risk factors for ARF/RHD are driven by social inequity. At greatest risk are children 5-14 years of age and pregnant women, particularly those facing social deprivation, isolation from health and educational services, or who cannot access housing suitable for the size of their families. (7, 13, 14) Four out of five people with RHD live in countries with a low development index, however this is reality for many Indigenous Australians and Pacific Islander communities of Australia. (8, 12, 13) Given the context of Australia's prosperity, universal health coverage and high development index, the existence of a preventable and uncommon disease such as ARF/RHD is a tremendously important public health and social justice issue. (13)

Prevention

The gold standard testing method relies on clinical diagnosis using the modified Jones criteria to categorise clinical symptoms and use of echocardiography based on the 2012 World Heart Federation evidence-based guideline. (15) When a patient commits to treatment, they must also make a commitment to endure physical, psychological and logistical burdens associated with receiving prophylaxis at the right time. Treatment for ARF/RHD is usually with benzathine penicillin G (BPG) by intra-muscular injection (IMI)

every 21 days (for high risk), to 28 days, for a minimum 10 years after the last episode of ARF, or until they turn 21 (whichever is longer). People with RHD may require secondary prophylaxis until 35–40 years of age. (16) The potential clinical course in the absence of an intervention and prevention strategies to counteract these include primordial, primary, secondary and tertiary prevention, illustrated in Table 1. Primordial prevention reduces the risk of ARF/RHD by addressing inequalities and social deprivation. (10, 13, 17) Primary prevention aims to improve clinical management of sore throats and skin infections to reduce the risk of ARF and its recurrence. (6, 18) Secondary prevention includes adherence to secondary prophylaxis through a consent-based register. (18) Tertiary prevention improves access to specialist services and long-term care, including medical and dental check-ups, echocardiograms and specialist reviews. (6, 16)Without prevention strategies, individuals with ARF/RHD are at genuine risk of increased complications or premature death (Table 1). (19)

Table 1 Potential clinical course of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in the absence of an intervention, and prevention strategies undertaken by New South Wales (NSW) Health at 30 May 2019. Sourced from NSW Health RHD Program

Casual pathway of ARF/RHD	**Prevention strategies**
Exposure to Group A Streptococcus (GAS) ↓ Bacterial GAS infection ↓	Primordial prevention Reduction in overcrowding, poverty and malnutrition Improved access to healthcare
Acute rheumatic fever (ARF) episode ↓ GAS infection & recurrences of ARF ↓	Primary prevention Treating sore throats with antibiotics in high risk populations Reduction in skin infections
Rheumatic heart disease ↓	Secondary prevention NSW RHD Register Regular antibiotics for people at risk of ARF recurrence
Complications of RHD ↓ Heart failure	Tertiary intervention Medical management of symptomatic RHD Heart surgery

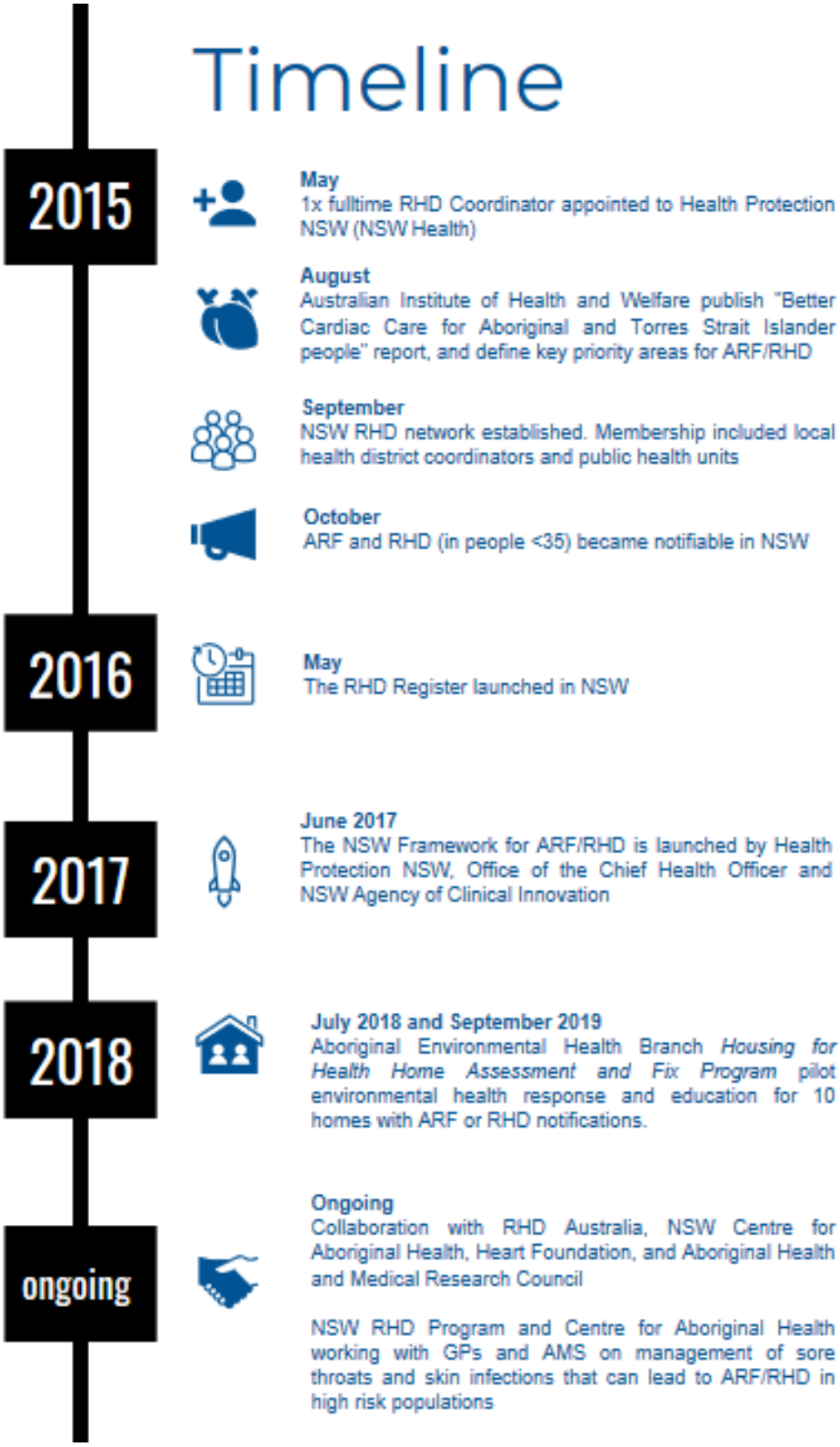
The NSW ARF/RHD Surveillance System and RHD Register

ARF/RHD is not notifiable across all Australian states and territories, nor is there requirement to have a RHD register. The variable uptake is attributed to differing jurisdictional needs and levels of perceived risk. In 2014 federal, state and territory health departments participated in the Better Cardiac Care (BCC) for Aboriginal and Torres Strait Islander People Forum. Initiatives to improve cardiac outcomes for Indigenous Australians were endorsed to address the high associated mortality compared to non-Indigenous Australians (1.7 times higher). A specific priority was to "Strengthen the diagnosis, notification and follow-up of RHD". (18) This led to the NSW ARF/RHD control program in 2015. Table 2 outlines the national and jurisdictional positions on ARF/RHD and Figure 5 provides a timeline of actions since the BCC forum.

Table 2 National and jurisdictional position on acute rheumatic fever and rheumatic heart disease as notifiable conditions, and details of jurisdictional rheumatic heart disease registers, at 30 May 2019.

Jurisdiction	Year ARF notifiable	Year RHD notifiable	Year RHD register was created
Commonwealth	Not nationally notifiable		A national data collection system for register data is in development
Australian Capital Territory	Not notifiable	Not notifiable	No register
New South Wales	2015	2015 (<35 years age)	May 2016
Northern Territory	1994	Not notifiable	Top End (1997) and Central Australia (2000) merged in 2007
Queensland	1999	Not notifiable	2009
South Australia	2016	2016	2012. SA uses NT's RHD Register platform
Tasmania	Not notifiable	Not notifiable	No register
Victoria	Not notifiable	Not notifiable	Cases are referred to specific clinics available to children and adults
Western Australia	2007	2015	2010

Figure 5 Timeline of New South Wales Health program activities relating to acute rheumatic fever and rheumatic heart disease from 1 May 2015 and 30 June 2019



ARF/RHD is managed in NSW by a surveillance system based on the case definition for a confirmed, probable or possible case in the NSW ARF/RHD Control Guideline: (16)

Acute rheumatic fever

Confirmed: "Clinical definitive evidence and laboratory suggestive evidence or Rheumatic (Sydenham's) Chorea (with other forms of chorea excluded)." (16)

> *Probable: "Clinical definitive evidence or clinical suggestive evidence and laboratory suggestive evidence and where ARF is considered the most likely diagnosis by the treating clinician." (16)*
>
> *Possible: "Clinical definitive evidence or clinical suggestive evidence and laboratory suggestive evidence and where the treating clinician has less confidence about ARF as the correct diagnosis, but other differential diagnoses have been excluded." (16)*

Rheumatic heart disease

> *Confirmed: "Clinical definitive evidence in a person less than 35 years of age. An echocardiogram with valve changes consistent with RHD as defined by the World Heart Federation criteria" (16)*

The consent-based RHD Register was launched in May 2016 for people with ARF or RHD (under 35 years of age). NSW Health works with local health districts to enrol cases onto the register to enable long term management. Individuals can go on the register if they are not considered notifiable in NSW, (diagnosed with RHD over the age of 35 years of age or who have had episodes of ARF in other jurisdictions but not in NSW) or should their clinician feel this is beneficial for the individual to maintain treatment. (16) Although the surveillance system and register in NSW have two different functions, they are both overlapped, housed in the NSW Notifiable Conditions Information Management System (NCIMS) administrative package. The type of information collected on the surveillance system and register is in Table 3.

Table 3 Information available on the New South Wales (NSW) Acute Rheumatic Fever and Rheumatic Heart Disease (RHD) Surveillance System and RHD Register at 30 June 2019

Information	Details	Authorisation to use information
Demographic	Name, date of birth and address Family or next of kin contact details	• NSW Health staff with access to the NSW Notifiable Conditions Information Management System • Other groups to assist with the care of people who are on the register (with consent from the individual, including: • General Practitioners (GPs) and staff at the patient's local clinic to remind about appointments • Specialists involved in the patients' care plan. • NSW RHD Network • Identified data from the Register can be provided to Medicare to look for patients lost to follow-up • De-identified data to the National data collection.
Dates, treatment and appointments	Dates of illness, death, treatment or related appointments	
Health practitioner and specialist information	GP and/or local health clinic details	
	Heart tests or operations (past and future)	

Flow of information

For diagnoses made at primary or secondary health services (ACCHS, GP or hospital), the clinician notifies the jurisdictional PHU, where staff or the LHD Coordinator will follow up the case. Each LHD was required to nominate a coordinator (not appointed by PHU). The LHD Coordinator may have a clinical or a public health role and may be located elsewhere (e.g. Cardiac Clinic). Ideally, patient consent and enrolment onto the Register is requested by the clinician at the point of notification (Figure 6) however many jurisdictions do this later in the process. The PHU enters the notification onto NCIMS. All individuals on NCIMS have a numerical identifier and any notifiable disease they may have will be reported under this identifier. The LHD Coordinator is engaged (if not already) and obtains consent to the RHD Register (if not already consented). The LHD Coordinator liaises with the patient, family and the treating clinician to ensure the patient is engaged with primary care services, has a case manager and is consented to the register where appropriate. The RHD Coordinator is based centrally and liaises with care providers to ensure treatment, referrals and appointments occur. They are also

responsible for overseeing the RHD Register, preparing audits and reporting to stakeholders, the NSW RHD Network.

Active surveillance is an essential component for case finding due to the complex diagnostic pathway and chance that ARF/RHD will not be investigated when an individual presents to a health service. (6) Active surveillance uses 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD) codes I 00-002 relating to ARF and ICD codes I 05-09 relating to RHD (for individuals under the age of 35) and includes those who have died in hospital. A list of these codes is routinely obtained from the Combined Admitted Patient Epidemiology Data (CAPED) by the RHD Coordinator, who provides these possible cases to the PHU or LHD Coordinator to review and follow up.

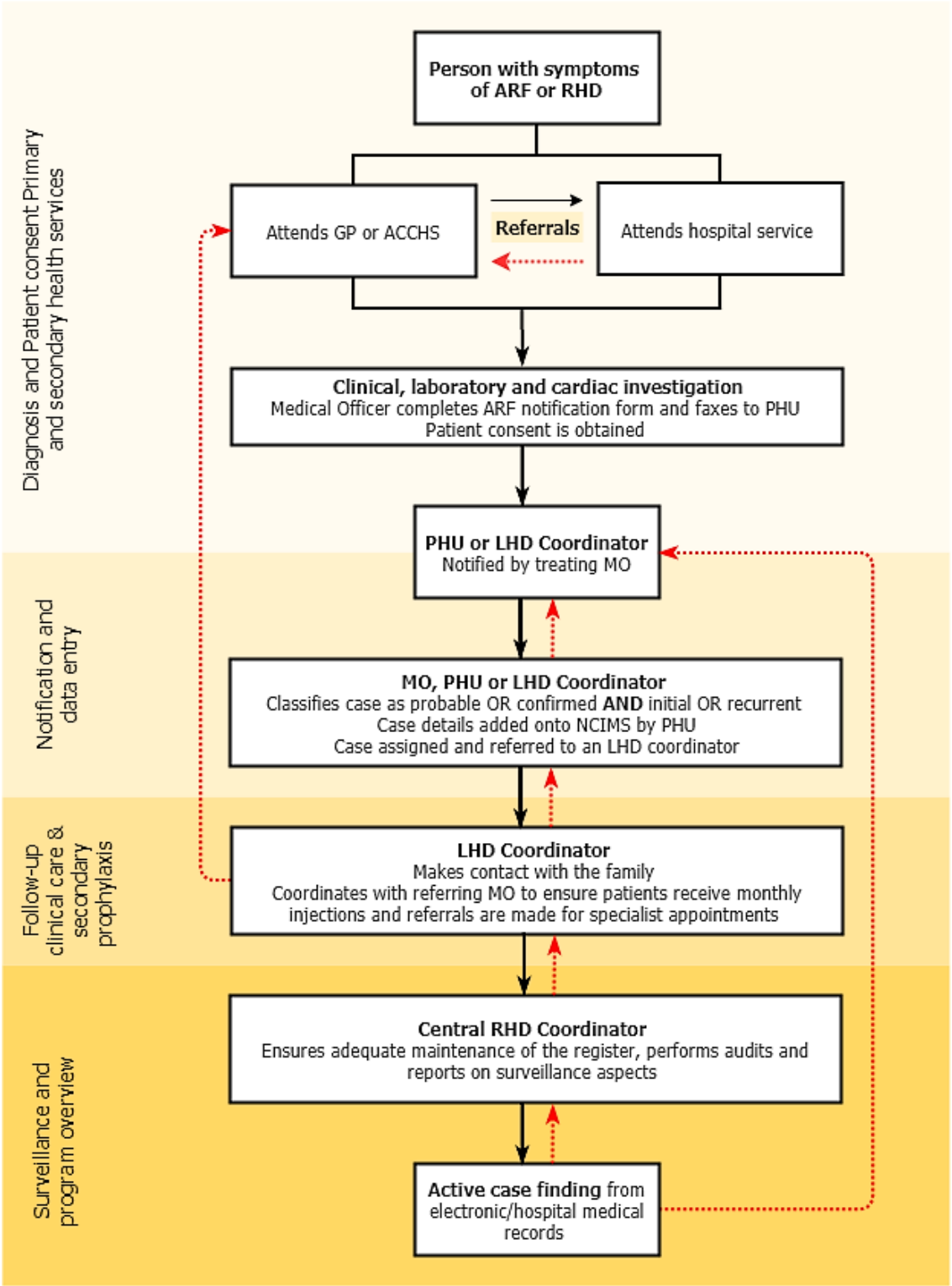
Governance

The NSW RHD network comprises public health staff and clinicians involved in ARF/RHD management at all levels. Governance of the system was centralised in the Communicable Diseases Branch (CDB).

Legislation

Decisions and responsibilities of the program are under Schedule 1 of the NSW Public Health Act 2010. People interacting with the surveillance system and register comply with notifiable disease legislation by following the NSW ARF/RHD control guideline. (16)

Figure 6 Flow of data for the NSW acute rheumatic fever and rheumatic heart disease surveillance system



Cost

Since January 2015, an estimated $583,750 has been invested into the overall RHD program. Costs were allocated toward the appointment of a centralised RHD Coordinator, education and awareness materials, and face to face meetings (Table 4).

Table 4 Funding to the acute rheumatic fever and rheumatic heart disease surveillance system by financial year 2014-2019

Financial year	Funding	Inclusions
2014-2015	$27,500+ $7,500	MAE scholar (25%) 1-day workshop May 2015
2015-2016	$12000+ $7,500	1 FTE RHD coordinator + Resources 1-day communicable disease workshop
2016-2017	$150,000+ $13,500	1 FTE RHD coordinator + Resources 0.1 FTE Program Manager
2017-2018	$153,750+ $13,500	1 FTE RHD coordinator + Resources 0.1 FTE Program Manager
2018-2019	$157,500+ $13,500 $27,500	1 FTE RHD coordinator + RHD network F2F Workshop + Resources FTE Program Manager MAE scholar (25%)
Total	$583,750	

Evaluation objectives

The objectives of the evaluation were to:

1. Determine whether the surveillance system had met the objective to monitor the epidemiology of ARF/RHD, and gain participation onto the RHD Register. (16)
2. Assess the usefulness of the surveillance system and register by measuring attributes based on the CDC guidelines. (4)
3. Present findings and recommendations to the NSW RHD Coordinator in the form of a final report which can be used to inform stakeholders.

Ethics

The evaluation was undertaken under the ANU HREC approval 2017_909.

Methods

The evaluation of the NSW ARF/RHD Surveillance System including the RHD Register was undertaken in five stages.

i. Project planning and development

A project proposal was developed with the NSW RHD Coordinator and Program Manager in November 2018 to confirm evaluation objectives and other project parameters including stakeholder consultation and interviews, attribute assessment and the type of data required to complete the evaluation.

ii. Stakeholder engagement

Ministry of Health, public health unit staff and LHD Coordinators involved in notification, data entry, follow-up, clinical care and secondary prophylaxis of ARF/RHD were engaged as stakeholders. The RHD Program Manager informed the RHD network about the evaluation during routine teleconferences and also communicated that a network discussion would occur at the NSW RHD Network face to face meeting in April 2019.

iii. Stakeholder interviews

The US CDC Updated Guidelines for Evaluating Public Health Surveillance Systems was used to evaluate the surveillance system and register. (4) ARF and RHD were evaluated separately as directed, in line with ARF/RHD reporting at the CDB. Three surveys were conducted using research methods in healthcare epidemiology by Safdar et al. (20) including a face-to-face consultation with the NSW RHD Network, an online mixed-methods survey and semi-structured interviews with select local heath districts:

Face-to-face consultation with NSW RHD Network

Public health unit staff, LHD coordinators, RHD Coordinator and the RHD Program Manager discussed key barriers, strengths and improvements needed in the surveillance

system and register at the NSW RHD Network Forum in April 2019. At the meeting, stakeholders were informed that an online survey would be sent out to them, and that some would be approached to participate in a more in-depth semi-structured interview.

Online survey

A link to an online survey created with Google Forms was sent by email to 78 people in the NSW RHD Network, using open ended and closed questions to measure the performance of the surveillance systems attributes, including simplicity, data quality, acceptability, sensitivity, timeliness, representativeness, stability. Appendix A details the survey questions asked to specific stakeholders to evaluate these attributes. A process flow chart was created that described the surveillance system in partnership with the stakeholders, and review of existing documents. The accuracy of the flow chart was evaluated in the online survey.

Semi-structured interviews

Semi-structured interviews about system strengths and weaknesses were held with at least one local health district with the following characteristics:

- high case load/metro
- high caseload/regional
- median caseload/metro
- median caseload/regional areas
- low caseload/metro
- low caseload/regional

Ad hoc discussions were held with a senior analyst who had responsibilities around building and maintaining the system.

iv. Evaluation and desktop data analysis

Information from the stakeholder interviews were collated and analysed using Microsoft Excel. A Microsoft Excel (21) .csv dataset of all ARF/RHD cases from 1 October 2015 to 30 June 2019 was extracted from NCIMS and analysed with Microsoft Excel (21) and STATA 15 (5) to calculate indirect age-standardised rates and conduct a descriptive analysis of ARF/RHD notification data in NSW. Confirmed and probable cases of ARF/RHD were defined as per NSW Health's ARF/RHD control guidelines (16) by notification date (not date of onset of symptoms). Using descriptive epidemiology, these cases were described person, place and time; clinical and laboratory features; Aboriginal and Torres Strait Islander status, and Maori and Pacific Islander status. Possible and excluded cases were included in the analysis of active surveillance and the RHD Register. This was relevant to describe the overall system and assess the sensitivity of active surveillance. Additionally, some individuals who consented to the RHD Register ultimately did not meet the case definition for a confirmed or probable case. Appendix A outlines the desktop data analysis undertaken for each attribute.

v. Production of a final report

A bound volume chapter was produced which outlined evaluation findings, conclusions, recommendations and lessons learnt.

<u>Pilot</u>

The online survey and semi-structured interview were piloted at a local health district to ensure the research methods used to make the survey resulted in an understandable, focused tool with minimal burden on resources required from the participant. (20)

Evaluation of attributes

Usefulness

"A public health surveillance system is useful if it contributes to the prevention and control of adverse health-related events, including an improved understanding of the public health implications of such events." (4)

The evaluation framework provided by the CDC *Updated Guidelines for Evaluating Public Health Surveillance* Systems was used to assess the usefulness of the surveillance system and register by measuring key attributes listed in the framework including flexibility, simplicity, data quality, sensitivity (of active surveillance), predictive value positive (of the RHD Register), acceptability, representativeness, timeliness and stability. (4)

Simplicity

"The simplicity of a public health surveillance system refers to both its structure and ease of operation". (4)

A flowchart was created describing the overall surveillance system (Figure 6) and shown to online survey participants who were asked:

a) Is the flowchart accurate? If no, please describe alternative processes used.
b) How simple is the process of notifying a case to the PHU? (Very simple, Simple, Neutral/unsure, Difficult, Very difficult)
c) How simple are methods used to collect and manage the data on the surveillance system (NCIMs)? (Very simple, Simple, Neutral/unsure, Difficult, Very difficult)
d) Do you feel you have received adequate training and supervision to record and enter data? (Yes, Unsure, No)
e) Do you think that the system design allows for easy follow-up of cases? (Yes, Unsure, No)

f) How easy is it to ascertain a confirmed case using the diagnostic criteria? (Very easy, Easy, Neutral/unsure, Difficult, Very difficult)

Flexibility

"A flexible public health surveillance system can adapt to changing information needs or operating conditions with little additional time, personnel, or allocated funds." (4)

A discussion was held with a senior analyst to clarify the process of making changes onto the surveillance system and register. As NSW Health centrally coordinates and facilitates operating system changes, the RHD Coordinator and RHD Program Manager were asked:

a) Have any of the following items changed since the creation of the system? If yes, has the system successfully adapted to these changes?
    i. Case definition
    ii. Funding
    iii. NCIMs functionality
    iv. Medication changes
    v. Additional data sources

Data quality

"Data quality reflects the completeness and validity of the data recorded in the public health surveillance system." (4)

Data quality was assessed by measuring the proportion of complete and incomplete data for confirmed and probable cases of ARF/RHD. Data completeness was then assessed for the following information types:

a) Identifying/ contact information
b) Demographic
c) Important dates
d) Medical information

e) Symptoms

In the online survey, participants were asked to rank:

a) The usual speed to upload and download data (Very unsatisfactory, Unsatisfactory, Neutral/unsure, Satisfactory, Very good, Excellent)
b) The relevance of the data on the surveillance system (Very unsatisfactory, Unsatisfactory, Neutral/unsure, Satisfactory, Very good, Excellent)

Stability

"Stability refers to the reliability and availability of the public health surveillance system". (4)

A discussion was held with a senior analyst to further understand the stability of the surveillance system. To assess whether users of the surveillance system can rely on NCIMS to collect, manage and provide data without failure, online survey participants were asked to:

a) Rate the stability of the surveillance system when inputting or exporting data (Very unsatisfactory, Unsatisfactory, Neutral/unsure, Satisfactory, Very good, Excellent)

Sensitivity

"Sensitivity relates to "the proportion of cases of a disease detected by the surveillance system" and may "refer to the ability to detect outbreaks, including the ability to monitor changes in the number of cases over time." (4)

There were complexities in measuring the sensitivity and PVP in this surveillance system, given the absence of a baseline prevalence of ARF/RHD. In the CDC guidelines, sensitivity relates the proportion of true cases on the system, whilst the PVP relates to how many people without the disease are erroneously included as cases in the surveillance system.

For the purposes of this evaluation there was greater value in assessing specific aspects of the surveillance system for sensitivity and PVP. Active surveillance has been an integral tool in ARF/RHD surveillance, and it was important to analyse how many true cases were detected (sensitivity) because the system must be able to cast a wide net to ensure that these are detected. Sensitivity was calculated using the following formula:

$$\text{Sensitivity} = \frac{\text{True Positive (a)}}{\text{True Positive (a)} + \text{False Negative (b)}}$$

Where true cases detected through active surveillance were divided by the sum of true cases detected through active surveillance and cases detected through other surveillance (e.g. indicator based). However, this calculation must be interpreted with caution as there is no baseline prevalence available for ARF/RHD in NSW. Desktop data analysis identified the proportion of cases found through clinical notification or active surveillance:

Detected by active surveillance	ARF OR RHD present				Total
	Disease present	(n)	Disease Absent	(n)	
Yes	True positive	a=	False positive	c=	a+c
No	False negative	b=	True negative	d=	b+d
Total		a+b		c+d	

Confidence intervals for sensitivity were automatically calculated using the Microsoft Excel *Analytical Tools for Public Health* by Public Health England. (22) The tool provides the following explanations as to how the confidence intervals are calculated:

The proportion is given by: $p = \frac{O}{n}$

where:

O is the numerator observed number of individuals in the sample/population having the specified characteristics;

n is the denominator total number of individuals in the sample/population.

Using the Wilson Score method, the 100(1–*a*)% confidence limits for the proportion *p* are given by:

$$p_{lower} = \frac{\left(2O + z^2 - z\sqrt{z^2 + 4Oq}\right)}{2\left(n + z^2\right)}$$

$$p_{upper} = \frac{\left(2O + z^2 + z\sqrt{z^2 + 4Oq}\right)}{2\left(n + z^2\right)}$$

Where: *q* is 1–*p*; *z* is the $100(1–a/2)^{th}$ percentile value from the Standard Normal distribution. For example, for a 95% confidence interval, *a* = 0.05 and *z* = 1.96 (i.e. the 97.5th percentile value from the Standard Normal distribution).

We were unable to calculate specificity of the system as the proportion of true negatives are unknown. Online survey participants were asked:

a) How effective is active surveillance in finding cases? (Very effective, Effective, Neutral/Unsure, Ineffective, Not effective)

Predictive value positive

"Predictive value positive (PVP) is defined as is the proportion of reported cases that actually have the health-related event under surveillance" **(4)**

The predictive value positive was calculated as follows to find how many notifications (probable and confirmed) did not meet the case definition (PVP).

$$PVP = \frac{\text{True Positive}}{\text{True Positive + False Positive}}$$

The PVP was calculated for the RHD Register because false positives on a register program would likely result in an individual unnecessarily adhering to regular injections with secondary prophylaxis.

Acceptability

"Acceptability reflects the willingness of persons and organizations to participate in the surveillance system". (4)

Desktop analysis determined to what degree were active surveillance cases followed up. Questions were asked in an online survey to measure the acceptability of the system:

a) The interactions between myself and other stakeholders are satisfactory (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)
b) The overall system is acceptable to me (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)

c) The information I receive such as reports or PopNet[§] is appropriate (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)

d) The information I receive at network meetings is appropriate (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)

e) I am satisfied with the outcomes of the information flow (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)

Representativeness

"A system that can describe the disease under surveillance over time and in a population by place and person". (4)

Representativeness involved ascertaining whether the information in the surveillance system reflects the occurrence of ARF/RHD in NSW. Populations excluded from the surveillance system were identified and NSW rates based on surveillance data was calculated and compared to national rates. Desktop data analysis will quantify the proportion of those who consented to the register versus those that did not. In the online survey, participants were asked:

a) Do you think that the system data accurately represents what is happening in NSW? (Yes, Unsure, No)

[§] PopNet is NSW Health online platform for the public health network to share information with each other.

Timeliness

"Timeliness reflects the speed between steps in a surveillance system". (4)

Timeliness was determined by calculating the median and range of days it takes for a case to consent to the register, information on delays and how these are impacted by Active surveillance. Online survey participants were asked:

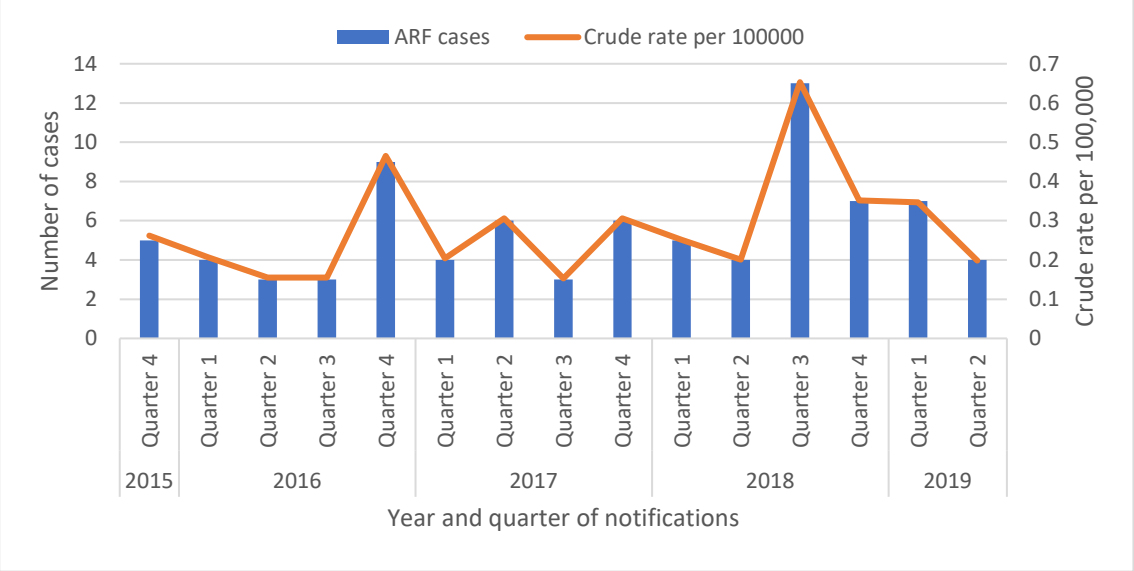
a) How timely is the system? Rank the systems ability to keep cases up to date with scheduled treatment. (Very timely, Timely, Neutral, Unreliable, Very unreliable)

Results

Epidemiology of acute rheumatic fever in New South Wales

There were 83 individuals who met the confirmed (n=63) and probable (n=20) case definition for ARF between 1 October 2015 and 30 June 2019, with a median of 5 cases per quarter (range 3-13 cases). The overall average crude notification rate per 100,000 population per year was 0.3 cases (Figure 7).

Figure 7 Number and crude rate per 100,000 of acute rheumatic fever notified in New South Wales by year and quarter, 1 October 2015 to 30 June 2019



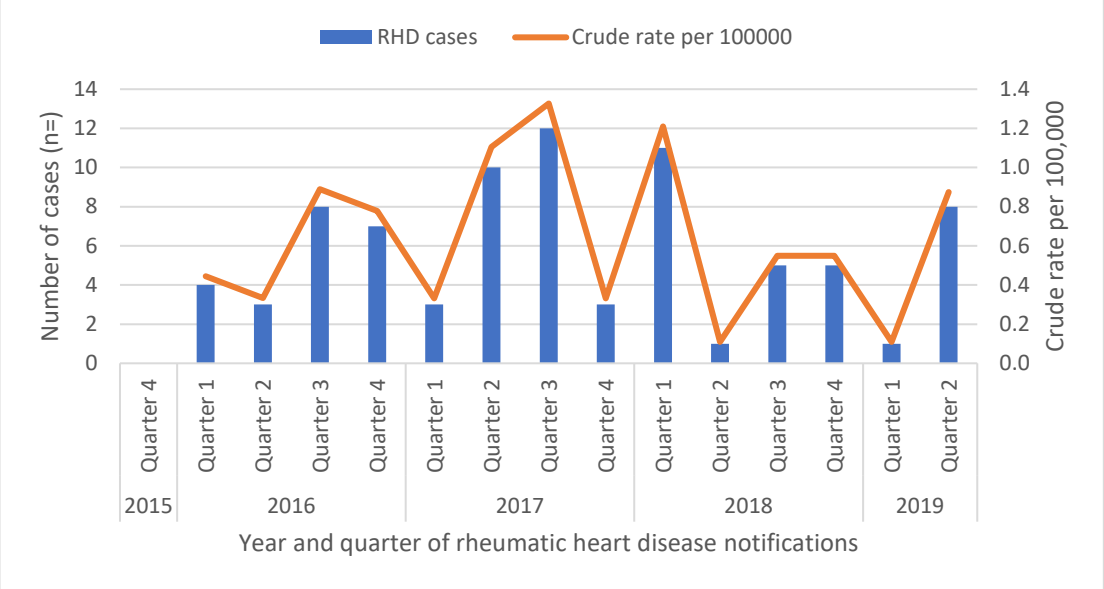
Most cases were in Western Sydney (n=27), Hunter New England (n=14), South Western Sydney (n=9) and Northern NSW (n=9). Forty-nine percent (n=41) were Indigenous Australians with a crude rate of 4.8 per 100,000 per population year and an indirectly standardised rate of 4.6 per 100,000 per population year (95% Confidence Interval (CI) 3.3-6.2) (Appendix B). Twenty-seven per cent (n=22) were Pacific Islander or Maori. Consistent with Australian and international research (6, 8), children <15 years were most affected with 63% (n=52) of all ARF notifications (Figure 7). The median age at diagnosis was 13 years (standard deviation 11.8 years, 95%CI 10.4-15.6). Forty-five per cent (n=37) of all ARF notifications were in children aged 10-14 years, and 46% of all

cases were female (n=37).

Epidemiology of rheumatic heart disease in New South Wales

During the same period there were 81 individuals who met the confirmed case definition for RHD (median 5 cases per quarter, range 0-12 cases). The overall average crude notification rate per 100,000 population per year was 0.2 cases (Figure 8 8). These reported rates are higher as the population of people aged <35 years are used to calculate rates given that RHD is only notifiable in people aged <35 years.

Figure 8 Number and crude rate per 100,000 of rheumatic heart disease notified in New South Wales by year and quarter, 1 October 2015 to 30 June 2019



The majority lived in Western Sydney (n=27) and South Western Sydney (n=19). In Western Sydney, 74% (n=20) were Pacific Islander. The majority of Indigenous Australians with RHD lived in Hunter New England (n=5) and Mid North Coast (n=5) (Appendix C). Indigenous Australians were overrepresented with a crude rate of 4.1 per 100,000 per population year. Children under 15 years of age accounted for 30% (n=43) of all RHD. The median age at diagnosis was 13 years of age (standard deviation 8.7 years, 95% CI 11.1-14.9). Children aged 10-14 accounted for 32% (n=37) of all RHD notifications, and 62% of all cases were female (n=50).

The ARF/RHD Surveillance System and Register

At 30 June 2019 a total of 482 individuals were recorded on the surveillance system. Of these, 164 met the case definition for ARF (n=83) or RHD (n=81) and were eligible for inclusion onto the RHD Register (Table 5).

Table 5 Health information about all individuals on the New South Wales acute rheumatic fever and rheumatic heart disease surveillance system.

Condition	Alive	Died	Unknown	(blank)	Total
Acute Rheumatic Fever - Initial	171	3	1	14	190
Case - Confirmed	58			5	63
Case - Possible	20		1		21
Case - Probable	15			4	20
Excluded	78	3		5	86
Rheumatic Heart Disease	261	12		19	292
Case - Confirmed	69	2		10	81
Case - Possible	31			1	32
Excluded	161	10		8	179
Grand Total	432	15	1	34	482

Sixty-one people consented to the RHD Register, of which 59 met the confirmed or probable case definition for ARF/RHD. Most were from local health districts with high caseloads. Seven individuals were recorded as having withdrawn consent from the RHD Register. As per data entry guidelines people have only withdrawn consent if there is an earlier entry saying they have granted consent.

Table 6 Local health districts who had received consent to the New South Wales rheumatic heart disease register between 1 October 2015 to 30 June 2019*.

LHD name	**Year of consent (brackets indicate additional cases that were on the RHD Register but had withdrawn consent)**					**Grand Total**
	2015	**2016**	**2017**	**2018**	**2019**	
Western Sydney	1	9 (-2)	5 (-1)	4	1	20
Hunter New England			3	6	4	13
Western NSW		6		3		9
Mid North Coast		1	4	(-1)		5
South Western Sydney		1	1 (-1)	2		4
South Eastern Sydney				2		2
Northern Sydney		1		1		2
Northern NSW	(-1)		1		1	2
Nepean Blue Mountains			1			1
Illawarra Shoalhaven				1		1
Grand Total	**1**	**18**	**15**	**19**	**6**	**59**

*2015 data includes October to December (3 months). 2019 data includes January to June (6 months)

Benzathine penicillin was the secondary prophylaxis for 36 (61%) cases. Three (5.1%) used phenoxymethylpenicillin and one (1.7%) used erythromycin. Nineteen (32.2%) did not have any treatment recorded (Table 7). At 30 June 2019, 89% (n=54) were alive. It was unknown whether the remaining cases were alive due to data incompleteness.

Table 7 Individuals on the New South Wales acute rheumatic fever and rheumatic heart disease (RHD) surveillance system by treatment and consent status to the RHD Register, 1 October 2015 to 30 June 2019.

Condition	Consent to the register			
	Granted	Withdrawn	Eligible	Total
Acute Rheumatic Fever - Initial	**30**	**2**	**50**	**83**
Benzathine penicillin	19		16	35
Other antimicrobial/ antimalarial			1	1
Phenoxymethylpenicillin	2	1	3	6
No treatment indicated	9	1	30	41
Rheumatic Heart Disease	**29**	**4**	**48**	**81**
Benzathine penicillin	17		13	30
Erythromycin	1			1
Phenoxymethylpenicillin	1			1
No treatment indicated	10	4	35	49
Total	**59**	**6**	**99**	**164**

The majority saw a GP (47%) or AMS (31%) as their primary care provider (Table 8). The primary care provider was unknown for 8% (n=5) on the RHD Register.

Table 8 Primary care provider for individuals who consented to the New South Wales rheumatic heart disease register between 1 October 2015 to 30 June 2019.

Primary care provider	Acute Rheumatic Fever	Rheumatic Heart Disease	Grand Total
GP	13	15	28
AMS	10	8	18
(blank)	2	3	5
Hospital	4		4
Justice Health	1	1	2
Youth Health Service	0	2	2
Grand Total	**30**	**29**	**59**

The severity of disease was not recorded for almost a third of cases on the register (Table 9). Two of four cases who withdrew consent were categorised as having severe disease.

Table 9 Severity of rheumatic heart disease (RHD) and consent to the NSW RHD Register

Severity of RHD	Consent type			Grand Total
	Granted	Withdrawn	(blank)	
Mild	6	0	5	11
Moderate	4	0	3	7
Severe	9	2	12	23
(blank)	10	2	28	40
Grand Total	29	4	48	81

Survey Results

Online survey

The online survey was emailed to 78 people and had a 23% completion rate (n=18), representing 69% of all LHDs (n=16) (Table 10). The low response rate was mostly due to varied proxy server permissions across NSW Health, a factor that was unknown until some LHDs indicated they could not open the survey due to firewalls. The proxy server changed at the Ministry of Health, creating barriers to access survey data for analysis. Although there was a low individual response rate it was reasonable given that a very small number of staff would be responsible for ARF/RHD notifications per LHD.

Semi-structured interviews

Semi-structured interviews were in person or over the phone, and included LHDs from metropolitan and regional areas (Table 10).

Table 10 Online survey response rates for local health districts by location characteristics and caseload type for the NSW acute rheumatic fever and rheumatic heart disease control programme at 30 June 2019.

Caseload and area type	Online survey				Semi-structured interviews (n)
	LHDs in category (n)*	LHDs participated (n)	LHDs participated (%)	Staff responses (n)	
Surveillance and program overview level	NA	NA	NA	2	0
High case load/metro	2	2	100	2	1
High caseload/regional	3	2	66.7	4	1
Median caseload/metro	2	1	50	2	0
Median caseload/regional	4	3	75	5	1
Low caseload/metro	2	1	50	3	1
Low caseload/regional	2	1	50	1	0
Justice health (low caseload)	1	1	100	1	0
Grand total	16	11	68.8	18	4

*Number

NSW RHD Network Face to Face Meeting

Themes from the network meeting focused on reporting, low clinician awareness and issues with stakeholder engagement. Feedback from this consultation is woven into the attributes they applied to.

Attributes of the ARF and RHD surveillance system and the RHD register

Results from the online survey and feedback from the semi-structured interviews were recorded for the following attributes.

Simplicity

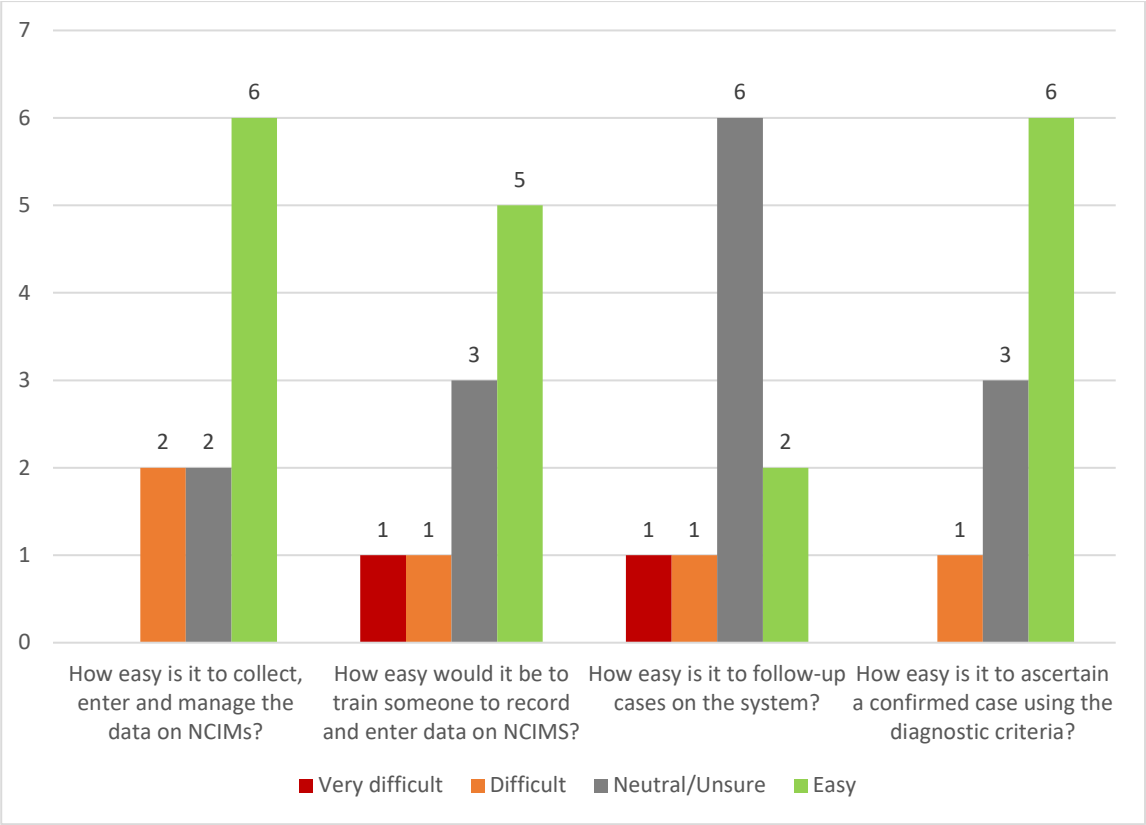
Recommendation

- Ensure LHDs are aware of the NCIMS user guide, and who they can speak to if they are unsure of training, diagnosis and follow-up of cases
- Nominate 'champions' of the RHD network who can provide ground knowledge of these processes, particularly for LHDs with minimal or no cases.

Methods to input data, follow-up cases and ascertain a confirmed case using the diagnostic criteria were thought to be simple, as was accessing the RHD Register, an advantage of being nestled within the surveillance system. (Figure 9). Despite differences across LHDs, 83% (n=15/18) of respondents agreed the flowchart accurately described the surveillance system. Variations in the flow of information included LHDs who received cases solely via active surveillance, and others with limited or no notifications via primary health services. Feedback from the online survey included:

> *"We are never notified by a doctor, always via active surveillance. We went case finding and randomly found two boys, who are now on Bicillin"*
>
> *"All cases except two have been notified via active case finding. We have not received a notification from a doctor treating a person with symptoms. The two cases that were not identified via active case finding, were identified via word-of-mouth"*
>
> *"GP's and AMS rarely refer to our PHU. The bulk of referrals are from hospitals or active surveillance "*

Figure 9 Online survey responses relating to the simplicity of the NSW acute rheumatic fever and rheumatic heart disease (RHD) surveillance system, including the RHD Register (n=10), at 30 June 2019.



Although the structure of the system was thought to be simple and easy to use, the simplicity of the system was affected by data quality. Suggestions to improve simplicity were provided by stakeholders:

> *"Improve automation of register follow-up."*
>
> *"Streamline/automate follow-up processes (more Register than surveillance system)."*

Summary

Methods for entering and analysing the data were simple. Staff are trained to use NCIMS as part of routine public health work. An explanation of NCIMS variables is available in a user guide however reference to this was not mentioned by stakeholders. Most were unsure about how easy it would be to follow-up cases on NCIMS which was anticipated given this is done centrally.

Data Quality

Recommendation

- Schedule centralised audit of ARF/RHD notification data to improve completeness
- Work with clinicians to design strategies to improve clinical awareness around diagnosis
- Addition of a field that indicates the date when an individual has been asked to consent to the RHD Register, separate to whether they have consented or not
- Ensure that all variables are described in the NCIMS data entry guidelines

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Data completeness for confirmed and probable cases of ARF/RHD was 25%, which was anticipated due to varied information requirements for each individual on the surveillance system. Patient identification and demographic information was mostly complete, including the variables: birth date, gender, race[**] and address. No telephone number was listed for 96 individuals (58.1%), and three individuals (1.8%) had no contact information at all. Consent status for the RHD Register was not recorded for 60% of individuals. There is no indicator that a request for consent had occurred. Medical information, including who notified the condition, whether the case was hospitalised and how they were diagnosed was varied. Severity of illness data was missing for 124 individuals (75%), including a third of people who were on the RHD Register. There were high levels of incompleteness relating to symptoms and duration of illness.

Data completeness of key variables, all of which have 164 fields, are presented in

[**] See limitations section for comments on the use of the word 'race' as a variable and inclusion of this terminology in this chapter

Appendix D. Some errors were detected in the dataset. For example, one person had the variable 'race' listed as 'not Aboriginal', but their specific culture was listed as 'Aboriginal'. The town 'Blackett' was incorrectly recorded as 'Blacklet' on two occasions. In the online survey, 83% of participants were satisfied with the data quality of the system (Figure 10). Much feedback relating to data quality was solution-based and related to building linkages with other programs such as Medicare and medical practice software.

> *"A system that enables GP's to directly refer online from their own medical databases. Ministry of Health provides education and resources to GPs and hospital clinicians"*

> *"Improve linkage with Medicare data - if they've had the vaccination, ECHO, specialist appointment, etc then it should show on their Medicare record"*

Figure 10 Online survey responses relating to the data quality of the NSW acute rheumatic fever and rheumatic heart disease (RHD) surveillance system, including the RHD Register (n=8), at 30 June 2019.

Summary

As data is directly entered into a singular state-wide computer system (NCIMS), any

authorised user can generate ARF/RHD reports but is mostly relied upon centrally. This process does simplify the overall process of the system. Although it was easy to identify who had been identified through active surveillance, it is less simple to analyse data and determine how cases were notified onto the system as there are some records missing about of where information about the case came from.

Flexibility

Recommendation

1. Ensure the procedure for making amendments and changes to the surveillance system is detailed in a handover guide. This procedure should include describing the priority of the request to guide administrators.

Findings

Data for the evaluation was easily downloaded and integrated into other computer programs (Microsoft Excel (21) or imported directly into STATA 15 (5)). There were minor changes to the surveillance system including adjustments to NCIMS functionality and integrating additional data sources to improve information collection and patient follow-up on the RHD Register. Interviewed individuals were asked what degree of success the system had in adapting to these changes.

> *"I think the changes to NCIMS functionality have made it easier to collect information on various aspects follow-up for patients on the register."*
>
> *"NCIMS changes are slow but possible - functionality includes workflows, ability to add additional fields for data collection."*

The system has proven flexible for the management of cases who have changed address:

> *"The system & register is great in managing cases that move across LHD/state borders"*
>
> *"Allow ongoing monitoring of patients. Helps ensure people don't get lost in the system when moving"*

A senior analyst clarified that to make changes to the surveillance system, a NCIMS Change Request/Issue Form on PopNet should be submitted to the Senior Applications Administrator. A weekly meeting facilitates these requests on a priority basis, which may

explain why the changes appear to be slow. There was no information readily available that described this process.

Summary

The surveillance system and register have been flexible enough to respond to the changing needs of ARF/RHD, demonstrating capacity to easily accommodate changes. Over the last four years, the system has evolved from an empty database to having 482 potential cases notified into it. The system has been flexible enough to accommodate the unique characteristics of each case particularly as they meet or are excluded against the case definition. A definitive result on flexibility was difficult to ascertain as there have been no significant changes to test it.

Stability

Recommendation

Organise the network drive so that all information pertaining to the tasks of central staff are simple to locate. This could be in the form of a document that lists all the information that is available and where to access it.

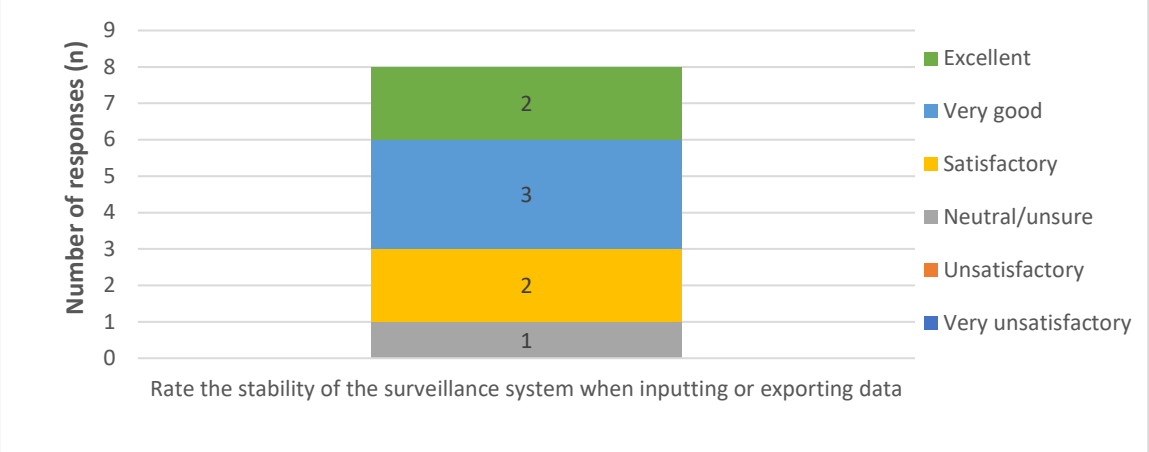
Findings

From a system perspective, the surveillance system and register are stable, an advantage of being housed in NCIMS where outages are rare. Clear processes occur if issues arise including emailing staff about any outages or issues that are being changed or repaired. No respondent was unsatisfied with the stability of the system with 83% reporting the system to be satisfactory to excellent. (Figure 11). The stability of the system was identified as a strength for some.

> *"Centrally collected on NCIMS, is a very stable system with good security systems and backup. Available to PHUs and LHD coordinators."*

> *"The strengths of the register are the centralised surveillance system in NCIMS, availability of state-wide surveillance & register information with 24/7 access via on-call."*

Figure 11 Online survey responses relating to the stability of the NSW acute rheumatic fever and rheumatic heart disease (RHD) surveillance system, including the RHD Register (n=8), at 30 June 2019.



From a program perspective, the system is not stable. There was no guide available to easily handover the role of the RHD Coordinator that includes methods to export data to produce reports or standard operating procedures of the position. The surveillance system and the RHD Register are essentially the one database (NCIMS). There is no way to extract register or surveillance system information exclusively, so it is confusing to distinguish between the two. Separating RHD Register data from the surveillance system is a manual process on Microsoft Excel (21) which requires clearer instruction.

Both online survey and semi-structured interviews highlighted that despite some opinion that this role could be managed at the LHD level, most areas rely heavily on this central position for notifications through active surveillance, information and reporting.

> *"The RHD coordinator role. This really could be completed by the local PHU."*
>
> *"Currently very reliant on the RHD Coordinator for reporting purposes, and two people for ongoing management of follow-up."*
>
> *"Despite education we don't get notified of ARF/RHD until the RHD Coordinator notifies us (luckily only a few!)."*

Summary

There was strong evidence to suggest that the surveillance system and register are stable and can be relied upon to collect, manage and provide data without failure. The positive feedback demonstrates the benefits to having the surveillance system and register housed in NCIMS. As one staff member coordinates the program, more detail about data analysis and reporting procedures are required to ensure sustainability of the overall program.

Sensitivity

Recommendation

1. A prevalence study on ARF/RHD is necessary to understand the context of ARF/RHD in NSW.
2. An evaluation on active surveillance alone is necessary to determine whether the processes and specificity of the system is acceptable.
3. Ensure that active surveillance is based the cases residential jurisdiction
4. Improve strategies to improve clinician awareness around diagnoses

---

Findings

Desktop data analysis found that the majority of notifications were detected through active surveillance. Other cases were notified through doctors, hospitals, incidental finding and other health authorities (Table 11).

Table 11 Proportion of acute rheumatic fever and rheumatic heart disease cases found through active surveillance or clinical notification

Condition and detection method	Disease present		Disease not present		Grand Total
	Case - Confirmed	Case - Probable	Case - Possible	Excluded	
ARF - Initial	63	19	21	86	189
Active surveillance	45	12	19	84	160
Doctor	7	3	1		11
Hospital	9	4		1	14
Incidental finding by PHU				1	1
New Zealand health authority			1		1
NSW RHD Coordinator	1				1
School Principal		1			1
(blank field)	1				1
RHD	81		32	179	292
Active surveillance	68		31	178	277
Doctor	4		1		5
Hospital	6			1	7
Immunisation Team	1				1
New Zealand	1				1
(blank field)	1				1
Grand Total	144	20	53	265	482

Active surveillance was integrated into the system to improve case ascertainment and fix issues relating to the complex diagnostic pathways of ARF/RHD, both of which rely on clinical diagnosis. Aside from diagnoses made through hospitals and clinicians, other potential cases have been notified through the NSW RHD Coordinator, school principal, New Zealand health authorities, Immunisation team and an incidental finding by a PHU.

> *"It is likely that a doctor will never see a case of ARF or RHD in their entire career, especially if their training had been in inner-metro areas or areas with low prevalence."*

The calculated result of active surveillance was highly sensitive at 76.2% (95% CI: 68.96-82.51). Of the 482 individuals on the surveillance system, 91% (n=437) were identified through active surveillance. Of the 437, 34% (n=125) were confirmed as either ARF (36%, n=57) or RHD (25%, n=68). Based on calculations, active surveillance had high sensitivity and low specificity to detect potential cases with an overall 76.22% (95%CI 68.96-82.51) probability that the individual identified through active surveillance will be diagnosed when the disease is present.

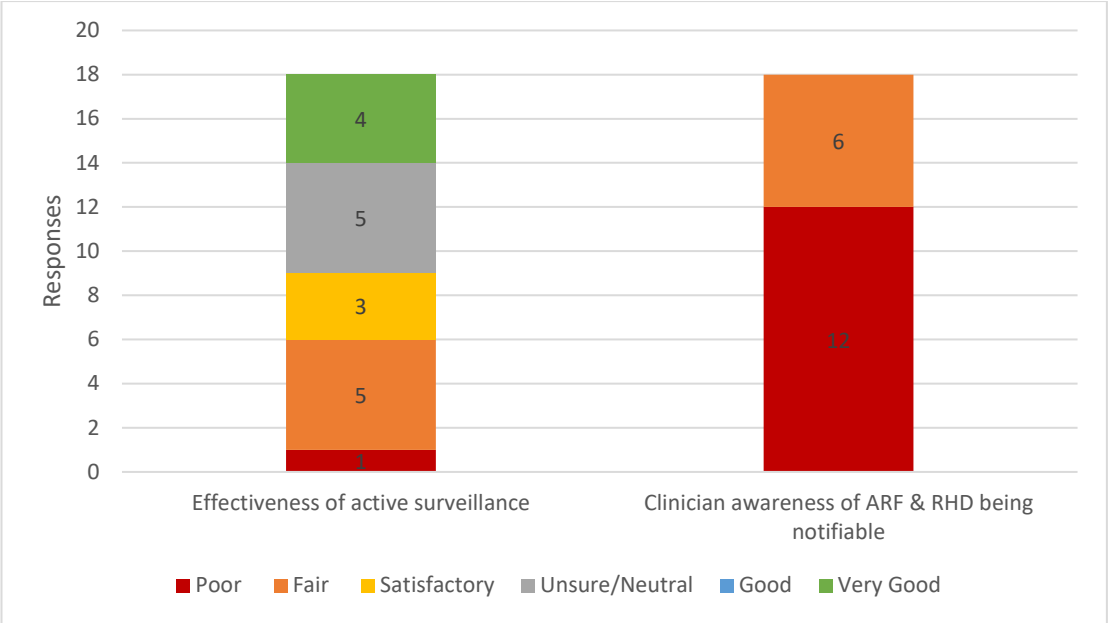
These results should be interpreted with caution. The baseline prevalence of ARF/RHD is not known in NSW, and the case definition (particularly for ARF) is based on complex clinical diagnoses. One of the key issues highlighted with the system related to low clinician awareness, and as such we cannot truly determine that the case definition is specific enough to capture all cases or be confident that all cases in the community who are admitted to hospital are detected by clinicians or active surveillance.

This concern was echoed by the network:

> *"I suspect there are a lot of unreported cases. Data from active surveillance often pertains to patients' months after discharge."*
>
> *"Active surveillance over-estimates number of cases due to poor specificity and issues with ICD-10 coding for ARF and RHD. It also only picks up cases severe enough to present to hospital. Poor recognition of ARF and RHD as diseases in children in NSW is likely to lead to under diagnosis. Under reporting is also likely to occur."*
>
> *"Cases admitted near jurisdictional border missed as NSW does not have data access".*

Perceptions around the effectiveness of active surveillance were mixed. In the online survey, seven individuals reported that active surveillance satisfactory or very good, five were unsure or neutral, and six people felt that it was poor to fair (Figure 12). Without a baseline, it was difficult to determine whether the system accurately described the occurrence of ARF and RHD over time and its distribution in the population by place and person. However, the system is making progress toward establishing this. The information collected on NCIMS is able to effectively describe the epidemiology of ARF and RHD in NSW as shown in the demographic section of this paper. All areas interviewed that had tertiary or major hospitals reported that cases from other LHDs are often sent to these hospitals with severe illness, often being the first time ARF or RHD had been diagnosed. These cases were then picked up by active surveillance and submitted for follow up to the LHD where the case presented. During the evaluation, this process was changed whereby the RHD Coordinator submits active surveillance line lists to LHDs for follow up based on the cases known residence.

Figure 12 Effectiveness of active surveillance and levels of clinician awareness of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in New South Wales (n=18), at 30 June 2019.



Misdiagnosis or underdiagnosis will affect notification rates which will influence the sensitivity, specificity and representativeness of the system. All respondents of the online survey, qualitative interviews and the network consultation felt that clinician awareness about ARF/RHD was not satisfactory which would also imply that sensitivity is not high (Figure 12). A number of respondents reported sending information to GPs and AMSs with mixed results.

"Would be helpful to resend information to all the medical services in the LHD and the PHNs on notification. This was last sent in 2015 and helped raise awareness that RHD is notifiable."

"I think knowledge among medical staff in our metro LHD is very low, even Cardiologists."

"Unless people are out educating it can be assumed that it is low. Unless they worked in the NT they are fully unaware of the symptoms or that it is notifiable. A 6 year old female was seen at (hospital name) ED, with severe chorea. She couldn't toilet or feed herself and the ambulance thought she had taken pills. Only an overseas doctor picked up on it."

"After presenting a case study at a paediatric conference, three weeks later an ED doctor picked up on a case. Three other recent cases were picked up after a presentation."

"Up until January 2019, we had cases with at least three and up to seven ED presentations.

All presented with symptoms, not one was diagnosed. We had a big education blitz (at the town) by holding an evening seminar with 52 clinicians including people from PHUs, AMS's and Paediatrics – the whole town was there. Since then we have been getting diagnoses from primary care providers, so people are not getting to point where they have to turn up to the ED. In the future, when get a diagnosis in a new town – we're going to the town."

Although guidelines exist for potential ARF/RHD outbreaks, and screening programs have detected clusters of ARF/RHD such as in the Northern Territory, it is not known whether this was influenced by other factors such as increased clinician awareness. (23) At this stage we are unable to determine whether the surveillance system is able to detect clusters or outbreaks in NSW.

Summary

Active surveillance is an effective tool to detect ARF/RHD in NSW compared to indicator based surveillance methods, however without a baseline it cannot be determined active surveillance does capture all cases on ARF/RHD. A limitation of active surveillance is that it does not use emergency department data and may not be sensitive to the entire population. Diagnosis requires the case/carer having health seeking behaviour, ability to access a health facility and then to be diagnosed correctly by a clinician. Clinician awareness was highlighted as a critical issue affecting the sensitivity of the system.

Predictive value positive

Recommendation

Review probable cases on the RHD Register to ensure they are appropriately assigned according to the case definition.

Findings

It was anticipated that there would be minimal (if any) false positives on the RHD Register, as much caution is taken to avoid administering unnecessary secondary prophylaxis to an individual. Of the 61 people who consented to the RHD Register, two (3.3%) were excluded as cases. However, these were likely to have a diagnosis of ARF or RHD but were notified outside NSW so were not counted for surveillance purposes, but placed on the Register as a means to provide follow-up. As 59 met the confirmed or probable case definition (true positives) it was determined that the PVP of the RHD Register at 30 June 2019 was 96.7%. This calculation should be interpreted with caution as the baseline prevalence of ARF/RHD is not known in NSW. Further, three of the eight probable ARF cases on the RHD Register appear to only have enough evidence to be assigned as a possible case.

Summary

There were a low number of false positives on the RHD Register, and therefore high confidence that cases are not unnecessarily provided with prophylaxis.

Acceptability

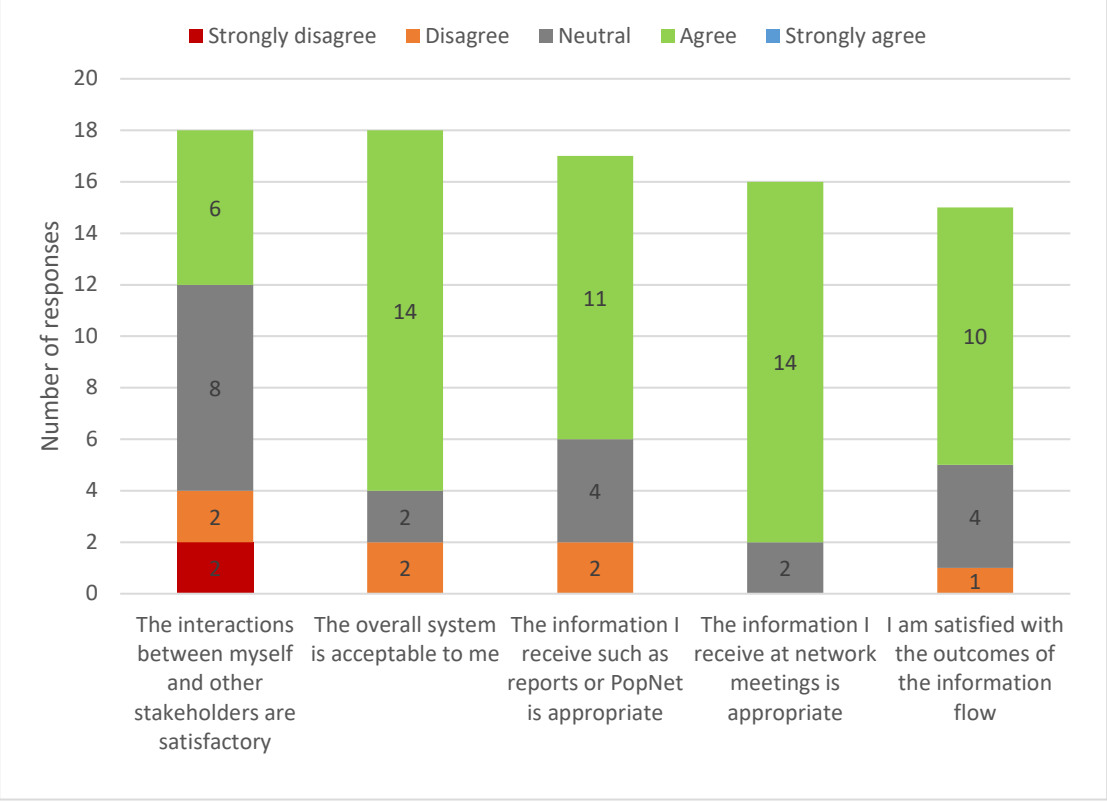
Recommendation

1. Improve engagement with stakeholders at primary and secondary health level, and develop strategies to improve clinician awareness.
2. Streamline quarterly ARF/RHD reports based on stakeholder feedback (this action was completed at the time of writing)

Findings

Sixty-five per cent (n=55) of online survey respondents felt the system was acceptable. Almost a quarter (n=20) were neutral about acceptability, which was not unexpected given the differing characteristics of the jurisdictions surveyed. Eleven per cent (n=9) did not find the surveillance system to be acceptable (Figure 13).

Figure 13 Online survey responses relating to acceptability of the NSW acute rheumatic fever and rheumatic heart disease (RHD) surveillance system, including the RHD Register (n=18), at 30 June 2019.



Acceptability of information sharing

Most agreed the information received at meetings was acceptable, however some felt there was little space to focus on complex LHD-specific issues. This was emphasized at the stakeholder session, where many felt the NSW RHD Network teleconferences were too long and could be focused differently to ensure issues can be discussed. Others felt the regular teleconferences should be LHD-specific as some areas have higher case volumes and some have none, however it was recognised that this would place a burden on the RHD Coordinator and minimise opportunities to discuss matters as a network. The quarterly and annual ARF/RHD reports were not read by the majority of the network, who agreed that presenting key data upfront and having less pages of information would improve the acceptability of the reports.

Stakeholder interactions

Some stakeholders were very willing to participate in the system by providing timely, accurate, complete and consistent data, while others expressed a level of frustration with imbalances in engagement across primary and secondary health services. Although the online survey presented a largely neutral or acceptable picture of interactions between relationships with primary and secondary health services, thematic analysis of qualitative information highlighted difficulties in stakeholder interactions and engagement at the LHD level.

> *"LHDs were asked to identify their LHD Coordinators. Some coordinators are more proactive or stronger than others."*
>
> *"The relationship with the LHD Coordinator is difficult"*
>
> *"There seems to be difficulties in understanding the role of the PHU and RHD Coordinator"*

"Lack of uniformity in commitment to the RHD program in different LHDs. Lack of dedicated resources to carry out case management"

"The system aims to engage primary health care providers to provide local care to patients. Developing network of LHD coordinators with some increased engagement over time."

As ARF/RHD is intrinsically linked to inequity, this disease is an important social justice issue that a surveillance system alone cannot fix. Therefore, meaningful collaboration between jurisdictions and clinicians is essential to improve ARF/RHD outcomes in NSW. Feedback about stakeholder interactions at the primary health care level raised concerns about awareness, engagement and issues around notification and follow-up:

"There were several cases I only found out about via word of mouth from AMS staff"

"Hopeless - the AMS is apathetic at kindest, the LHD coordinators are nice but don't grasp their role isn't to treat, just to facilitate patients"

"I think we need to work closer with AHMRC in developing the relationships within ACCHSs. Some areas are more engaged than others. Funding has not changed, however further funding would allow more local engagement and education"

"Large number of cases of people being managed in bulk billing medical practices"

"Notification of cases from clinicians is slow or non-existent. Getting clinician response to obtaining consent from patients for adding to register is difficult"

"Engaging GPs to provide information on follow-up is sometimes challenging. Some of the LHD Coordinators do not have the time or resources to manage RHD cases and can be difficult to engage"

"Lack of uniformity of access to subsidies for treatment in different populations in NSW"

Low clinician awareness impacting acceptability

All respondents believed that clinician awareness of ARF/RHD was not acceptable. Most clinicians are trained in metropolitan areas and may never see a case of ARF in their careers. High and median caseload LHDs reported that children in their jurisdictions have presented to emergency departments numerous times before ARF/RHD was investigated. These children often became so unwell they were transferred to tertiary hospitals and diagnosed for the first time there. Many had disease so severe they required surgery.

Some districts reported attempts to increase clinician awareness with mixed success. One LHD highlighted the power of a holistic whole-of-health approach to improving ARF/RHD awareness in high-risk areas, and has demonstrated positive results through closer community bonds and increased case notifications.

> *"A great deal of emphasis is placed on the register and not enough on how to improve the identification of ARF cases by GPs"*
>
> *"Low knowledge about ARF/RHD in NSW. Low understanding about the requirement for notification. Large number of cases being managed in primary care clinics with one case"*

Summary

Despite the positive feedback around the system in terms of reporting, network meeting information and outcomes of the information flow, aspects of the system are not acceptable. Key themes highlighted issues in reporting and fractures in interactions with other stakeholders relating to roles, responsibilities and level of engagement. Low clinician awareness was also identified as an issue affecting the acceptability of the system.

Representativeness

Recommendation

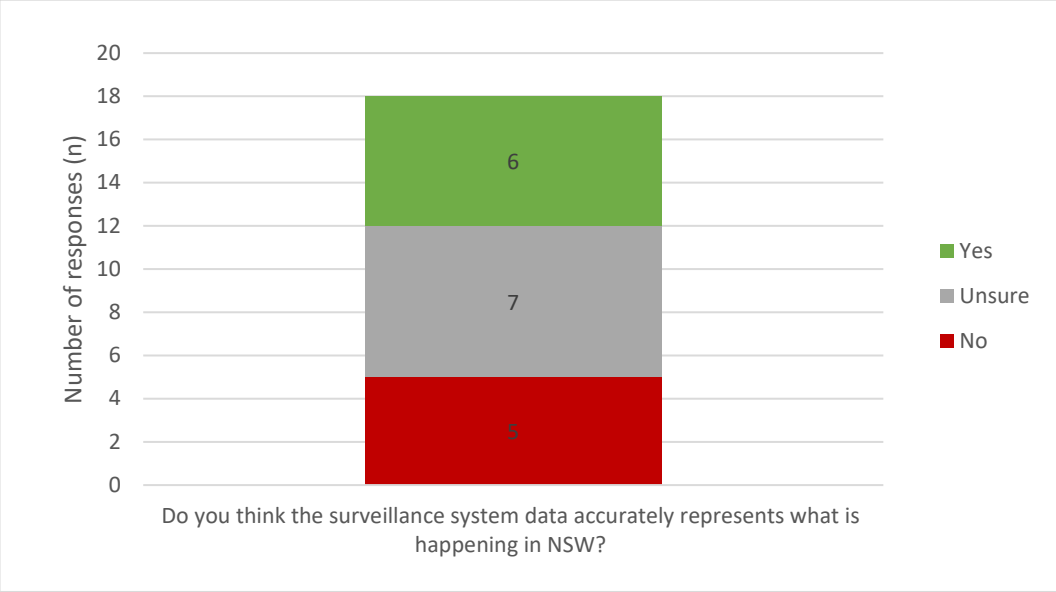
Establish the burden of ARF/RHD for at-risk groups, potentially through a prevalence study and determine whether this would be appropriate for ARF and RHD.

Findings

It unlikely that the surveillance system is representative of the true burden of ARF/RHD in NSW (6). Anecdotal information from the RHD Coordinator stated that since the implementation of the surveillance system and register, the burden of ARF/RHD in NSW has been higher than anticipated. People diagnosed with RHD over the age of 35 are not notifiable in NSW and not included on the system. Although RHD screening programs in other parts of Australia have contributed to regional baseline denominator data, this has not occurred in NSW. (23) Rates are required to determine the representativeness of the surveillance system. The notification rate of ARF per 100,000 population per year in NSW was 4.8 per 100,000 for Indigenous Australians and 0.1 per 100,000 for non-Indigenous Australians, under the national rate of 85 per 100,000 for Indigenous Australians and 4 per 100,000 for non-Indigenous Australians. The notification rate of RHD per 100,000 population per year in NSW was 4.1 per 100,000 for Indigenous Australians and 0.4 per 100,000 for non-Indigenous Australians, lower than national rates of 85 per 100,000 for Indigenous Australians and 4 per 100,000 for non-Indigenous Australians. In other parts of Australia, rates of ARF/RHD appear to increase with remoteness of location so it would not be reasonable to use denominator data from elsewhere to gauge representativeness. (7) In the online survey, a third of respondents (n=6, 33%) felt confident that the system accurately represents the true burden in NSW.

The majority were not confident of this, with 39% unsure and 28% not confident (Figure 14). The main concern relating to representativeness was under-reporting and missed notifications. Case increases had occurred in areas after clinician education targeted in that community.

Figure 14 Online survey responses relating to representativeness of the NSW acute rheumatic fever and rheumatic heart disease (RHD) surveillance system, including the RHD Register



"I know there have been missed notifications. What I don't know is how many more are missing"

"I have concerns that the true incidence of ARF/RHD is much greater than the current notifications suggests. I see great benefit in the development of a prevalence study."

"Likely under-representation of burden of disease."

"Need a clearer link between PHUs and clinicians to ensure relevant data flow"

Summary

NSW rates are likely to change with the implementation of a screening program. At this stage the representativeness of the system cannot be quantified through data analysis. The surveillance system is not likely to be representative of the prevalence of RHD in

adults over 35 years of age as these individuals are not notifiable in NSW.

Timeliness

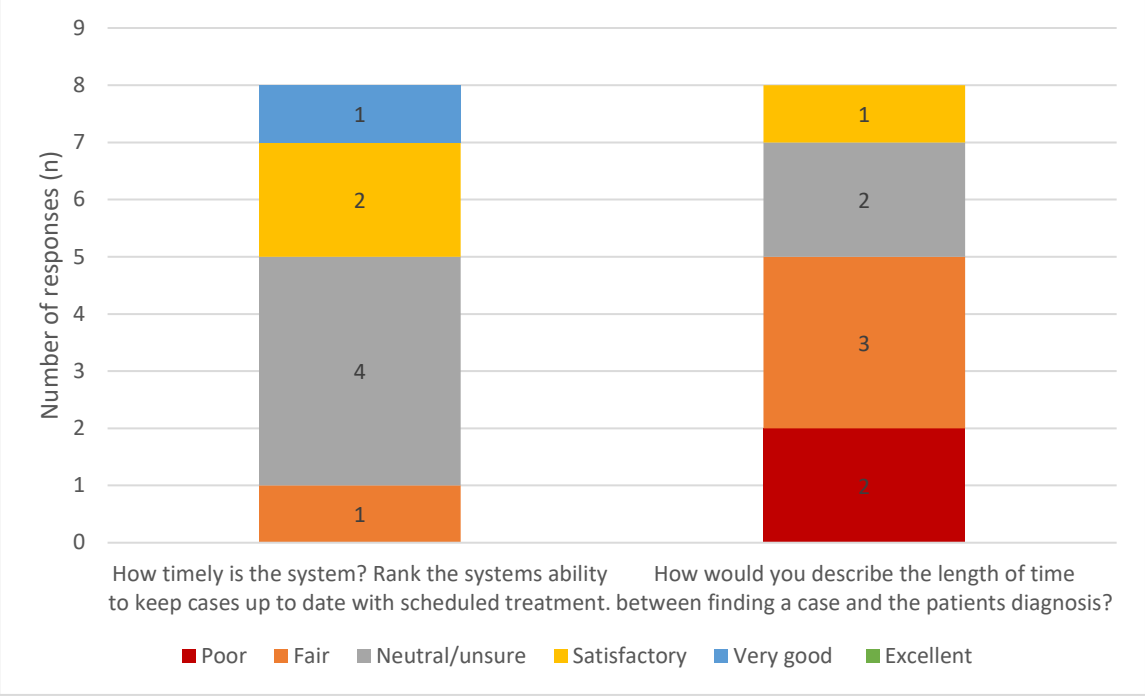
Recommendation

1. Review active surveillance protocols to ensure follow-up is efficient and useful.
2. Increase clinician awareness of ARF/RHD to strengthen timeliness of indicator based surveillance.

Findings

Almost 40% of respondents felt that the timeliness of the system to keep up to date with scheduled treatment was satisfactory to very good, however 65% felt the length of time it took between finding a case and the patient's diagnosis was poor to fair (Figure 15).

Figure 15 Online survey responses relating to timeliness of the NSW acute rheumatic fever and rheumatic heart disease (RHD) surveillance system, including the RHD Register



The median number of days from diagnosis date to consent date was 16 days and ranged from -225 to 1021 days. This means there were instances where a case had already

consented to the register before they were notified on the surveillance system. When asked how timeliness is affected by active surveillance at the program level:

> *"Active surveillance means that it takes at least 3 months for cases to be reported. It probably doesn't improve timeliness, but it will reduce under reporting."*
>
> *"Active surveillance is only reported at least one quarter in arrears so cases identified through that process should be more a mop-up rather than the primary source of identification. Hopefully as awareness builds, those cases will be notified before they are found on active surveillance."*
>
> *"Active surveillance is not timely, but it is working, not in kids though."*
>
> *"We do not have any active cases in our LHD but I have registered patients from other LHDs. I'm not sure I hear about all potential patients"*
>
> *"Register is a good means of cross checking notifications against EMR but data often happens months after discharge"*

Summary

The timeliness of the system is one of the most important attributes because without it, children with ARF run the risk of disease progression to RHD, which may result in early death. As such, it is crucial that the system can detect cases early. Active surveillance can take months, yet this has been the most useful method to find cases.

Discussion on usefulness of the system

This evaluation assessed whether the ARF/RHD surveillance system and RHD Register fulfilled its purpose for surveillance, to monitor the epidemiology of ARF/RHD in New South Wales; and prevent recurrence of ARF and severity of RHD through enhanced case follow up via the NSW RHD register.

Establishing the ARF/RHD surveillance system in NSW undoubtedly had a positive public health impact through increased understanding of the epidemiology of ARF/RHD in the context of NSW, focused mobilisation of resources, increased awareness and capacity for RHD network staff, and support for patients to receive timely and appropriate treatment. At this point it appears the greatest priority relates to the acceptability of the system, particularly around strengthening relationships between primary and secondary health services. This would require initiatives to address low clinician awareness which may be done through sharing processes that have worked for other LHDs.

From a systems perspective the system is simple, stable and flexible. Centrally, the system was useful in identifying risk areas for environmental health related primordial prevention strategies, including Housing for Health interventions in areas of higher prevalence. Instabilities were detected relating to the program sustainability. There is one staff member responsible for the central coordination of the program, and it is important that there is a detailed handover available for this position in the event of sudden staffing changes. There is a RHD Management Protocol to handover notification management and follow-up of RHD cases, and the knowledge of this and where to access it should be clear. Although the majority of respondents in the online survey felt that it was easy to ascertain a case using the diagnostic criteria, Australian research has pointed to limitations to the Jones criteria. Some Indigenous Australian cases with ARF

have been found not to meet the criteria (6), and if the criteria were to ever change to accommodate for this, it may potentially be more difficult to ascertain cases.

Due to fragmented stakeholder relationships at differing health care levels it is unknown whether the system has led to improved clinical, behavioural, social or policy practice as a whole. Most certainly clinician awareness has improved in some areas however it should be noted this was mostly dependent on the initiative of local health districts who developed and led their own interventions.

The surveillance system has stimulated research intended to lead to prevention or control. Since the ARF/RHD became notifiable, some local health districts with higher caseloads have undertaken their own studies to address inequities experienced by communities affected by ARF/RHD. This includes assessments on the number of times a case attends a health facility before being correctly diagnosed, improvements in case ascertainment after clinician education and best practices to engage communities.

Without understanding the prevalence of ARF/RHD in NSW, it is unknown whether cases on the surveillance system were representative of the true burden. While information on the system has been used to develop epidemiological and surveillance reports to the NSW RHD Network, this information was not available in the public domain at 30 June 2019. This was made publicly available in October 2019 which may be valuable to those wanting to improve their understanding of the overall RHD program, surveillance, and outputs of the RHD Register.

Before the system was launched it was anticipated that indicator-based surveillance would not be efficient in determining cases due to low clinician awareness levels. While active surveillance has been successful in finding cases, this generates large number of possible or excluded cases. Active surveillance is also not timely, which is a critical factor

to avoid disease progression. Some LHDs have found timeliness to diagnoses has improved, particularly for indicator-based surveillance after appropriate education and engagement has been delivered to a particular community.

It is likely the system has prevented the recurrences of ARF and reduced the severity of RHD for some individuals, particularly through the enrolment of cases onto the RHD Register. Just over a third of confirmed and probable cases on the surveillance system are enrolled on the RHD Register. It was difficult to determine through the data whether every individual had been asked if they would like to consent to the register. The predictive value positive for the RHD Register is high, however this should be reviewed for the entire surveillance system along with sensitivity. The process of consent is a controversial topic, particularly as to whether it is necessary, culturally appropriate, or if there should be more communications between the register and the case. These questions will be best answered through an appropriate consultation process with stakeholders and communities, particularly Indigenous Australians and Pacific Islanders. Achieving consent and adherence to secondary prophylaxis can be influenced by the provision of culturally appropriate and holistic support services. (18)

Limitations

When the pilot was undertaken, it was unknown at the time was that this was one of the few local health districts that were able access Google Forms, and later proxy servers at NSW Health changed which barred access to this program. Regarding the low response rate in the online surveys, in hindsight, to have prevented that issue occurring I could have checked the internet accessibility of LHDs instead of assuming information technology (IT) rules were uniform across the state although I argue that this was a reasonable assumption to make. All NSW Health employees abide by the same IT policies, which assumes you are meeting these. The survey platform I used, Google Forms, was the most suitable and available program for me to use at the time and was able to be accessed by the LHD where I piloted the study. The reason I chose this program was because I was unable to access other survey programs including Formstack or RedCap due to licensing, access and login reasons. It is remarkable that epidemiologists rely so heavily on surveys yet there appears to be no standard survey platform used across NSW Health. Another limitation was through not including GPs/AMS/clients in the evaluation. This was initially planned for however given resources available the evaluation focused on the surveillance aspects only.

There was not enough scope in this surveillance evaluation to explore potential biases the system may have on populations such as older people or people from culturally and linguistically diverse backgrounds. Although the RHD Register appears useful in following up cases for secondary prophylaxis, the value of having a voluntary consent-based register warrants further analysis. At 30 June 2019 just over a third of cases consented to the RHD Register, requiring understanding as to whether all cases have been asked to consent.

The final limitation was in relation to the datasets that I received having the variable 'race'. I raised the question around the appropriateness of using terminology such as this, as the term 'race' is a clear social construct, not biological. I have left this terminology in the chapter, to be consistent with reporting, and to hopefully elicit future conversations as to the appropriateness and acceptability of words like this in datasets and reporting in contemporary public health.

Recommendations

Recommendations from each attribute section have been collated in this section for the convenience of the NSW RHD Program.

Table 12 Recommendations for the New South Wales acute rheumatic fever and rheumatic heart disease surveillance system including the RHD Register

Attribute	Recommendations
Simplicity	1. Ensure LHDs are aware of the NCIMS user guide, and who they can speak to if they are unsure of training, diagnosis and follow-up of cases 2. Nominate 'champions' of the RHD network who can provide ground knowledge of these processes, particularly for LHDs with minimal or no cases.
Data Quality	3. Schedule centralised audit of ARF/RHD notification data to improve completeness 4. Work with clinicians to design strategies to improve clinical awareness around diagnosis 5. Addition of a field that indicates the date when an individual has been asked to consent to the RHD Register, separate to whether they have consented or not 6. Ensure that all variables are described in the NCIMS data entry guidelines
Flexibility	7. Ensure the procedure for making amendments and changes to the surveillance system is detailed in a handover guide. This procedure should include describing the priority of the request to guide administrators.
Stability	8. Organise the network drive so that all information pertaining to the tasks of central staff are simple to locate. This could be in the form of a document that lists all the information that is available and where to access it.
Sensitivity	9. An evaluation on active surveillance alone is necessary to determine whether the processes and specificity of the system is acceptable. 10. Ensure that active surveillance is based the cases residential jurisdiction 11. Improve strategies to improve clinician awareness around diagnoses
Predictive value positive	12. Review probable cases on the RHD Register to ensure they are appropriately assigned according to the case definition.
Acceptability	13. Improve engagement with stakeholders at primary and secondary health level, and develop strategies to improve clinician awareness. 14. Streamline quarterly ARF/RHD reports based on stakeholder feedback (this action was completed at the time of writing)
Representativeness	15. Establish the burden of ARF/RHD for at-risk groups, potentially through a prevalence study and determine whether this would be appropriate for ARF and RHD.
Timeliness	16. Review active surveillance protocols to ensure follow-up is efficient and useful. 17. Increase clinician awareness of ARF/RHD to strengthen timeliness of indicator based surveillance

Conclusion

Acute rheumatic fever and rheumatic heart disease are of high public health importance, particularly due to the inequities associated with the disease, and the high morbidity and inequities associated with the disease. The ARF and RHD surveillance system and the RHD register have met their objective to monitor the epidemiology of ARF/RHD in NSW through a centralised, simple however just above a third of eligible cases have enrolled onto the RHD Register. There are aspects of the surveillance system and register that require improvement, and these include strengthening elements of stakeholder engagement and clinician awareness. Building stakeholder relationships between the primary and secondary health care levels with a secondary aim to increase clinician awareness will dramatically improve the acceptability of the system. Low clinician awareness also impacts the timeliness of the system, which is crucially important to avoid preventable disease progression in an individual with ARF/RHD.

More action is required centrally to ensure that stakeholders who identified ARF and RHD as priority actions are engaged with the overall programme, so that LHDs can be supported on improving engagement within their own jurisdiction. Consultation is required to determine whether the consent process is culturally appropriate for Aboriginal and Torres Strait Islander people, and whether the register should provide information back the case or their family. Overall the surveillance system and register must be equitable for all, particularly Aboriginal, Torres Strait Islander and Pacific Islander people; and this evaluation may provide a foundation to build future work around this.

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Appendices

Appendix A. Tool to measure attributes of the acute rheumatic fever and rheumatic heart disease (RHD) surveillance system and RHD Register

Attribute	Survey question	Assessment method			
		Desktop	PHU staff	LHD Coord	RHD Coord
Usefulness	What does the system do well?		X	X	X
	What are weaknesses of the system?		X	X	X
	What improvements would you make to the system?		X	X	X
Simplicity	A flowchart will outline the system and describe the flow of case management and data.	X			
	Is the flowchart accurate? If no, please describe alternative processes used.		X	X	X
	How simple is the process of notifying a case to the PHU? (Very simple, Simple, Neutral/unsure, Difficult, Very difficult)		X		
	How simple are methods used to collect and manage the data on NCIMs (Very simple, Simple, Neutral/unsure, Difficult, Very difficult)		X	X	
	Do you feel you have received adequate training and supervision to record and enter data? Yes, Unsure, No		X	X	
	Do you think that the system design allows for easy follow-up of cases? Yes, Unsure, No		X	X	
	How easy is it to ascertain a confirmed case using the diagnostic criteria? (Very easy, Easy, Neutral/unsure, Difficult, Very difficult)		X	X	

Attribute	Survey question	Assessment method			
		Desktop	PHU staff	LHD Coord	RHD Coord
Flexibility	Discussion held with senior analyst to clarify process of making changes to the system				
	Have any of the following items changed since the creation of the system? If yes, has the system successfully adapted to these changes?				
	1. Case definition				X
	2. Funding				X
	3. NCIMs functionality				X
	4. Medication changes (Bicillin)				X
	5. Additional data sources				X
	If no to these, this attribute would be difficult to assess and be less important than other attributes.				
Data quality	Proportion of complete and incomplete data (Demographic and contact information, important dates, medical information, symptoms)	X			
	Percentage of 'unknown, blank or missing' fields	X			
	Data entry errors (NCIMs Data Entry guidelines)	X			
	The usual speed to upload and download data (Very unsatisfactory, Unsatisfactory, Neutral/unsure, Satisfactory, Very good, Excellent)	X	X		X

Attribute	Survey question	Assessment method			
		Desktop	PHU staff	LHD Coord	RHD Coord
	The relevance of the data on the surveillance system (Very unsatisfactory, Unsatisfactory, Neutral/unsure, Satisfactory, Very good, Excellent)				
Stability	Discussion with a senior analyst to understand stability of the system.	X			
	Rate the stability of the surveillance system when inputting or exporting data (Very unsatisfactory, Unsatisfactory, Neutral/unsure, Satisfactory, Very good, Excellent)		X		X
Sensitivity	Proportion of cases found through clinical notification or active surveillance	X			
	How effective is active surveillance in finding cases? (Very effective, Effective, Neutral/Unsure, Ineffective, Not effective		X	X	X
Predictive value positive	Proportion of cases enrolled on the RHD Register who did not meet the case definition for ARF/RHD	X			
Acceptabil-ity	The interactions between myself and other stakeholders are satisfactory (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)	X			
	The overall system is acceptable to me (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)		X	X	
	The information I receive such as reports or PopNet is appropriate (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)		X	X	

Attribute	Survey question	Assessment method			
		Desktop	PHU staff	LHD Coord	RHD Coord
	The information I receive at network meetings is appropriate (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)		X	X	
	I am satisfied with the outcomes of the information flow (Strongly agree, Agree, Neutral, Disagree, Strongly disagree)		X	X	
Represent-ativeness	Proportion of groups who consent to the register versus not consenting	X			
	Do you think that the system data accurately represents what is happening in NSW? (Yes, Unsure, No)				X
Timeliness	Time to consent to the register	X			
	Information on delays	X			
	How are these impacted by Active surveillance?	X			X
	How timely is the system? Rank the systems ability to keep cases up to date with scheduled treatment. (Very timely, Timely, Neutral/unsure, Unreliable, Very unreliable)		X	X	X

Appendix B. Notifications and rates of acute rheumatic fever in NSW by Indigenous status and local health district, 1 October 2015 to 30 June 2019

Local health district (LHD)	Aboriginal	Aboriginal & Torres Strait Islander	Torres Strait Islander [a]	Pacific Islander or Maori	Other [b]	Grand Total	Overall rate per 100,000	Crude rate per 100,000 Indigenous [c]	Crude rate per 100,000 Non-Indigenous [d]
Albury Wodonga & Murrumbidgee [e]	2	0	0	1	0	3	0.3	3.8	0.1
Central Coast	1	0	0	0	0	1	0.1	2.1	0
Far West	0	0	0	0	0	0	0.0	0	0
Hunter New England	13	0	0	0	1	14	0.4	6.5	0
Illawarra Shoalhaven	0	0	0	0	1	1	0.1	0	0.1
Justice Health	0	0	0	0	0	0	NA	NA	NA
Mid North Coast	3	0	0	0	0	3	0.4	5.9	0
Nepean Blue Mountains	1	0	0	1	1	3	0.2	2.3	0.1
Northern NSW	8	0	0	0	0	8	0.7	14.1	0
Northern Sydney	0	0	0	1	3	4	0.1	0	0.1
South Eastern Sydney	1	0	0	0	0	1	0.0	3.1	0
South Western Sydney	0	0	1	4	4	9	0.2	1.6	0.2
Southern NSW	0	0	0	0	0	0	0.0	0	0
Sydney	0	0	0	0	0	0	0.0	0	0
Western NSW	9	0	0	0	0	9	0.9	7.3	0
Western Sydney	1	1		15	10	27	0.7	3.4	0.7
Grand Total	39	1	1	22	20	83	0.3	4.8	0.1

a) Other includes people who are not of Indigenous, Pacific Islander or Maori descent. This category includes unknown ancestry for 3 cases across ISLHD, SWSLHD and WSLHD.

b) Indigenous includes Aboriginal and/or Torres Strait Islander descent.

c) Non-Indigenous includes people who are not of Aboriginal and /or Torres Strait Islander (n=1). e

d) Albury Wodonga was combined with Murrumbidgee for meaningful rate calculations, and due to management of these cases by Murrumbidgee LHD.

e) Justice Health case is Pacific Islander (Samoan) notified in 2019 and not included in rate calculations

Appendix C. Notifications and rates of rheumatic heart disease in NSW by Indigenous status and local health district, 1 October 2015 to 30 June 2019

Local health district (LHD)	Aboriginal	Pacific Islander or Maori	Other [a]	Grand Total	Overall rate per 100,000	Rate per 100,000 Indigenous [b]	Rate per 100,000 Non-Indigenous [c]
Albury Wodonga & Murrumbidgee [d]	1	1	0	2	0.41	2.8	0.2
Central Coast	0	0	0	0	0.00	0.0	0.0
Far West	0	0	0	0	0.00	0.0	0.0
Hunter New England	5	0	0	5	0.04	3.7	0.0
Illawarra Shoalhaven	1	0	2	3	0.02	2.8	0.5
Justice Health [e]	0	1	0	1	NA	NA	NA
Mid North Coast	5	0	1	6	0.04	14.3	0.4
Nepean Blue Mountains	1	1	0	2	0.01	3.3	0.2
Northern NSW	3	0	0	3	0.02	7.8	0.0
Northern Sydney	0	1	1	2	0.01	0.0	0.1
South Eastern Sydney	1	1	4	6	0.04	4.7	0.3
South Western Sydney	1	5	13	19	0.14	2.3	1.0
Southern NSW	0	0	0	0	0.00	0.0	0.0
Sydney	0	0	0	0	0.00	0.0	0.0
Western NSW	4	1	0	5	0.04	4.8	0.3
Western Sydney	2	20	5	27	0.20	4.9	1.4
Grand Total	24	31	26	81	0.59	4.1	0.4

a) Other includes people who are not of Indigenous, Pacific Islander or Maori descent. This category includes unknown ancestry for 3 cases across ISLHD, SWSLHD and WSLHD.

b) Indigenous includes Aboriginal and/or Torres Strait Islander descent.

c) Non-Indigenous includes people who are not of Aboriginal and /or Torres Strait Islander (n=1). e

d) Albury Wodonga was combined with Murrumbidgee for meaningful rate calculations, and due to management of these cases by Murrumbidgee LHD.

e) Justice Health case is Pacific Islander (Samoan) notified in 2019 and not included in rate calculations

Appendix D. Data completeness of key variables in the NSW ARF/RHD surveillance system, 1 October 2015 to 30 June 2019.

Category	Variable	Number of incomplete fields	Percentage incomplete (%)	Percentage complete (%)
Identifying/ contact information	Event ID	0	0.0	100
	Full name	0	0.0	100
	Street	7	4.2	95.8
	City	4	2.4	97.6
	State	0	0.0	100
	Zip	4	2.4	97.6
	Country	4	2.4	97.6
	Jurisdiction	0	0.0	100
	Owning jurisdiction	0	0.0	100
	Statistical local area	0	0.0	100
	Telephone number	96	58.1	41.9
Demographic	Gender	0	0.0	100
	Birth date	0	0.0	100
	Country of birth	5	3.0	97
	Race (see limitations section)	0	0.0	100
	Ancestry or ethnic origin	20	12.1	87.9
	Specific cultural or ethnic group	21	12.7	87.3
	Primary language	18	10.9	89.1
Important dates	Diagnosis date	96	58.2	41.8
	Notification received date	0	0.0	100
	Earliest received or create date	0	0.0	100
	Event date	0	0.0	100
	Public health follow-up	0	0.0	100
	Consent date	99	60.0	40
	Consent status	99	60.0	40
Medical information	Condition	0	0.0	100
	Case type (case definition)	0	0.0	100
	Reporter type	4	2.4	97.6
	Reporter type address	153	92.7	7.3
	Reporter type city	143	86.7	13.3
	Case hospitalised	21	12.7	87.3
	Severity stage classification	124	75.2	24.8
	Patient on drugs	85	51.5	48.5
	Positive throat culture	122	73.9	26.1
	Positive throat culture date	153	92.7	7.3
	Diagnosed by echocardiogram*	91	55.2	44.8
Symptoms	Symptoms	27	16.4	83.6
	Symptom onset date	58	35.2	64.8
	Duration of symptoms	138	83.6	16.4
	Carditis	110	66.7	33.3
	Chorea	124	75.2	24.8
	Elevated CRP	94	57.0	43
	Elevated ESR	102	61.8	38.2
	Erythema marginatum	131	79.4	20.6
	Fever	107	64.8	35.2

Category	Variable	Number of incomplete fields	Percentage incomplete (%)	Percentage complete (%)
	Mono arthralgia aseptic	139	84.2	15.8
	Mono arthritis aseptic	137	83.0	17
	Polyarthralgia	106	64.2	35.8
	Polyarthritis	122	73.9	26.1

*Using the 2012 World Heart Federation diagnostic criteria

Chapter 6

Teaching experience

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Chapter 6 Table of Contents

Acronyms

ANU	Australian National University
EHO	Environmental Health Officers
GP	General Practice
LFF	Lessons From the Field
LHD	Local Health District
MAE	Master of Philosophy in Applied Epidemiology
NSW	New South Wales
PHU	Public Health Unit

Prologue

During the Master of Philosophy in Applied Epidemiology (MAE) placement I participated in a number of teaching activities, demonstrating competency in this area. As per the requirements under the MAE competencies I designed and delivered a Lesson from the Field (LFF) for my peers. I also developed a half day workshop on Q fever for Environmental Health Officers (EHOs) across New South Wales (NSW). co-prepared a case study on foodborne disease outbreaks for the Australian National University (ANU) Indigenous Summer School and worked as an Academic Tutor for Indigenous undergraduates through Western Sydney University's Badanami Centre.

Lessons learnt

During this time, I learned valuable lessons from my peers through participation in all the LFFs. Peer to peer learning provided an insight into the diversity of talents coming from all people in our cohort. During my own LFF I learnt how to structure a lesson using Robert Gagné's Nine Steps of Instruction. (1) This was important as I used the same structure to develop a half-day workshop on Q fever at the NSW Health Policy and Practice Day.

Lesson from the Field

For the lessons from the field (LFF), my role was to develop and present a lesson to a small group of MAEs base on a challenge I had experienced in my placement. At intervals of 6 to 8 weeks one group member was scheduled to present to the others. The lessons were on the following topics:

1. Investigation of cancer clusters: Belinda Jones
2. Clinical epidemiology - Preventative screening: Cushla Coffey
3. Nginda MAE waala wiitha (Throwing the MAE into the fire!): implications of investigating disease with limited Indigeneity data: Charlee Law
4. Causal Diagrams in Epidemiological Research: Jana Sisnowski
5. Linked Data Analysis: Julia Maguire
6. Rapid Risk assessment for outbreak investigation: Bernadette Kenny

I developed a worksheet and dataset for my peers to work on before the LFF, and the answers would make up a large part of the discussion in the lesson. I developed a Master Sheet which is included in this chapter, which included questions, answers and conversation prompts for the lesson. When the worksheet was returned, I collated the responses and decided which person I would prompt to give feedback for further discussion to the group. When the worksheet was returned, I collated the responses and decided which person I would prompt to give feedback during the group discussion. Throughout the MAE I also worked as an academic tutor for Western Sydney University, which will be explained further in the appropriate section.

The lesson from the field (LFF) was completed in February 2018. The Gamilaraay title ‘nginda MAE waala wiitha’ means “throwing the MAE into the fire”. I felt this was an appropriate feeling for those who are put into situations where they suddenly have

questions but don't know how to ask them. Many of my peers were doing data linkage projects and expressed interest in gaining a better understanding about what to do around inconsistent or missing Aboriginal and/or Torres Strait Islander status data. I saw an opportunity in these questions to start a conversation about some of the reasons why the data might be like that in the first place, and prompted the group to explore why someone may want to identify in one organisation but not in another, and some ways we can consider and analyse these data. The Q fever investigation in Chapter 3 had challenges with missing Aboriginal and/or Torres Strait Islander status data. The ways we were able to improve this were also included in the LFF. I provided hyperlinks to resources as well as the page numbers of texts to lead the reader to an answer as the activity was not a lesson in how to find information, but about gaining an understanding about specific matters that are well described in specific reports and documents. I also wanted to show that nothing is perfect in health, and there is no one size fits all approach to choosing how to analyse and interpret Aboriginal and/or Torres Strait Islander data. But if we can start understand the systemic and institutional barriers around health service access and delivery, then perhaps we can increase our chances of having more accuracy in the future about Aboriginal and/or Torres Strait Islander status data. The flow-on effects from this would result in the improvement of public health resource mobilisation, which in my opinion, is what public health is all about. The LFF is detailed in Appendix A.

Additional teaching roles

1. Development of workshop and case study

NSW Environmental Health Policy and Practice Workshop

The NSW Environmental Health Policy and Practice Workshop was held on 18-19 February at Northside Conference Centre, Crow's Nest. The objectives of the workshop were to build professional development for Environmental Health professionals in NSW, provide a networking opportunity and to discuss strategies to improve collaboration in the Environmental Health Network. Q fever was one of five workshop topics, with 101 people in attendance at the Q fever workshop on Day 2. Attendees included Public Health Unit Directors, Environmental Health Officers, Environmental Health Branch staff, Public Health Registrars, Aboriginal Environmental Health Officer Trainees and Public Health Officer/Aboriginal Population Health Trainees.

The Q fever workshop included a presentation on Animal Epidemiology and Serotyping which provided an overview on Q fever in animals as well as animal care and welfare.

I presented the second session on Human Epidemiology and use of the Q Fever Series of National Guidelines (SoNG) documents and how these apply to EHOs. The presentation provided an overview of the human epidemiology for Q fever, risk factors and management strategies from both public health and regulatory approaches.

I also wrote a scenario and workshop activity on communication strategies in Aboriginal communities. This was presented by another presenter, while I assisted participants with the activity. Attendees formed groups and worked through a case scenario to identify what environmental risk factors may be causing Q fever in a rural community. They then identified public advice and management strategies to reduce exposure to risk factors and limit further cases. Evaluation forms were distributed and returned with

a 68% response. Most responses were positive with the Q fever session (and Clandestine Drug Labs session) receiving the most positive feedback. The presentation for the session is located in Chapter 7: Presentations.

2. Tutoring as an Academic Tutor for Western Sydney University

During my MAE I tutored undergraduates through Western Sydney University's Badanami Centre. I provided tutoring for Toxicology, Epidemiology, Field Project (a year-long environmental health project), Food Safety and Environmental Risk Assessment.

3. Indigenous Summer School at ANU

I co-produced a case study and workshop on foodborne disease outbreaks for the ANU Indigenous Summer School. My other Aboriginal MAE peers also worked on this with me. This is presented in Chapter 7: Presentations.

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Appendices

Appendix A. Lesson from the Field Master Sheet

Nginda MAE waala wiitha! (Throwing the MAE into the fire!)

The implications of investigating disease with limited Indigeneity data

Worksheet distributed 24 January 2018
The LFF Skype conference is scheduled for **Wednesday 14 February 2018** at **6.00pm EST.** The answers are due back on **Monday 12 February 2018.**
All participants need to log into Skype as usual. If anybody has problems during the teleconference, message the group in the Skype text field or text the LFF Whatsapp Group.

Instructions

This LFF has four parts:	
Part 1	has calculations relating to a dataset with poor indigeneity data
Part 2	has short answer questions about which algorithm to use when improving data
Part 3	has no particular right/wrong answer and is primarily to get you thinking about factors influencing Indigeneity identification
Part 4	has calculations that should show the different outcomes that may arise from too much missing Indigenous data.

There are three readings which you may find useful for this LFF. These are:

1. The quality of Indigenous identification in administrative health data in Australia: insights from studies using data linkage
2. Data about and for Aboriginal and Torres Strait Islander Australians Intro on page 4 and page 27 is useful, but if you look at the contents page it may help you in the future (2)
3. National best practice guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people 2012 Part 5, page 41 (3)
4. National best practice guidelines for collecting Indigenous status in health data sets Page 2,3, 13-15) (3)

For further reading, this article is quite good, provides a basic overview about how racism is a significant barrier to Aboriginal health improvement. (4) Let me know if you have not received these with this document.

Learning objectives

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

1. Understand the issues and importance around using Indigenous data in research
2. Be aware of some different algorithms used to derive Aboriginal status across different datasets and know some ways to minimise some of the drawbacks of using the 'Ever-Indigenous' algorithm commonly used in health.
3. Understand some factors contributing to mixed Indigeneity data on datasets on both sides (patient/health)
4. See the potential impact of conducting research with high and low Indigeneity data by completing basic tables.

SCENARIO

You are a MAE working in Enterics and Zoonoses the Communicable Diseases Branch at the Ministry of Health. Due to various pressures from the public relating to Q fever awareness and vaccination funding, the Minister of Health is now extremely interested in this topic.

At the same time, your team has just produced an annual zoonoses report which has described a disproportionate rate of Q fever infection amongst Aboriginal NSW residents compared to non-Aboriginal residents. Unsurprisingly, the Minister wants a reason for this immediately.

Your role in this is to:

Determine whether any LHDs, occupational exposures or vaccine exposures are of potential interest for Q fever in Aboriginal people, by doing basic data analysis tasks

Assess the data quality and determine whether you have enough evidence to undertake a full investigation on this matter.

PART 1

Open up the Excel spreadsheet LFF dataset. After eyeballing the Raw data tab, refresh the Pivot table in the Counts by LHD tab and fill in the Dataset 1 table.

#	Question	Suggested answer
1	What PHU has the highest column percentage of Aboriginal Q fever cases in NSW?	Summer PHU

Despite higher Aboriginal column % counts in this PHU, you decide to investigate West PHU as they have the highest Q fever counts for the time period, and the highest number of Unknown Aboriginal status.

Repeat the process for the **Occupational pivot** and **Vaccine pivot** tables

#	Question	Suggested answer
2	What seems to be the main occupational risk factors associated with Q fever for Aboriginal people?	Farming, stock yard work
3	What are the main reasons Aboriginal Q fever cases are unvaccinated?	Too young, employer delay/refusal
4	What is the quality of the dataset? Is it acceptable to commence an analysis that will provide answers to the Minister? Why or why not?	No. The unknown status is too high
5	What could be done to improve this dataset?	Source Indigeneity data to minimise Unknowns

PART 2

You decide to investigate the Indigenous status of those who have not specified their Aboriginality (categorised as Unknown, Not stated and blanks) using the hospital electronic medical record system, Powerchart. You look at three algorithms and determine the best fit for your situation. See part 5 of the AIHW paper, pg. 41, for guidance. (3)

Which algorithm is which (ever-Indigenous, frequency-based, single-source)? Fill in the blanks[††].

#	Algorithm type	How Aboriginal status is determined
6	*Ever-Indigenous algorithm*	A person is recorded as Aboriginal on any data set, even if the person is recorded as non-Indigenous on all other data sets.
7	*Frequency-based algorithms*	A person is recorded as Aboriginal on more than one dataset
8	*Single source methods*	A person is recorded as Aboriginal based on the status listed on the 'most trusted' dataset

More information (3)

(This section to be discussed in the LFF)

This approach is the most widely used method for determining Indigenous status because of its simplicity and minimal data requirements, particularly where there are only two data sets to link.

This approach allows for validation of a person's Indigenous status from at least two other data sets. It is widely used because of its simplicity and minimal data requirements.

This approach uses the Indigenous status from a single data set which is assessed to have high quality information about Indigenous status and therefore to be considered as having a higher level of trust than others

[††] In this Master Sheet, blanks are filled with recommended answers, written in *Italics*

As you only have two datasets, you have chosen to use the 'Ever-Indigenous' algorithm.

#	Questions written in bold and suggested answers written in Italics
9	**Why is the 'Ever-Indigenous' algorithm commonly used in health research, and why is it a good fit for your current purpose?**
	Suggested answer *This is the most widely used method for determining Indigenous status because of its simplicity and minimal data requirements, particularly where there are only two data sets to link.*
10	**Name one benefit and one limitation of using the Ever-Indigenous algorithm to determine the Indigenous status of your cases.**
	Suggested answers *BENEFITS* *Minimal data requirements, particularly where there are only two data sets to link.* *Simplest of all the methods for deriving Indigenous status* *LIMITATIONS* • *Inconsistencies in a person's status are not accounted for even if most of the datasets state 'not Indigenous even if that database is of lower quality as the others.* • *The algorithm is prone to over-count due to errors in data processing and the quality of the linkage process. Errors in the coding may cause some non-Indigenous people to be incorrectly coded as being Indigenous.* • *Another drawback of the 'ever-Indigenous' approach is related to the quality of the linked data used in deriving an individual's Indigenous status, especially where the linked data set is created from probabilistic linkage (AIHW 1.5.3. pg. 9). (3)*
11	**Why might we be less likely to choose the frequency-based algorithm?**
	Suggested answer • *It could be argued that the frequency-based algorithm may be better as it validates a person's Indigenous status by using confirmation through another dataset. For health this may not be always appropriate as there may be complex reasons why a person will identify in one health place and not another. (3)*
	Discussion for the LFF • *An example of the above could be an Aboriginal and/or Torres Strait Islander person identifying at a GP but never at a hospital. For many people being in a hospital environment conjures up memories of racism and mistreatment, leading to mistrust towards the existing health system.*

#	Questions written in bold and suggested answers written in Italics
	• *Despite the increased burden of disease, Aboriginal and/or Torres Strait Islander patients are three-quarters as likely as non-Indigenous people to undergo a procedure once admitted to hospital, with studies showing there may be systematic differences in the treatment of patients identified as Indigenous in Australia's public hospitals.(2)* • *Other studies show that Aboriginal people have to wait longer for surgery and are referred later for specialist treatment. There are also many scenarios of Aboriginal people thought to be seriously intoxicated when in fact they were seriously ill.* • *The systemic differences in care provided by hospitals contribute to low levels of trust in hospitals and hospital case by many Aboriginal people. The 2008 National Aboriginal and Torres Strait Islander Social Survey found that only around 60% of Aboriginal and Torres Strait Islander people felt hospitals could be trusted(2)* • *This level of distrust is reflected in the fact that Aboriginal and Torres Strait Islander people are five times as likely to leave hospital against medical advice or be discharged at their own risk compared to other Australians. (2)*
12	**What do you think you could do to minimise some limitations associated with this algorithm?** *Suggested answer* • *If you are using a health database, check written notes associated with another health service that they may attend* • *If unsure of the Indigenous status of the case, where appropriate you could contact the PHU, health service or the case themselves*

PART 3

Within the Excel file, open the tab titled "Powerchart data". Copy and paste the updated Indigeneity data into the Q fever dataset to update those with unknown status. Ensure the Case ID is in numerical order for both tabs! Before you rerun your analysis, you start to wonder why Aboriginal status is so inconsistent across databases. We are all in health, so we should all have similar data, right?

The National best practice guidelines for collecting Indigenous status in health data sets page 2,3, 13-15 (3) and the article by the Central A (4, 5) may help you with this.

#	Question	Suggested answers
13	What sort of factors may influence whether an Indigenous person identifies on some health databases but not on others?	• *Institutional racism* • *May fear that they will receive different levels of care* • *Premises is not culturally appropriate* • *Inconsistent hospital collection practices and admission forms* • *Patient aversion to identifying religious or cultural origins* • *Concern for privacy and confidentiality* • *Lack of patient understanding what the information is used for and how it is used* • *Language barriers*
14	What factors may influence whether the interviewer accurately records Indigenous status onto a health database?	• *May assume that the person is not Aboriginal based on their name or appearance* • *May not be trained, encouraged or prompted to ask the question* • *Health staff reluctance to ask 'sensitive' questions* • *Status information may be obscurely recorded on the form* • *Systemic and institutional racism*
15	Name a reason why accuracy of Indigenous status is so important in health research. ‡‡	• *Data quality – definition of public health issues* • *Appropriate mobilisation of public health resources* • *Closing the gap*

‡‡ Data about and for Aboriginal and Torres Strait Islander Australians Intro on page 4 and the journal may help with this one.

PART 4

Using the updated Q fever dataset, you rerun your pivot tables. Rerun the Counts by LHD, Occupation and Vaccination status.

#	Question	*Suggested answers*
16	What seems to be the main occupational risk factors associated with Q fever for Aboriginal people?	*Shearing, farming*
17	What are the main reasons Aboriginal Q fever cases are not vaccinated?	*Employer delay/refusal, too young and chose not to have vaccine*
18	What are the main differences between the datasets after improving Aboriginal and/or Torres Strait Islander status data?	*LHD, shearing wasn't even on the radar before, personal choice not to be vaccinated was not listed*
19	If 10% of your dataset had missing Indigeneity data, would you continue to investigate this issue?	*Yes, in health this is in line with our ABS pop dataset*
20	Would you steer your study in a different direction now? Why or why not?	*Yes, probably warrants an investigation now as the risk factors are varied between Aboriginal and Non-Aboriginal populations*

Appendix B. Lesson from the field feedback

What did you like about this LFF?

- *I really enjoyed this topic. I have experience in Indigenous health research in the Northern Territory and a keen interest in the area. Dealing with Indigenous status of records where Aboriginality has not been identified is a very topical issue in Queensland. Indigenous status is poorly recorded on health condition notification records. The reasons behind why Indigenous status may not be recorded are not well understood by many researchers and important to highlight. The readings were excellent and very useful. I used some of the content in my dissertation. It was great to learn further about projects other MAEs are undertaking.*
- *A well organised and clearly presented LFF which included an initial explanation of the structure of the LFF and the learning objectives.*
- *The Excel spreadsheet which Charlee prepared for the exercises worked perfectly. The LFF exercises using the Excel spreadsheet clearly demonstrated how missing data on Aboriginal status results in incorrect interpretations of the data.*
- *Question 2 provided us with an understanding of the algorithm types for determining indigeneity; ever-Indigenous, frequency-based and single source. Question 3 encouraged us to think about various reasons why Indigenous status might be inaccurately recorded.*
- *The topic was a great choice for an LFF- missing Indigeneity data is relevant to a lot of public health work in Australia and can be extrapolated to a range of other scenarios in which key population information might be missing differentially. The short data analysis section at the beginning was a great way to demonstrate in very simple terms the impact of missing data on the conclusions that may be drawn.*

What could have been improved?

- *It would have been interesting to learn a bit more about strategies to improve reporting of Aboriginal status at the time of notification. Also, I was wondering if there is any research assessing the accuracy of the ever-Indigenous approach?*

To what extent has this LFF been useful for your work?

- *The LFF inspired me to take further action beyond the program. I will also be advocating for the Indigenous status field to be a compulsory component of the case report forms for lead.*
- *This LFF was a great illustration of how missing data could potentially prevent or misdirect public health action. More generally, it has reinforced the importance of 'knowing your data' and possible questions to ask when working with secondary data and particularly with linked data were information may be derived in a number of ways.*
- *In my MAE placement, we attempt to pursue missing data on Aboriginal status for the notifiable diseases by asking the doctor who requested the laboratory test but, this LFF made me think more about the accuracy of this data and other options for determining Aboriginal status and the importance of accurate data for a variety of notifiable diseases.*

Appendix C. Collated resources for the NSW Policy and Practice Day

a. Agenda for the workshop

2019 Environmental Health Workshop

Northside Conference Centre - Cnr Pole Lane & Oxley St, Crows Nest

Day 1: Monday 18 February 2019

Facilitated by: Matthew James

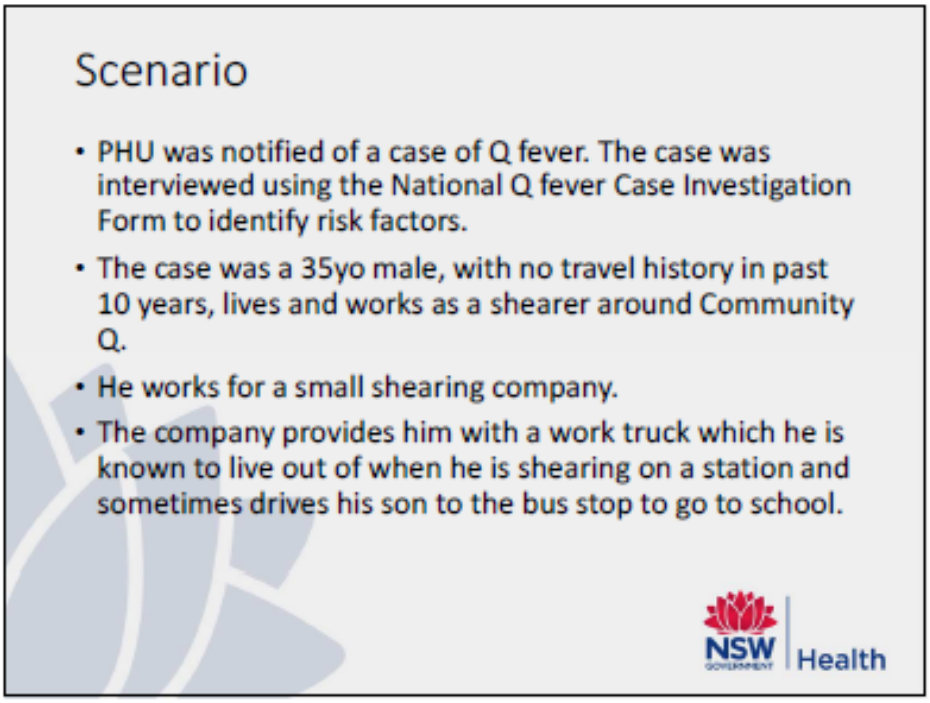
Time	Topic	Topic Chair	Speaker
8:45 – 9:15	Registration		
9:15 – 9:25	Welcome to Country		Uncle Allan Murray
9:25 – 9:30	Workshop Opening Address		Dr Richard Broome
9:30 – 9:45	Introduction of Environmental Health Branch		EHB Managers
9:45 – 10:30	Legislation and Environmental Health (private water supplies and its challenges)	Sinead Hansen	Glendon Lee
10:30 – 10:45	Morning Tea		
10:45 – 11:45	Regulation and legislation – Case study: the Flint Michigan water crisis	Sinead Hansen	Rachael Martin Josh Tickell Leslie Jarvis Sinead Hansen
11:45 – 12:45	Lunch		
12:45 – 13:25	Health Risk assessment of Clandestine Labs	Tabitha Holliday	Dr Jackie Wright
13:25 – 14:00	Clandestine Labs – Role and responsibilities of a Police Officer		Detective Senior Constable Dan Walker
14:00 – 14:20	Clandestine Labs – Roles and responsibilities of the local government		Sharon O'Regan
14:20 – 14:45	Clandestine Labs – Health risks in Forensic clean-up		Josh Marsden Dr Jackie Wright
14:45 – 15:00	Afternoon Tea		
15:00 – 15:20	Clandestine Labs – Panel discussion	Tabitha Holliday	Dan Walker Josh Marsden Dr Jackie Wright Sharon O'Regan
15:20 – 15:30	Point Source Air Pollution – NSW issues update	Matthew James	Matthew James
15:30 – 16:20	Ambient Air Pollution and (Rapid) Risk Assessment		John Frangos
16:20 – 16:50	Methyl Bromide – EPA Campaign Update		Patricia Fabiano
16:50 – 17:00	Day 1 Wrap Up		Matthew James
17:00	Networking: Casual Drinks/Food (At participant's own expense)		Crows Nest Hotel

Day 2: Tuesday 19 February 2019

Facilitated by: Matthew James

Time	Topic	Topic Chair	Speakers
9:00 – 9:55	Introduction to Environmental Health Network	Aditya Vyas and Stephanie Ferrer	Richard Broome Tony Burns
9:55 – 10:15	Using social media to improve engagement with targeted health protection messages		Catherine Bateman-Steel Keira Glasgow
10:15 – 10:35	Working with local councils and academics to improve arbovirus surveillance		Tony Kohlenberg Paul Williamson
10:35 – 10:50	Morning Tea		
10:50 – 11:30	Engaging with communities on high outrage environmental health issues	Aditya Vyas and Stephanie Ferrer	Craig Dalton
11:30 – 12:00	Scoping out options for internal and external communication from the EH Network		Geoff Prendergast
12:00 – 13:00	Lunch		
13:00 – 13:25	Q Fever – Animal Epidemiology and Serotyping	Hopi Yip	Ann-Margret Withers (RSPCA) Gemma Ma
13:25 – 13:45	Q Fever – Human Epidemiology and use of the guideline document for an EHO		Charlee Law
13:45 -15:00	Q Fever – Scenario and Workshop activity: Communication strategies in Aboriginal communities		Hopi Yip Stephanie Fletcher-Lartey
15:00 – 15:15	Afternoon Tea		
15:15 – 16:00	Workshop review exercise		Dr Jeremy McAnulty Matthew James
16:00 – 16:15	Workshop evaluation/Wrap up		Chair/ participants

b. Q fever workshop scenario presentation and instructions



Scenario

- He also enjoys recreational shooting with his dogs.
- The case says that his wife, child and a couple of his colleagues have been unwell. They have the following symptoms:
  - Influenza-like illness, fever, chills, sweats, severe headache, weakness, nausea, cough, weight loss
- He encouraged his friends and got his family tested for Q fever. The wife and child tested positive for Q fever.

NSW Health

Activity

- Review Q fever factsheets and control guidelines
  - Series of National Guidelines (SoNG) for Q fever (http://www.health.gov.au/internet/main/publishing.nsf/Content/cdna-song-q-fever.htm)
  - NSW Health Q fever factsheet (https://www.health.nsw.gov.au/Infectious/factsheets/Factsheets/qfever.PDF)
- How could the case's family be positive if they don't have any occupational risk exposures?
- Where and how could environmental health fit into this investigation?

NSW Health

Scenario

ID Team asked you to assist with the investigation because you have a good relationship with Community Q through the Aboriginal Communities Water and Sewerage Program.

[redacted]

Community Q

New South Wales

Population:	247
Postcode:	2831
Location:	• 591 km (367 mi) NW of Sydney • 217 km (135 mi) NW of Dubbo • 56 km (35 mi) W of Coonamble
LGA:	Coonamble Shire
State District:	Barwon
Federal Division:	Parkes

NSW GOVERNMENT Health

The case's home is across from concrete and aggregate company, as well as a golf course that has many kangaroos. The sale yards is about 1km away.

NSW GOVERNMENT Health

Activity

- How would you help the ID team to gain access to Community Q and the case's home for an environmental health investigation?
- What are the potential Q fever risk factors for the case?

NSW Health

Scenario

- In the home, the ID Team helped the case's family to complete the National Q fever Case Investigation Form individually.
- You were also able to have a quick look around the home and the community to see if there are clues for Q fever risks.
- After sharing a few cuppas with the CEO of the Community Q Local Aboriginal Lands Council and community residents, you found out that word has gone around the community and people are worried about Q fever.

NSW Health

In the home

NSW Health

Outside the home

Outside the home

NSW GOVERNMENT Health

Activity

- From the environmental health investigation, what are the possible risks of Q fever exposure for the case's family and Community Q?
- What could be done to reduce the risk of Q fever in the family home and in Community Q?
- Where can someone access support or other environmental health solutions for the family/community?
- How to improve community awareness of Q fever?

NSW GOVERNMENT Health

Q fever risks and prevention

- The case contracted Q fever from shearing
  - Support the case to contact SafeWork NSW
- His family may have contracted Q fever from contact with contaminated shearing equipment and clothing and/or birth material from their dog
  - Education on Q fever risks and exposure pathways
  - Separate work clothes and equipment from family laundry
  - Separate sleeping space for people and pets
  - Hand hygiene education (Mr Germ) and hygiene pack

NSW SafeWork NSW

Q fever risk in Community Q

- Dogs and wildlife roaming in community
  - RSPCA animal health

RSPCA New South Wales

- Recreational hunting
  - Education: AMS/GP/PHU/ RSPCA
- Dust from unsealed road concrete aggregate plant across the road and from nearby sale yards
  - Hose down, planting etc
  - Roads and Maritimes Services (unsealed road)
  - POEO (sale yards and concrete aggregate plant)
  - Development applications (sale yards and concrete aggregate plant)

NSW GOVERNMENT Health

Q fever awareness

- How to improve community awareness of Q fever?
  - Organise a community education session on Q fever with local Aboriginal Medical Services, GP and PHU.
  - Follow up visit to the community to ensure the message is clear provide additional information and support if required.

NSW Health

NSW Health Q fever factsheets
https://www.health.nsw.gov.au/Infectious/diseases/Pages/qfever.aspx

Series of National Guidelines (SoNG) for Q fever
http://www.health.gov.au/internet/main/publishing.nsf/Content/cdna-song-q-fever.htm

NSW Health

c. Q fever workshop scenario handouts

NSW GOVERNMENT Health

Q Fever Investigation

The PHU was notified of a case of Q Fever. The case was interviewed using the standard Q Fever investigation questionnaire to identify risk factors.

The case is a 35yo male, with no travel history in the past 10 years. He lives and works as a shearer for a small shearing company around Community Q.

The company provides him with a work truck which he is known to live out of when he is shearing on a station. Sometimes he drives his son to the bus stop to go to school.

He also enjoys recreational shooting with his dogs.

The case says that his wife, child and a couple of his colleagues have been unwell. They have the following symptoms: Influenza-like illness, fever, chills, sweats, severe headache, weakness, nausea, cough, weight loss.

He has encouraged his friends and family to get tested for Q Fever. His wife and child tested positive for Q Fever.

Activity

- Review Q Fever questionnaire, factsheets and control guidelines
- How could the case's family be positive if they don't have any occupational risk exposures?
- Where and how could environmental health fit into the case investigation?

The ID Team asked you to assist with the investigation because you have a good relationship with Community Q through the Aboriginal Communities Water and Sewerage Program.

The case's home is across from concrete and aggregate company, as well as a golf course that has many kangaroos. The sale yards is about 1km away.

Activity

- How would you help the ID team to gain access to Community Q and the case's home for an environmental health investigation?
- What are the potential Q Fever risk factors for the case?

In the home, the ID Team helped the case's family to complete the National Q Fever Case Investigation Form individually.

You were also able to have a quick look around the home and the community to see if there are clues for Q Fever risks.

After sharing a few cuppas with the CEO of the Community Q Local Aboriginal Lands Council and community residents, you found out that word has gone around the community and people are worried about Q Fever.

Activity

- From the environmental health investigation, what are the possible risks of Q Fever exposure for the case's family and Community Q?
- What could be done to reduce the risk of Q Fever in the family and in Community Q?
- Where can someone find access to support or other environmental health solutions for the family/community?
- What are some ways of improving community awareness of Q Fever?

Q fever

Q fever is a bacterial infection that can cause a severe flu-like illness. For some people, Q fever can affect their health and ability to work for many years. The bacteria are spread from animals, mainly cattle, sheep and goats. Even people who do not have contact with animals may be infected. A safe and effective vaccine is available to protect people who are at risk. Screening is required to identify who can be vaccinated.

What is Q fever?

Q fever is a disease caused by the bacterium *Coxiella burnetii*. It is spread to humans from cattle, sheep and goats and a range of other domestic and wild animals. Even people who do not have contact with animals may be infected.

What are the symptoms?

Many infected people have no or few symptoms. People who do become sick often have a severe flu-like illness. Symptoms begin about 2-3 weeks after coming into contact with the bacteria and typically include:

- high fevers and chills
- severe 'drenching' sweats
- severe headaches, often behind the eyes
- muscle and joint pains
- extreme fatigue (tiredness)

Patients may also develop hepatitis (inflammation of the liver) or pneumonia (infection of the lungs). Without treatment, symptoms can last from 2-6 weeks. Illness often results in time off work, lasting from a few days to several weeks. Most people make a full recovery and become immune to repeat infections. Occasionally, people develop chronic infections up to 2 years later which can cause a range of health issues including heart problems (endocarditis). This is more common for pregnant women, people with weakened immune systems or previous heart problems. About 10% of patients who are sick with acute Q fever go on to suffer from a chronic-fatigue-like illness which can be very debilitating for years.

How is it spread?

People usually get infected by breathing in the Q fever bacteria that is in the air or dust. Cattle, sheep and goats are the main sources of infection, however a wide range of animals including domestic and feral dogs and cats, feral pigs, horses, rabbits, rodents, alpacas, camels, llamas, foxes, and Australian native wildlife (including kangaroos, wallabies and bandicoots) can also spread the bacteria to humans. Infected animals often have no symptoms. The bacteria can be found in the placenta and birth fluids (in very high numbers), urine, faeces, blood or milk of animals who are infected with or carry the bacteria. The bacteria can survive in the soil and dust for many years and be spread over several kilometres by the wind.

You can get infected with Q fever by:

- breathing in the bacteria that is in the air or dust:
  - while birthing, slaughtering or butchering infected animals (especially cattle, sheep or goats). These activities carry a very high risk of infection.
  - when handling infected animals, infected animal tissues, fluids or excretions or animal products or materials that have been infected including wool, hides, straw, manure fertiliser and clothes (e.g. washing clothes worn when birthing, butchering or slaughtering animals)
  - while herding, shearing or transporting animals
  - while mowing grass contaminated by infected animal excretions
  - when visiting, living or working in/near a high-risk industry
- direct contact with infected animal tissue or fluids on broken skin (e.g. cuts or needlestick injuries when working with infected animals)
- drinking unpasteurised milk from infected cows, sheep and goats.

Who is at risk?

Workers in the following occupations are at high risk of Q fever:

- abattoir and meat workers
- livestock and dairy farmers and farm workers
- shearers, wool classers/sorters, pelt and hide processors
- stockyard/feedlot workers and transporters of animals, animal products and waste
- veterinarians, veterinary nurses/assistants/students and others working with veterinary specimens
- wildlife workers working with high-risk animals (including Australian native wildlife)
- agriculture college staff and students (working with high-risk animals)
- laboratory workers (working with the bacteria or with high-risk veterinary specimens)
- animal shooters/hunters
- dog/cat breeders, and anyone regularly exposed to animals who are due to give birth
- people whose work involves regular mowing in areas frequented by livestock or wild animals e.g. council employees, golf course workers or staff of mowing businesses in regional and rural areas.

All workers who enter workplaces in which Q fever may be present are also at risk of infection. This includes tradespeople, contractors, labour hire workers, sales representatives, buyers and council workers.

Other people may be at risk of Q fever through contact with high-risk animals outside of work. Infections have also occurred in regional and rural areas by breathing in infected dust and particles in the environment.

Other people at increased risk of Q fever include:

- family members of those in high-risk occupations (from contaminated clothes, boots or equipment)
- people living on or near a high-risk industry (e.g. neighbouring livestock farms, stockyards housing cattle/sheep/goats, meatworks, land being fertilised with untreated animal manure)
- visitors to at-risk environments (e.g. farms, abattoirs, animal saleyards and agricultural shows)
- horticulturists or gardeners in environments where dust, potentially contaminated by animal urine, faeces or birth products, is aerosolised (e.g. lawn mowing)

How is it prevented?

A safe and effective vaccine (Q-VAX®) is the best way to prevent Q fever infection. Vaccination is highly recommended for people who work or intending to work in high-risk occupations. Vaccination is also recommended for everyone aged 15 years and over who has the potential to be exposed to Q fever during activities outside of work, or in the environments in which they live or visit.

For those who are not immune (through vaccination or past infection), the following measures can reduce the risk of infection:

- wash hands and arms thoroughly in soapy water after any contact with animals
- wear a properly fitted P2 mask (available from pharmacies and hardware stores) and gloves and cover wounds with waterproof dressings when handling or disposing of animal products, waste, placentas, and aborted foetuses. This should not be considered a substitute for Q fever vaccination.
- wear a properly fitted P2 mask when mowing or gardening in areas where there are livestock or native animals
- wash animal urine, faeces, blood and other body fluids from equipment and surfaces where possible
- remove and wash dirty clothing, coveralls and boots worn during high-risk activities in outdoor wash areas. Avoid taking these items home to reduce the risk of infection to your household. If you do take them home, bag and wash them separately (should only be handled by those immune to Q fever)

How is it diagnosed?

The initial suspicion of a Q fever diagnosis is based on symptoms and an understanding of the possibility of coming into contact with the bacteria in the previous 6 weeks. Make sure your doctor is aware if you belong to one of the risk groups described above. Blood tests are required with repeated testing two to three weeks after symptoms begin to confirm the diagnosis.

How is it treated?

Early treatment with antibiotics can get you better sooner and reduce your risk of long-term complications. It is important to seek early medical attention if you develop symptoms of Q fever and are in one of the groups at risk of infection. Chronic (long-term) Q fever infection may require long-term antibiotics.

What is the public health response?

Laboratories must notify the local public health unit of any confirmed Q fever cases. Public health unit staff investigate each case to determine the likely source of infection, identify other people at risk of infection, ensure control measures are in place and provide information to cases.

Further information

See related factsheets Q fever vaccination, Q fever and farms and Q fever for veterinary staff.

For further information please call your local public health unit on **1300 066 055**.

Q fever and veterinary staff

Q fever is a bacterial disease that can cause a severe flu-like illness. It is spread to humans from a range of domestic and wild animals. All veterinary staff should be screened, and if needed, vaccinated against Q fever at least 2 weeks before starting work.

What is Q fever?

Q fever is a disease caused by the bacterium *Coxiella burnetii* that is spread to humans from animals.

What are the symptoms?

Acute Q fever infection can cause a severe influenza-like illness. Patients may also experience hepatitis (swelling of the liver) and pneumonia (infection of the lungs). Chronic (long-term) infections can occur. This is more common in pregnant women, those with weakened immune systems and heart problems. Some patients go on to suffer from a chronic-fatigue-like illness which can be very debilitating for years.

If you are diagnosed by your doctor with Q fever, you should tell your employer. They are required to provide a safe workplace, which includes controlling for the risk of Q fever. They must notify SafeWork NSW about Q fever infections in employees that may have been acquired in their workplace.

What animals can spread Q fever?

The main sources of infection are cattle, sheep and goats. However, a wide range of other animals can be reservoirs of *Coxiella burnetii* and can transmit the bacterium to humans directly or indirectly including domestic and feral dogs and cats, feral pigs, horses, rabbits, rodents, alpacas, camels, llamas, foxes, Australian native wildlife (notably kangaroos, wallabies and bandicoots), some birds and several species of ticks.

Infected animals usually do not have symptoms. Rarely, infected animals can experience abortion (particularly goats), stillbirth, infertility and pneumonia.

How can Q fever be transmitted from animals to veterinary staff?

Q fever bacteria are found in the placenta and birth fluids (in very high numbers), urine, faeces, milk and blood of animals who are either infected or carriers of the bacteria. Infected dust can form from the bacteria in these tissues, fluids and excretions. The bacteria can survive in air spaces for up to two weeks and in the soil and dust for years. The wind can spread the bacteria over several kilometres.

Veterinary staff can contract Q fever by:

- direct contact with infected animals, animal tissues or animal products
  - by breathing in infectious particles or dust. Birthing, caesarean sections and other activities involving direct contact with infected birth products have an especially high risk of infection.
  - through broken skin e.g. cuts or needle stick injuries when working with infected animals
- indirect contact from infected materials or fomites
  - by breathing in infectious particles or dust when handling contaminated materials (especially equipment and clothing in contact with infected birth products)
- contact with the bacteria in a contaminated environment
  - by breathing in infectious particles or dust from animals, animal products or materials (e.g. hides, straw and manure fertiliser) or in areas where birthing and caesarean section occur

Chapter 7

Presentations

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Chapter 7 Table of Contents

My son Henry and I at the 9th Southeast Asia and Western Pacific Bi-Regional Training Programs in Epidemiology and Public Health Interventions Network (TEPHINET) Scientific Conference.

Vientiane, Laos. November 5-9, 2018

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Prologue

During the Master of Applied Epidemiology (MAE) I delivered a number of presentations at local, state and international levels, including:

- 3x Field reports for the MAE at Australian National University (ANU)
- 3x Placement reports for Health Protection NSW (HPNSW)
- Immunisation Policy and Practice Day 2017
- *Salmonella* presentation to NSW Department of Primary Industries, Australian Veterinary Association and HPNSW
- Conducting ethical research in vulnerable populations, ANU
- 16th PHAA National Immunisation Conference Adelaide
- 9th Southeast Asia and Western pacific Bi-regional TEPHINET Scientific Conference, Vientiane, Laos. November 5-9, 2018
- Environmental Health Policy and Practice Day: Q fever in Aboriginal communities, February 2019

Table 1 outlines the presentations delivered during the MAE. As there were numerous, a sample of presentations is included in this chapter. Appendix A details a *Salmonella* presentation to the Health Protection NSW and the Department of Primary Industries. Appendix B is a presentation of the audit of the Australian Immunisation Register at the 9th Southeast Asia and Western Pacific Bi-Regional TEPHINET Scientific Conference in Laos from 5-9 November 2019, and Appendix C details a Q fever presentation delivered at the Environmental Health Policy and Practice Day in February 2019.

Table 13 Presentations delivered during the Master of Philosophy in Applied Epidemiology at the Communicable Diseases Branch, Health Protection NSW 2017-2019

Study name	Presentation
An Audit of the Australian Immunisation Register	Immunisation Policy and Practice Day 2017 Long oral: 9th Southeast Asia and Western Pacific Bi-Regional Training Programs in Epidemiology and Public Health Interventions Network (TEPHINET) Scientific Conference. Vientiane, Laos. November 5-9, 2018
Investigation into increased Q fever notifications in Aboriginal people living in Western NSW local health district	Short Oral: 16th PHAA National Immunisation Conference 2018. Adelaide, South Australia. June 5-7, 2018 Nginda MAE waala wiitha! The implications of investigating diseases with limited data Environmental Health Policy and Practice Day: Q fever in Aboriginal communities, February 2019
Multi-state outbreak of Salmonella Typhimurium caused by a novel multi-locus variable number tandem repeat analysis type, 2018-19	Rapid fire presentation Communicable Disease Control Conference 2019. Canberra, Australian Capital Territory. November 19-21, 2019.
Evaluation of the NSW Acute Rheumatic Fever and Rheumatic Heart Disease Surveillance System, including the Rheumatic Fever Register	NSW RHD Network Workshop
Other	3x Field reports for the MAE at Australian National University (ANU) 3x Placement reports for Health Protection NSW (HPNSW) Conducting ethical research in Aboriginal Communities, ANU Salmonella presentation to NSW Department of Primary Industries, Australian Veterinary Association and HPNSW

Appendix A. *Salmonella* presentation to the Health Protection NSW and the Department of Primary Industries

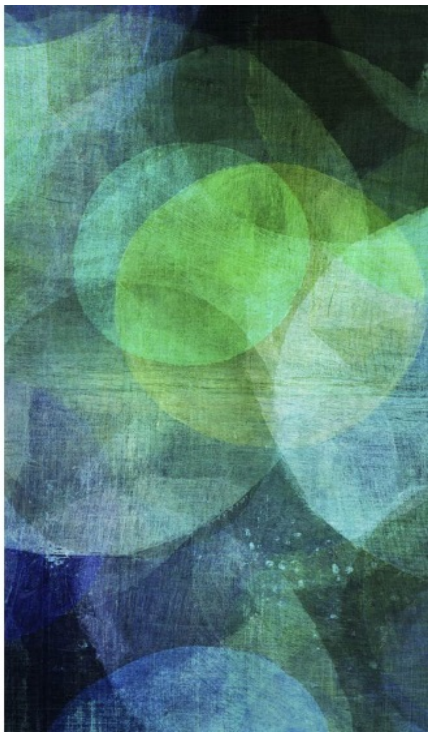
SAVING LIVES AND PROTECTING INDUSTRY THROUGH FOOD SAFETY

Health Protection NSW and
NSW Department of Primary Industries

Joint Annual Report 2016
Salmonella: surveillance, monitoring and investigations

NSW Health

NSW Department of Primary Industries



PURPOSE AND SCOPE OF REPORT

- Strengthen mechanisms for Salmonella surveillance and response
- Synthesise and analyse Salmonella data
- Provide epi analysis of key serovars detected in 2016
- Discuss current and emerging Salmonella trends
- Highlight key joint achievements
- Identify gaps in the approach and strategic direction to enhance surveillance
- Provide information to external stakeholders on the status of Salmonella in NSW

To meet these objectives, NSW Health and the NSW DPI hold weekly meetings, together with the NSW Enterics Reference Laboratory (CIDMLS-ICPMR, Pathology West)

NSW GOVERNMENT Health

PathologyWest
ICPMR Westmead
supporting hospitals and local communities

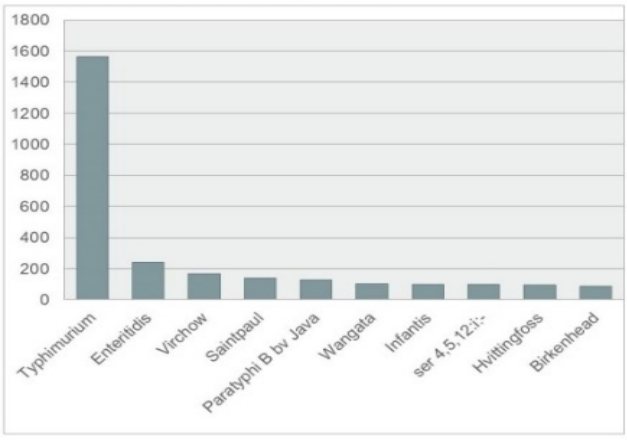
NSW GOVERNMENT Department of Primary Industries

- ~ Updates
- ~ New clusters detected (including WGS)
- ~ Foodborne disease outbreaks
- ~ New and emerging issues

SECTION 1: HUMAN HEALTH SURVEILLANCE

IN THIS SECTION.....

TOP 10 *SALMONELLA* SEROVARS, NSW, 2016



Salmonella serovar	Confirmed cases
Salmonella Typhimurium	1575
Salmonella Enteritidis	245
Salmonella Virchow	167
Salmonella Saintpaul	141
Salmonella Paratyphi B bv Java	127
Salmonella Wangata	104
Salmonella Infantis	100
Salmonella ser 4,5,12:i-	99
Salmonella Hvittingfoss	95
Salmonella Birkenhead	88

SALMONELLA ENTERITIDIS

Nomenclature: *Salmonella enterica subsp. enterica serovar Enteritidis*

Antigenic formula: 1,9,12:g,m:- (O:9 (D_1) serogroup)[14]

SUMMARY 2016	
Case count	245
Reported hospitalisations	42
Reported deaths	0
Notification rate per 100,000	3.1

WHAT DO WE KNOW ABOUT *S.*ENTERITIDIS?

Reservoir: Foodborne, particularly poultry, contaminated eggs and egg products[2]

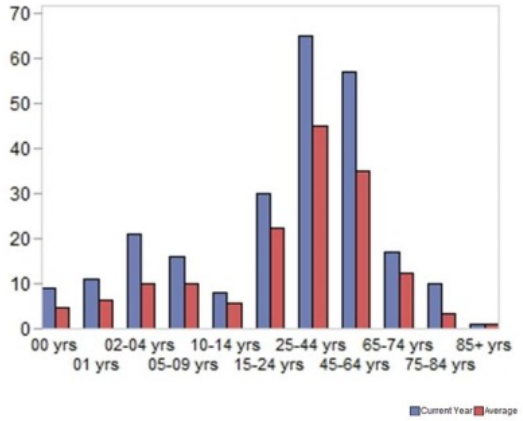
Geographic distribution: Widely distributed across the northern hemisphere[3] including Canada, Europe, the UK and North America[1].

Concerns: *S.*Enteritidis can infect the internal contents of eggs transferred from the oviducts of infected chickens. This can cause major issues for large commercial laying flocks[3], however this is not endemic in Australia.

Outbreaks: Cases of *S.*Enteritidis (phage type 4) in Australia are mostly associated with overseas travel and the causes of locally acquired infections are generally unknown[3].

AGE ANALYSIS

Age category of *S.*Enteritidis infections compared to 5 year average, 2016, NSW



LOCALLY AND INTERNATIONALLY ACQUIRED INFECTIONS

Number of *S.*Enteritidis infections, NSW, 2006 to 2010*, by travel history

Year	Locally acquired	Overseas acquired	Unknown	Total
2010	12	133	3	148
2009	3	101	7	111
2008	29	72	0	101
2007	6	68	27	101
2006	4	43	22	69

* DATA TO BE UPDATED SHORTLY (2012 TO 2016)

EPIDEMIOLOGICAL SITUATION

Overall trend

55% increase in *S.Enteritidis* notification rate compared to 5 year average (2.1 per 100,000)

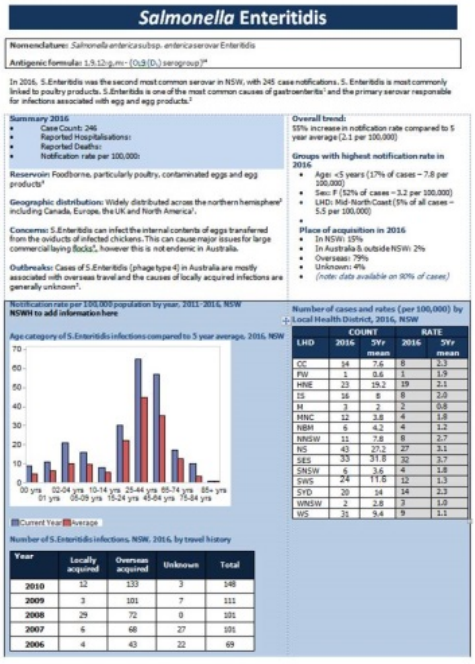
Groups with the highest notification rate in 2016

Age: <5 years (17% of cases – 7.8 per 100,000)

Sex: Female (52% of cases – 3.2 per 100,000)

LHD: Mid-North Coast (5% of all cases – 5.5 per 100,000)

BRINGING IT TOGETHER



***Salmonella* Enteritidis**

Nomenclature: *Salmonella enterica* subsp. *enterica* serovar Enteritidis

Antigenic formula: 1,9,12:g,m:- (O:9,(D$_1$) serogroup)[4]

In 2016, S.Enteritidis was the second most common serovar in NSW, with 245 case notifications. S. Enteritidis is most commonly linked to poultry products. S.Enteritidis is one of the most common causes of gastroenteritis[1] and the primary serovar responsible for infections associated with egg and egg products.[2]

Summary 2016
- Case Count: 246
- Reported Hospitalisations:
- Reported Deaths:
- Notification rate per 100,000:

Reservoir: Foodborne, particularly poultry, contaminated eggs and egg products[3]

Geographic distribution: Widely distributed across the northern hemisphere[2] including Canada, Europe, the UK and North America[1].

Concerns: S.Enteritidis can infect the internal contents of eggs transferred from the oviducts of infected chickens. This can cause major issues for large commercial laying flocks[3], however this is not endemic in Australia.

Outbreaks: Cases of S.Enteritidis (phage type 4) in Australia are mostly associated with overseas travel and the causes of locally acquired infections are generally unknown[3].

Overall trend:
55% increase in notification rate compared to 5 year average (2.1 per 100,000)

Groups with highest notification rate in 2016
- Age: <5 years (17% of cases – 7.8 per 100,000)
- Sex: F (52% of cases – 3.2 per 100,000)
- LHD: Mid-North Coast (5% of all cases – 5.5 per 100,000)

Place of acquisition in 2016
- In NSW: 15%
- In Australia & outside NSW: 2%
- Overseas: 79%
- Unknown: 4%
- *(note: data available on 90% of cases)*

Notification rate per 100,000 population by year, 2011-2016, NSW
NSWH to add information here

Age category of S.Enteritidis infections compared to 5 year average, 2016, NSW

Number of cases and rates (per 100,000) by Local Health District, 2016, NSW

LHD	COUNT 2016	COUNT 5Yr mean	RATE 2016	RATE 5Yr mean
CC	14	7.6	8	2.3
FW	1	0.6	1	1.9
HNE	23	19.2	19	2.1
IS	16	8	8	2.0
M	3	2	2	0.8
MNC	12	3.8	4	1.8
NBM	6	4.2	4	1.2
NNSW	11	7.8	8	2.7
NS	43	27.2	27	3.1
SES	33	31.8	32	3.7
SNSW	6	3.6	4	1.8
SWS	24	11.6	12	1.3
SYD	20	14	14	2.3
WNSW	2	2.8	3	1.0
WS	21	9.4	9	1.1

Number of S.Enteritidis infections, NSW, 2016, by travel history

Year	Locally acquired	Overseas acquired	Unknown	Total
2010	12	133	3	148
2009	3	101	7	111
2008	29	72	0	101
2007	6	68	27	101
2006	4	43	22	69

OTHER REPORT AREAS

- Outbreak investigations
- Case studies
- Trends and emerging issues

SECTION 2:
FOOD & ENVIRONMENTAL SURVEILLANCE

INCLUDES

- Findings of one of the sampling programs - e.g. egg farms surveillance
- Evidence that eggs are a significant source of human salmonellosis, based on comparison of data found on farms and human isolates
- Surveillance/outbreak follow up suggests that farms implicated in outbreaks have a higher prevalence of Salmonella that farms inspected on a routine basis
- Working with industry on an incident response plan for farmers & regulators

REFERENCES AND QUESTIONS

1. Liu Y, Shi X, Li Y, Chen Q, Jiang M, Li W, Qiu Y, Lin Y, Jiang Y, Kan B, Sun Q. The evaluation and application of multilocus variable number tandem repeat analysis (MLVA) for the molecular epidemiological study of *Salmonella* enterica subsp. enterica serovar Enteritidis infection. Annals of clinical microbiology and antimicrobials. 2016 Jan 29;15(1):4.
2. Threlfall EJ, Wain J, Peters T, Lane C, De Pinna E, Little CL, Wales AD, Davies RH. Egg-borne infections of humans with *Salmonella*: not only an S. enteritidis problem. World's Poultry Science Journal. 2014 Mar 1;70(01):15-26.
3. OzFoodNet Working Group. Foodborne disease investigation across Australia: annual report of the OzFoodNet network, 2003. Communicable diseases intelligence quarterly report. 2004;28(3):359.

Thank you

Appendix B. Australian Immunisation Register presentation at the 9th Southeast Asia and Western Pacific Bi-Regional TEPHINET Scientific Conference

Children overdue for immunisation
a question of coverage or reporting?

An audit of the Australian Immunisation Register

Prepared by Charlee Law
Master of Applied Epidemiology (MAE) Scholar
Australian National University
New South Wales (NSW) Health
November 2018

THE AUSTRALIAN NATIONAL UNIVERSITY ANU NSW GOVERNMENT Health

Overview: NSW Health

230 Public hospitals
17 Public health units

15 Local health districts (LHDs)

NSW Ministry of Health
Central driver

Health Protection NSW
Immunisation Branch

Immunisation policy responsibilities in Australia

Australian Government

- Overall immunisation policy under National Immunisation Program
- Reporting through Australian Immunisation Register (AIR)

States and territories

- Implement National Immunisation Program
- Implement state-based immunisation policies and programs

National Immunisation Program
A joint Australian, State and Territory Government initiative

Australian Immunisation Register (AIR)

NSW Public Health Network audit

How many 1 year old children are overdue on AIR?

What is their immunisation coverage?

- Does underreporting vary by
  - Reported vaccine coverage level
  - Socioeconomic status
  - Provider setting (urban, rural & remote)

The Australian Immunisation Register

- Assesses immunisation coverage at various levels
- Confirms immunisation status
  - Overdue/Fully immunised
- Determines eligibility
  - Childcare & Government assistance
- Resource mobilisation

National Immunisation Program

Australian Immunisation Register (AIR)

Rationale

- National coverage target 95%
- NSW coverage on AIR 94.1% (children 1 year of age)
- The unknown:
  - If coverage > national target
  - Contemporary barriers to immunisation or reporting

Methods

https://www.congreso-senc.com/

- Cross-sectional
- 491 NSW children
  12-<15 months
- >30 days overdue Sept 2017
- Sample and questionnaire to LHDs
- Sample reweighted for non-responders (n=77)

Results

https://www.independent.co.uk/life-style/health-and-families/health-news/britain-could-be-the-first-country-in-the-world-to-vaccinate-every-baby-against-meningitis-b-9208694.html

- Incorrectly reported as overdue
  34.9% (CI: 30.9-38.9%)
- Estimated coverage
  96.2% (CI: 95.9-96.4%)
- No significance: coverage level, socioeconomics, provider setting
- LHD important determinant of whether vaccines recorded correctly (12-54%)
- 11% less error in Aboriginal and Torres Strait Islander children

AIR incorrect: child actually vaccinated

Reasons for error on AIR	(n=)	(x%)
Data errors at provider level	102	71.3
Duplicate records	29	20.3
Child overseas vaccinated with evidence	7	4.9
Delays due to illness, vaccinated with evidence	2	1.4
Clinician errors (wrong dose recorded in record)	2	1.4
Not stated	1	0.7
Total	**143/414**	

Medicare number= Australia's universal health insurance number

AIR correct: child not vaccinated

Reasons offered for not vaccinating	(n=)	(x%)
Not stated	158	58.3
Vaccine refusal	54	19.9
Parental hesitancy	17	6.3
Vaccinated overseas no evidence	9	3.3
Vaccinated in Australia no evidence	8	3.0
Child overseas not vaccinated	8	3.0
Catch-up schedule	8	3.0
Child sick	5	1.8
Parent forgot to vaccinate	2	0.7
GP refusal	1	0.4
Interstate provider	1	0.4
Total	**271/414**	

Sensitivity analysis

Sensitivity analysis

All NSW	(n=)	% Incorrectly reported	95% CI	Reported coverage	True coverage	95% CI
Reported results	414	34.9	(30.9,38.9)	94.1	96.2	(95.9,96.4)
Setting non-response as fully vaccinated	491	45.8	(41.9,49.6)	94.1	96.8	(96.6,97.0)
Setting non-response as not vaccinated	491	29.0	(25.5,32.5)	94.1	95.8	(95.6,96.0)
'No evidence' to 'with evidence'	414	39.6	(35.5,43.7)	94.1	96.4	(96.2,96.7)

- Coverage exceeds AIR estimate (94.1%) and national benchmark (95%)

Limitations

- Non-response (n=77)
- Cross-sectional design
- Age range not generalisable to others
- Not tailored to measure those with different drivers

Conclusion

- Underreporting continues
- Reported estimates lower than 96.2%
- 34.9% incorrectly reported as overdue
- Data errors and duplicates primary cause for error
- Lower error for programs with active resources

Implications

- Treat publically reported data as minimum coverage estimate
- Improvements to reduce underreporting
- Measures to identify errors and duplicates
- Adds to evidence base to support programs

Acknowledgements

- NSW Australian Immunisation Register Working Group
  - Charlee Law, Rhydwyn McGuire, Mark Ferson, Su Reid, Colleen Gately, Jody Stephenson, Sue Campbell-lloyd, Salwa Gabriel, Tambri Housen, Vicky Sheppeard, Paul Corben, David Durrheim
- The NSW Public Health Network AIR Study Group
  - Lisa Allchin, Katie Anagnostou, Shopna Bag, Sue Botham, David Boucher, Sophie Carey, Hayley Carra, Kwendy Cavanagh, Trisha Collins, Rachelle Deaker, Michelle Dives, Bridget Doyle, Michelle Ferguson-Hannah, Linda Granger, Sheila Hamm, Wendy Holmes, Essi Huhtinen, Andrew Ingleton, Jane Jelfs, Emily Keighran, Judith Kennedy, Liz Kirk, Julie McLean, Dee McNamara, Jackie Milsom, Amy Nicholson, Clare Pearson, Juhel Pritchard, Tania Simpson, Angela Shirlaw, Jane Thomas, Marianne Trent, John Turahui, Natasa Veselinovic, Cheryl Wasley, Kristie Waters, Jennifer Wedd and Robert Whybrow
- National Centre for Immunisation Research & Surveillance (NCIRS)
- The NSW Public Health Network, Directors and Immunisation Coordinators

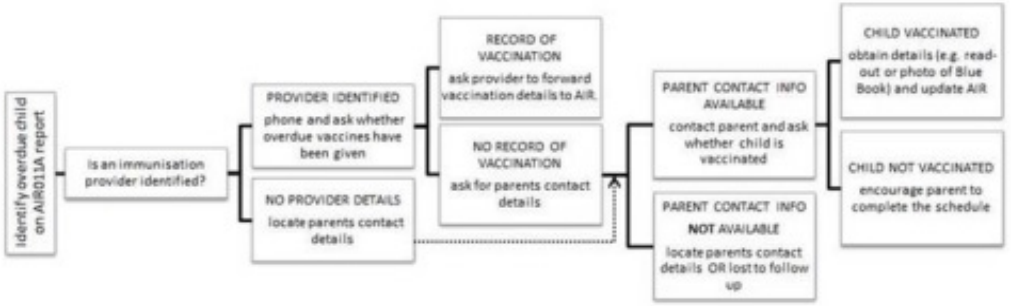
ขอบใจ! Thank you!

Questions?

Bonus slides in anticipation of questions

Q&A bonus slide

Audit tool
NSW Australian Immunisation Register (AIR) follow-up protocol



Q&A bonus slide

Flowchart depicting sampling frame and outcome

Q&A bonus slide

% incorrectly reported onto AIR, and reported vs true immunisation coverage for 1 year old NSW children

LHD name	n=414	% Incorrectly reported	95% CI	Reported coverage	True coverage	95% CI	p-value
LHD 1	42	44.6	(31.7,57.5)	94.0	96.7	(95.9,97.5)	
LHD 2	29	23.0	(9.5,36.5)	93.0	94.6	(93.7,95.6)	
LHD 3	45	51.9	(39.3,64.4)	93.7	97.0	(96.2,97.8)	
LHD 4	15	41.9	(21.5,62.2)	95.4	97.3	(96.4,98.3)	
LHD 5	46	30.8	(19.3,42.2)	93.5	95.5	(94.8,96.2)	
LHD 6	33	18.9	(7.5,30.2)	94.5	95.5	(94.9,96.2)	
LHD 7	23	29.9	(13.6,46.1)	94.2	95.9	(95.0,96.9)	
LHD 8	24	11.8	(1.9,21.6)	95.6	96.1	(95.7,96.6)	(p<0.0001)
LHD 9	43	54.3	(42.1,66.5)	95.8	98.1	(97.6,98.6)	
LHD 10	33	12.6	(1.4,23.8)	90.0	91.3	(90.1,92.4)	
LHD 11	28	21.7	(16.3,27.0)	92.5	94.1	(93.7,94.5)	
LHD 12	12	41.8	(25.9,57.7)	95.7	97.5	(96.8,98.2)	
LHD 13	16	45.1	(31.4,58.8)	96.0	97.8	(97.3,98.4)	
LHD 14	25	40.2	(28.9,51.5)	96.0	97.6	(97.2,98.1)	
All NSW	414	34.9	(30.9,38.9)	94.1	96.2	(95.9,96.4)	

Q&A bonus slide

Incorrect reporting on AIR by coverage area, rurality and socioeconomic status (SEIFA)

Measure	Variable	n=414	% Incorrectly reported	95% CI	p-value
Coverage area	Low coverage: <92%	66	36.7	(26.5, 46.9)	p=0.9
	Mid coverage: 92-94%	120	33.5	(25.9, 41.1)	
	High coverage: >94%	228	35.4	(30.2, 40.5)	
Rurality	Major City	268	34.9	(30.1, 39.8)	p=0.9
	Inner regional, remote and very remote	146	34.6	(30.3, 38.9)	
Socio-economic status	Low SEIFA	170	37.2	(30.7, 43.6)	p=0.2
	Mid SEIFA	147	29.8	(23.5, 36.1)	
	High SEIFA	97	37.9	(29.4, 46.3)	

05 NOV 2018

9th Southeast Asia & Western Pacific Bi-regional TEPHINET Scientific Conference

Vientiane, Lao People's Democratic Republic

November 5-9, 2018

Scientific Conference

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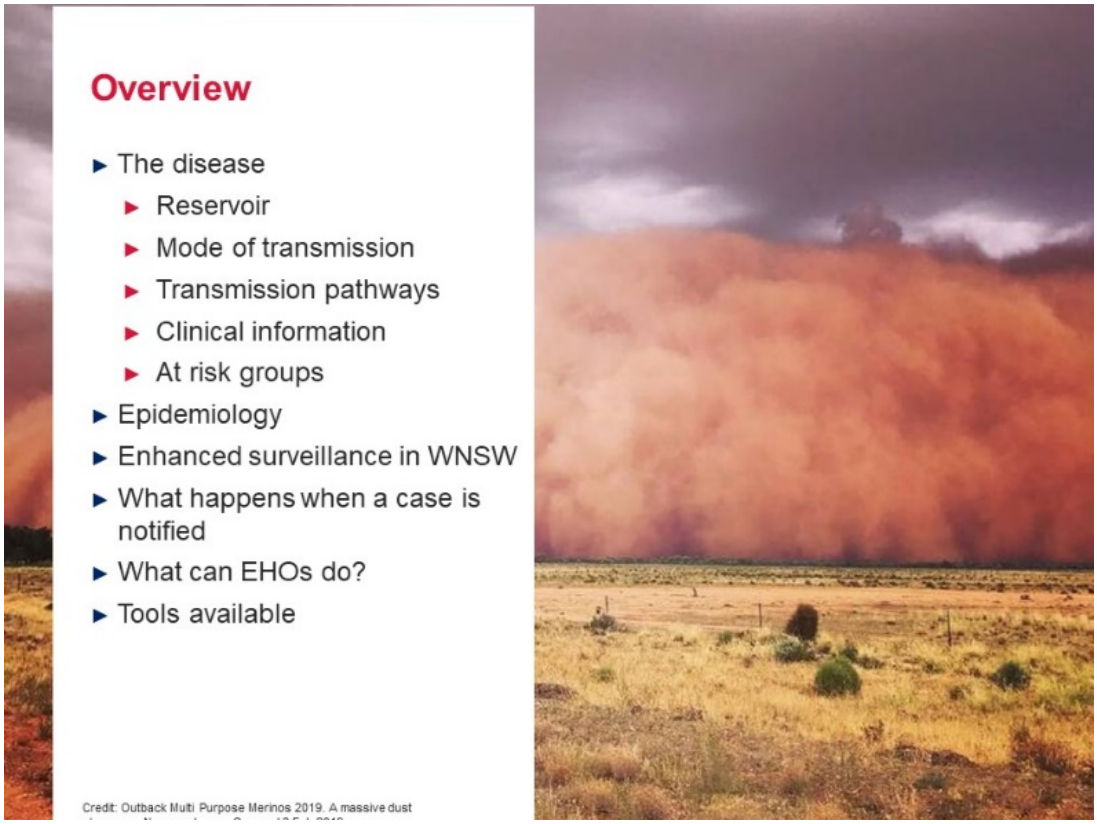
Q fever presentation at the Q fever Policy and Practice Day



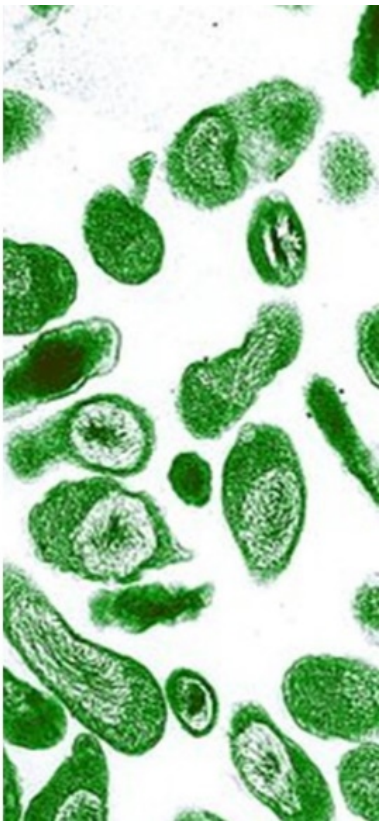
Q fever – the disease

- *Coxiella burnetii*
- Highly infective, gram-negative coccobacillus
- First described in 1937 in response to illness in abattoir workers and farmers
  - Described by Edward Derrick as Q (for query) fever
  - Isolated by Cox and Burnet
- Thought to be localised to SE-QLD
- Over the next 10 years it was realised to be of worldwide significance

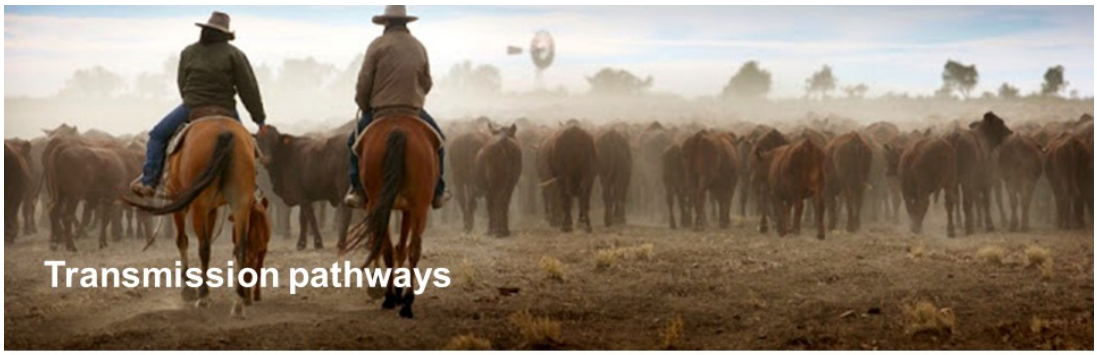
Edward Derrick

Frank Macfarlane Burnett

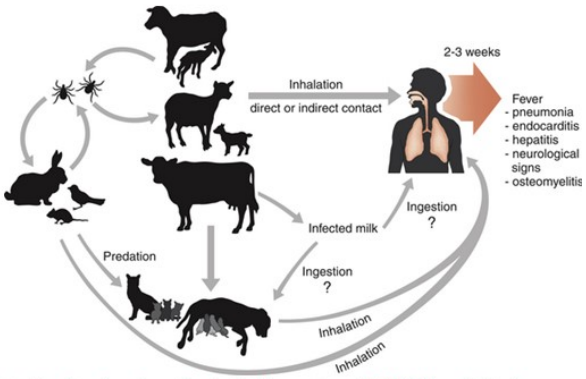
Image: https://fineartamerica.com/featured/q-fever-bacteria-coxiella-burnetii-tem-niaid.html?product=metal-print
http://oa.anu.edu.au/obituary/burnet-sir-frank-macfarlane-mac-12287



Reservoir



- Respiratory
  - Killing, butchering or birthing
  - Dust
- Percutaneous
  - Injury (cuts, needlestick)
- Vector-borne
- Foodborne
  - Unpasturised milk
- Person-to-person: rare



http://sandymcleantheoutbackartist.blogspot.com/2013/11/drought.html
http://veteriankey.com/coxiellosis-and-q-fever

Q fever is extremely efficient at staying alive

- Infection may result from a single organism
- Resists: desiccation, osmotic shock, UV light, chemical disinfectants
- Survives on:
  - wool at 15–20C for 9 months
  - meat in cold storage for >1 month
  - dust >1 year
- Killed by:
  - heat (>63C >30 minutes)
  - some chemicals
- Category B bioterrorism agent
- Occupational and environmental disease

Clinical information

- Incubation 2-3 weeks; range of 4 days to 6 weeks
- ~50% infected will be asymptomatic.
- Symptomatic
  - non-specific acute febrile illness
  - muscle aches
  - weakness
  - severe headaches
  - fatigue
  - 'drenching sweat'
- chronic illness that may affect the heart or liver; chronic fatigue
- CFR 1% to 2%

9

At risk occupational groups

- Abattoir and meat workers
- Agriculture, livestock and dairy farmers/workers
- Stockyard/feedlot workers and transporters of animals, animal products and waste
- Shearers, wool classers/sorters, pelt and hide processors
- Knackery workers
- Tannery workers
- Laundry workers handling clothing from at-risk workplaces
- Pet food manufacturing workers
- Vets, vet nurses/students/researchers
- Agriculture college staff and students
- Animal shooters/hunters
- Laboratory personnel who work with materials containing C.*burnetii*
- Wildlife/zoo workers and animal trainers
- Dog/cat breeders, anyone regularly exposed to parturient (female) animals.

10

Not on the list?

Plenty more exposure pathways to go around…

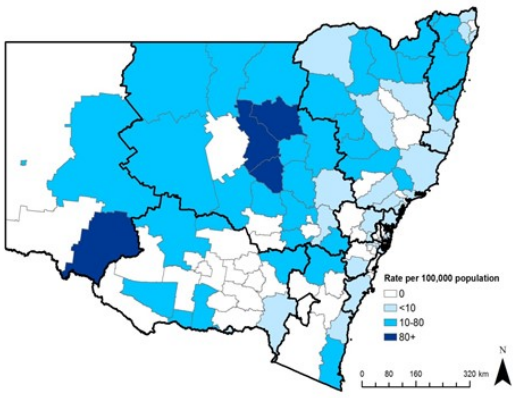
Non-occupational, environmental exposures

- People living on or in close proximity to a high risk industry
- Visitors to at-risk environments
- People living or working near livestock transport routes.
- People involved in mowing
- Immunosuppressed persons
- Pregnant women
- Persons with valvular heart conditions
- Persons with aneurysms/vascular grafts
- Recreational (golf, bushwalking)

11

Epidemiology

- Nationally notifiable
- **Geographic distribution:** Everywhere but NZ and Antarctica
- 207 cases in NSW, 2018
- WNSW, HNELHD, MNC, NNSW
- **Sex:** 69% male
- **Age:** Aboriginal <20yr and 20-29yrs; non-Aboriginal 50-59yrs
- **Concerns:** Rate higher in Aboriginal people: 5.6 per 100,000 (2016)



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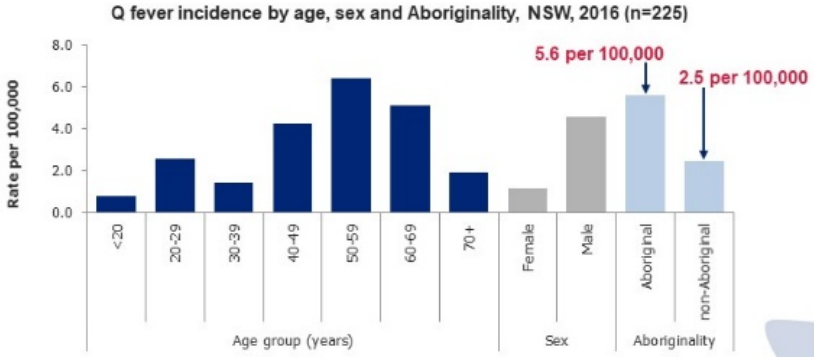
12

Q fever incidence by age, gender and Aboriginality, NSW, 2016 (n=225)

- Why was there was a disproportionate rate of Q fever infection in Aboriginal people relative to non-Aboriginal people in NSW in 2015-2016?
- Enhanced surveillance
  - Descriptive analyses of Q fever notification data (2012-2017)



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What did we do?

- Discussions with Safe Work NSW
- Q fever campaign was already running by NSWH
- Aboriginal Research Advisory Group
  - Aboriginal representatives from health, education and Aboriginal Community Controlled Organisations (AMS)
  - Identified pathways: translating data into public health initiatives
    - Safe Work NSW (jobseekers and current employees)
    - Shearing schools
    - Education sector (public, private and Catholic schools)
    - DPI (hunters and shooters)

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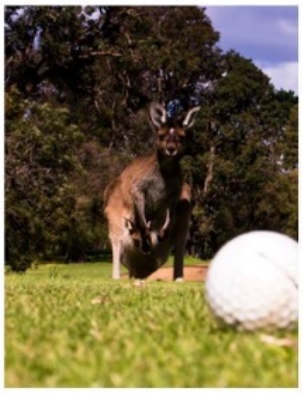
What happens when a case is notified?

- PHUs
  - work with providers and patients to ascertain cases
  - complete case investigation (questionnaire)
  - provide info on Q fever prevention and control
- Other agencies:
  - Workplace health and safety regulator (SafeWork NSW)
  - Animal health authority
  - Local government authority
  - Health authorities of neighbouring jurisdictions



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What can EHOs do?

- EH is not always involved in Q fever management but have roles that the CDB may not be able to fulfil
- Information requests (public/professional)
- Planning and compliance
  - DAs, town planning
  - dust prevention, air quality
- Health promotion and EH initiatives

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Aboriginal stockman Levi Farrellhe, who was trained at Waliburru Station. https://www.abc.net.au/news/2009-11-18/indigenous-stockman-levi-farrellhe-who-was-trained/1146448

What you can do in special situations

- **Cases and outbreaks linked to workplace/occupational settings**
  - Encourage case to contact SafeWork
- **Community clusters/Family clusters**
  - EH initiatives, education, health promotion
    - Health education (separate laundry, hygiene, domestic animals)
    - Value adding projects (HfH)
    - Initiatives (Mr Germ)

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Reducing exposures:

- Disinfection
  - hydrogen peroxide, sodium hypochlorite (at concentrations of >5%), and 2% formaldehyde
  - 1:100 dilution of household bleach is effective
- Town planning/DAs
  - Potential for windborne spread
  - Limit encroachment of residential dwellings on existing likely sources of Q fever (abattoirs, tanneries, stockyards)
  - Awareness of transport truck routes from potential businesses

Reducing exposures

- **Q fever vaccination** is the primary prevention measure for those at risk
  - Requires pre-vaccination screening
  - Aged15 years or over
- **Australian Q Fever Registry**
- **Resources are available to support Q fever vaccination**
  - E-learning module for medical staff
  - Vaccination and disease factsheets

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Reducing exposures

- Workplace design and safe work practices – e.g. a restaurant attached to a farm!
  - Restrict access to risk areas
  - Personal protective equipment
  - Thorough hand washing and cleaning worksite and tools
  - Dust minimisation
- Animal and environmental management – next presentation
  - Keep in mind safe disposal of animal birth products
  - Manure covering and removal
- Other: Pasteurisation of milk

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Tools available to EHOs

- Q fever SoNG
- Q fever campaign
  - Posters
  - Factsheets
  - Brochures
- Safe Work NSW
- ACCHOs
- Legislative powers