Applied Epidemiology in country Western Australia

A thesis submitted for the degree of Master of Philosophy (Applied Epidemiology)

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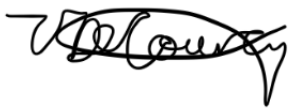
Originality Statement

I declare that this thesis is my own original work and does not contain any material written by another person, or any material previously submitted to fulfil the requirements of another degree or qualification, except where appropriately referenced in the text. Contributions by other persons to the research described in this thesis, including regarding study design, data collection and manuscript review, are acknowledged in the prologue of each chapter.



Virginia DeCourcy

27 October 2023

I conducted the majority of the research described in this thesis on the unceded land of the Whadjuk Noongar people, on the banks of the Derbarl Yerrigan (Swan River). I would like to acknowledge and pay my respects to their elders past and present, and those of Aboriginal and Torres Strait Islander peoples throughout Australia, and their continuing deep connection to and protection of the sacred environments where I am privileged to live and work.

Always was, always will be, Aboriginal land.

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I was lucky to learn from and work with colleagues from the Population Health team at WACHS Central Office throughout my placement. Thanks for welcoming me into the fold, for nodding along to my complaints, and for teaching me about WA pronunciations. Particular thanks to Karine Miller for supporting my placement, and to Tara Sanders for your indispensable admin assistance and your friendly hello every morning.

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Abstract

The Western Australia Country Health Service (WACHS) is one of seven Health Service Providers in Western Australia (WA) and is responsible for the delivery of health services in WA's seven country regions. Between March 2022 and December 2023 I undertook a field placement at WACHS to satisfy the requirements of the Master of Philosophy in Applied Epidemiology (MAE) degree program. This thesis describes the four projects I completed to address the required competencies of the MAE.

To meet the competency to investigate an acute public health problem, I investigated two gastroenteritis outbreaks in the South West region, one following an office Christmas lunch and the other at a residential boarding school. As neither outbreak had a confirmed aetiology, I investigated barriers to stool specimen collection and made recommendations to improve this in future outbreaks.

For the data analysis competency, I prepared both annual and quarterly reports for WACHS on notifiable diseases. This included descriptive analyses of notifications, and comparison with historical, state and national notifiable disease rates. I made recommendations to improve future editions of these reports, and developed templates to simplify future analyses.

For the surveillance system competency, I contributed to the establishment of a system to record and monitor family and domestic violence-related Emergency Department (ED) presentations across country WA. This included conducting a quantitative analysis to inform the functionality of the system, co-leading a consultation process with ED staff across seven WACHS sites, and liaising with internal stakeholders to ensure that data collected by the system is disseminated appropriately.

For the epidemiological study competency, I conducted a three-part mixed methods study investigating rheumatic heart disease (RHD)-related mortality in Western Australia between 2012 and 2021. This included a quantitative analysis of age-standardised mortality rates; a descriptive analysis of clinical and demographic characteristics among deceased persons recorded on the WA RHD Register; and a thematic qualitative analysis of in-depth stakeholder interviews.

The final chapter in this thesis describes my experience teaching epidemiology, including delivering a tutorial on age standardisation to first-year MAE scholars, and delivering a Lesson From the Field on qualitative interviewing for my MAE peers.

The projects described in this thesis contribute to public health and epidemiological knowledge, particularly in the areas of rural and Aboriginal health. Each project aims to inform public health action to improve the health of these populations.

Contents

Terminology

List of Abbreviations

ABS	Australian Bureau of Statistics
AIR	Australian Immunisation Register
ANU	Australian National University
ARF	Acute rheumatic fever
BPG	Benzathine penicillin G
CDC	United States Centre for Disease Control
CDCD	Western Australia Communicable Disease Control Directorate
CERC	Cardiovascular Epidemiology Research Group
CFU	Colony-forming units
CI	Confidence interval
DOH	Western Australia Department of Health
DOR	Date of receipt
ED	Emergency Department
EDDET	Emergency Department Data Exploration Tool
EHO	Environmental health officer
FDV	Family and domestic violence
FSANZ	Food Standards Australia and New Zealand
GP	General Practitioner
HIV	Human Immunodeficiency Virus
HREC	Human Research Ethics Committee
iGAS	Invasive group A streptococcal disease
LFF	Lesson from the field
LGBTQIA+	Lesbian, gay, bisexual, transgender, queer, intersex, asexual
MAE	Master of Philosophy in Applied Epidemiology
MCDC	Western Australia Metropolitan Communicable Disease Control
NFP	Not for profit
NT	Northern Territory
NYHA	New York Heart Association
ODOO	Optimal date of onset
OFN	OzFoodNet
OR	Odds ratio

PCR	Polymerase chain reaction
PHOCUS	Public Health Operations COVID-19 Unified System
PHU	Public health unit
QI	Quality improvement
RAT	Rapid Antigen Test
RHD	Rheumatic heart disease
RR	Rate ratio
RSV	Respiratory syncytial virus
SA	South Australia
SEIFA	Socioeconomic Indexes for Areas
WA	Western Australia
WACHS	Western Australia Country Health Service
WANIDD	Western Australia Notifiable Infectious Diseases Database

This thesis uses the term 'Aboriginal' to refer to people living in Western Australia (WA) who are either Aboriginal or Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of WA, and in line with the style guide for the WA Country Health Service. The term 'Aboriginal and Torres Strait Islander' is used to refer to the wider Australian context. No disrespect is intended to the Torres Strait Islander community in WA.

Chapter 1: Master of Philosophy in Applied Epidemiology Experience

Contents

Background

My two years as a Master of Philosophy in Applied Epidemiology (MAE) Scholar were challenging, rewarding, and expectation-defying. I applied for the MAE program with the assumption that the most valuable lessons I would learn would be technical in nature – with aims to master a statistical package; build confidence in managing a large dataset; and finally comprehend the purpose of indirect age standardisation. While I made strides towards each of these goals, I also learnt unexpected lessons during my field epidemiology training – including the value of combining qualitative and quantitative findings to make recommendations; the necessity of genuine engagement with data collectors in designing a surveillance system; the importance of communicating research findings well and to the right people; and the difficulty of progressing an outbreak investigation without any stool samples. I had the opportunity to travel throughout regional Western Australia (WA), to use three new programs for quantitative and qualitative analysis, to try my hand at making an infographic in Microsoft Word, and to work with the welcoming, knowledgeable staff at the WA Country Health Service (WACHS) Central Office. I am sure the skills I developed will be useful throughout my career, and am grateful to have earned my field epidemiology stripes in Australia's biggest (and most beautiful) state.

About the WA Country Health Service

WACHS is one of seven Health Service Providers in WA and a State Government statutory authority, governed by the *Health Services Act 2016*(1). WACHS is comprised of seven regions: Goldfields, Great Southern, Kimberley, Midwest, Pilbara, South West, and Wheatbelt, and provides health services for a population of over 530,000 people across 2.5 million square kilometres(2). These services are comprised of six regional hospitals, 15 district hospitals, 48 small hospitals and 31 health centres, and employ approximately 10,000 staff. Public health management in each region is overseen by local Population Health teams, who are responsible for communicable disease control; delivering health promotion and immunisation programs; and managing community and allied health services.

My MAE field placement was at Population Health in WACHS Central Office in Perth. The Central Office Population Health team provides coordination and advice for regional staff, covering a range of program and policy areas including public health, chronic conditions, family and child safety, and community and child health nursing. It also hosts the rheumatic heart disease (RHD) register and control program team. The majority of staff working in Population Health have backgrounds in nursing or allied health professions.

Perhaps atypically for an MAE placement, WACHS does not employ any epidemiologists or biostatisticians, and data analysis is not a routine part of operations for Population Health staff. When required, analytical expertise is ordinarily sought from the WACHS-wide Data & Analytics team, who

are responsible for managing WACHS databases, or from the Epidemiology Directorate or Communicable Disease Control Directorate (CDCD) within the WA Department of Health (DOH).

Field placement experience

The nature of the WACHS environment presented both opportunities and challenges for me as an MAE Scholar. While my colleagues were not able to assist or instruct me in highly technical skills in surveillance or statistical programs, my existing epidemiological skills were highly valued and this meant I was able to be involved in interesting projects with genuine operational relevance to WACHS. I developed strong skills in communicating epidemiological concepts succinctly to decision makers and colleagues. I learnt from the clinical experience and subject matter knowledge of central office colleagues, and was able to engage with health professionals on the ground for each of my major projects, which increased my appreciation for the complexities of rural, remote and Aboriginal healthcare in Australia.

For each of my major projects, I sought external advice and technical expertise to ensure that my epidemiological work was of a high standard. While this presented challenges in terms of organisation and communication, it was a good opportunity to connect with a range of stakeholders and build my understanding of the WA Health system. This included working with OzFoodNet on the outbreak competency; being guided by the Epidemiology Directorate at DOH on the quantitative element of the surveillance system competency; working in partnership with the Cardiovascular Epidemiology Research Centre at the University of Western Australia on the epidemiological study competency, and engaging with CDCD and Metropolitan Communicable Disease Control for the data analysis competency.

Overview of MAE requirements

During my field placement I conducted four major research projects to fulfil the MAE competencies. Table 1 outlines which of the following five chapters addresses each competency.

Table 1. MAE competencies addressed in each bound volume chapter

	Chapter 2	Chapter 3	Chapter 4	Chapter 5	Chapter 6
Investigate an acute public health problem or threat	✓				
Analyse a public health dataset	✓	✓	✓	✓	
Establish or evaluate a surveillance or other health information system			✓		
Design and conduct an epidemiological study				✓	
Conduct a targeted literature review	✓		✓	✓	

	Chapter 2	Chapter 3	Chapter 4	Chapter 5	Chapter 6
Prepare a report for a non-scientific audience		✓	✓		
Present at a national or international scientific conference				✓	
Prepare an advanced draft for publication in a peer-reviewed journal				✓	
Conduct a teaching session for first-year MAE scholars					✓
Prepare and conduct a Lesson From the Field for MAE peers					✓

Chapter two outlines my involvement in the investigation of two gastroenteritis outbreaks in the South West region of WA. For each of these outbreaks, I liaised with OzFoodNet to develop a case definition and characterised cases by person, place and time; analysed data on the demographics, exposures and symptoms of cases and controls; liaised with Environmental Health staff regarding specimen collection and laboratory testing, and wrote a summary report. As no stool samples were submitted in either outbreak, and no aetiology confirmed, I conducted a targeted literature review on barriers to sample provision in outbreaks. This work resulted in progression of a new information sheet on specimen collection for outbreak cases, including pictorial instructions and importantly, information on the reasons behind and value of submitting a sample.

Chapter three describes my work preparing notifiable infectious disease reports for WACHS, which included a quarterly snapshot report for the second quarter of 2023 and a longer annual report for 2022. I led the preparation of these reports, including seeking ethical approval from the Australian National University Human Research Ethics Committee and permission from data custodians, conducting descriptive analyses, selecting conditions to focus on in consultation with Central Office Public Health staff, drafting the reports, and coordinating the review, approval, and dissemination of each report. While an annual notifiable disease report has been prepared by WACHS staff since 2017, I added value to this routine work by adjusting the format of the reports to be shorter and focussed on key conditions, and creating templates to enable easy replication of the analyses for future reports. I also prepared a one-page summary of key trends for 2022 for circulation to stakeholders. In addition to the work outlined in the chapter, I also prepared the quarterly snapshot reports for the first and third quarters of 2023.

Chapter four details the work I conducted to establish a surveillance system to record family and domestic violence (FDV)-related presentations to Emergency Departments (EDs) in country WA, known as the 'FDV indicator'. This was a large project that I worked on throughout my placement,

including conducting a case-control analysis of existing ED presentations; travelling to seven WACHS EDs to consult with ED staff via focus groups; liaising with internal WACHS staff and decision-makers to ensure the system functions effectively; and preparing for the dissemination of data collected through the system to appropriate stakeholders. At the time of writing, a preliminary version of the system is in place, with the implementation of further enhancements planned for 2024. When used successfully, the system will prompt ED staff to screen for FDV, connect them with resources to improve FDV identification and response, enable an enhanced understanding of FDV trends in country WA, and inform resourcing and program decisions to reduce FDV-related morbidity and mortality. This is the first system of its kind to be implemented in Australia, and towards the end of my placement I was involved in discussions with several other health providers seeking to learn from WACHS' experience with the FDV indicator. As part of this project, I developed a lay summary of the rationale for the FDV indicator's functionality to share with internal and external stakeholders.

Chapter five presents the epidemiological study competency, comprising the results of a structured literature review on factors associated with rheumatic heart disease (RHD)-related mortality, and includes as an appendix an advanced draft manuscript detailing the results of a mixed methods study on RHD-related mortality in WA specifically. I was the Coordinating Principal Investigator on this project and worked on it throughout my placement. This involved developing a research question, study design and protocol in consultation with a wider research team; applying for ethics approval from two Human Research Ethics Committees; liaising with data owners to obtain data for two quantitative analyses; conducting nine semi-structured qualitative interviews; conducting data analysis for both quantitative and qualitative datasets; and drafting the manuscript. I also presented preliminary results from the project at the Communicable Diseases and Immunisation Conference in June 2023. The results of the study reinforce the importance of system changes to reduce RHD mortality in WA and provide useful evidence for WA policymakers.

Chapter six outlines the two epidemiology teaching sessions I delivered during my MAE candidature. These included a face-to-face tutorial on age standardisation that I delivered with two MAE peers to the cohort of first year MAE students in February 2023, and a Lesson from the Field on the benefits and process of conducting semi-structured qualitative interviews that I delivered to a group of MAE peers in January 2023.

References

1. *Health Services Act 2016 (WA)* s32–34.
2. WA Country Health Service. Annual Report 2021–2022. [Internet]. Perth: WACHS; 2023 Jan 6 [cited 2023 Sep 16]. Available from: https://www.wacountry.health.wa.gov.au/About-us/Publications/Annual-reports/WACHS-Annual-Report-2021-22.

Chapter 2: Investigation of two gastroenteritis outbreaks in Western Australia's South West

Contents

Prologue

This chapter describes my involvement in two gastroenteritis outbreak investigations, the first after an office Christmas lunch that occurred in December 2022, and the second at a residential boarding school in March 2023. This work was completed to fulfil the Master of Philosophy in Applied Epidemiology (MAE) competency to investigate an acute public health problem or threat. This chapter specifically addresses the following sub-competencies:

- Obtain preliminary information and describe data that have already been gathered;
- Develop a case definition for initiating a descriptive epidemiological study;
- Count cases, describe the outbreak by time, place, person, clinical and laboratory characteristics;
- Develop hypotheses and conduct an analytic study where appropriate; and
- Write a report and make recommendations.

My role

The Western Australia (WA) Country Health Service (WACHS) Central Office does not have responsibility for acute outbreak investigations. As a result, for the two outbreak investigations described in this chapter I worked with the OzFoodNet (OFN) team at the WA Department of Health and liaised with staff of the South West Public Health Unit (PHU). OFN is a national network responsible for the public health response to foodborne disease, and supports state-based epidemiology teams to investigate foodborne outbreaks(1). Both outbreak investigations in this chapter were initiated by OFN before I was brought into the team, including the design and dissemination of surveys. Therefore, my role in each outbreak began as survey response data was being collected.

I was responsible for cleaning and analysing data collected through the online survey tool, REDCap(2, 3). Guided by OFN staff, I developed and updated an outbreak case definition for each outbreak and conducted regular descriptive analyses of demographics, symptoms and exposures. I communicated results to OFN and other stakeholders in situation reports. I monitored the progress of environmental investigations, and prepared internal reports for OFN summarising the results of each investigation. For the school outbreak, I also monitored and cleaned data provided by school administrators, and compiled these with survey data to count cases. I liaised with PHU staff and school representatives in addition to OFN throughout this outbreak. With guidance from OFN, I conducted a case-control study to identify food exposures statistically associated with illness.

In both outbreaks, hypotheses about the cause of illness were constrained by the lack of stool and vomitus specimens provided. After the investigations concluded, I consulted existing research and PHU staff to determine barriers to specimen provision, and developed a proposal for a new patient information sheet on specimen collection for use during gastroenteritis outbreaks.

Lessons learnt

I had no experience in outbreak investigations before conducting this work, so each investigation provided a valuable learning experience that improved my field epidemiology skills. I developed subject matter knowledge of common foodborne pathogens, and refined my skills in descriptive and analytic epidemiology, including using statistics software (Stata) for analysis. I learnt about the multidisciplinary nature of an outbreak investigation team, and boosted my understanding of the role of different stakeholders. I came to appreciate the importance of regular team communication, especially following some confusion between outbreak team members as my own role was not well defined at the start of the investigation. An introductory meeting between key participants in the outbreak response would have alleviated this confusion, and I will encourage this in the future. I also learnt the value of positive relationships with representatives from affected institutions, who provided early information on the outbreak contexts, and disseminated surveys and infection prevention messages. Cooperation with representatives was successful, but the allocation of a single contact from the investigation team may have lessened confusion. Particularly, data quality could have been improved with clearer communication with the school regarding requirements for case information.

My experience in these outbreaks taught me that outbreak investigations do not always progress perfectly as per the steps recommended by the United States Centre for Disease Control(4). Real-world situations are complex and elements of a best-practice investigation may be impractical, impossible, or affected by external factors beyond the investigation team's control. As a result, a causative pathogen cannot always be identified, which makes the implementation of control and prevention measures difficult.

Public health impact

Despite not confirming a pathogen, both outbreak investigations resulted in recommendations to improve hygiene and food safety, which may reduce foodborne disease in these settings in the future. However, absence of confirmed aetiology meant that neither investigation could contribute to pathogen-specific public health knowledge, or make targeted recommendations to address the outbreak source. This work adds to existing evidence suggesting that determining disease aetiology is difficult without stool or vomitus specimens. The introduction of a new patient information sheet for WACHS PHUs aims to increase the rate of specimen collection in future gastroenteritis outbreaks.

Acknowledgements

Thanks to the OFN team for giving me the opportunity to work on these outbreaks and guiding me through the process of outbreak investigation. Particular thanks to Stacey Hong, whom I worked with on both outbreaks and reviewed a draft of this chapter. Thanks also to my supervisors for your guidance and feedback on the contents of this chapter. I acknowledge the work of the South West PHU on the on-the ground management of these outbreaks, and the work of the Environmental Health Directorate and local government environmental health officers (EHOs) on the environmental investigations.

Abstract

Background

OzFoodNet investigated two gastroenteritis outbreaks in Western Australia's South West region in December 2022 and March 2023. The first was among attendees of an office Christmas lunch and the second was among students and staff of a residential boarding school.

Methods

Demographic, food exposure, and symptom information were collected from individuals in each outbreak setting via an online survey on the RedCAP platform. A daily line list of absences was also provided by school administrators in the second outbreak. Descriptive analyses were conducted for each outbreak, and a case-control study undertaken for the school outbreak to examine relationships between food exposures and gastroenteritis. In each outbreak, environmental health officers collected food samples and kitchen swabs, which were tested for foodborne bacteria at PathWest Food Hygiene Laboratory.

Results

Attendees at the Christmas lunch consumed a range of dishes provided by a catering business, and 11 met the outbreak case definition. Illness experienced was relatively mild and short in duration, and no food exposure could be clearly linked to the gastroenteritis outcome. All environmental samples tested returned satisfactory microbiological results.

In the school outbreak, 32 cases and 37 probable cases were identified over a 14-day period. Students and staff consumed meals from the school kitchen and students shared bathroom and accommodation facilities. The case-control study identified two food vehicles statistically associated with gastroenteritis, but these were not confirmed via testing of food samples. Laboratory testing of school-produced milk detected higher than satisfactory levels of *Escherichia coli*, resulting in follow-up by the Environmental Health Directorate.

Despite requests, no stool samples were provided in either investigation.

Discussion

Both gastroenteritis outbreaks investigated were hampered by the lack of specimens provided by outbreak cases. Ultimately, no causative pathogen could be confirmed for either outbreak and control measures could not specifically address the outbreak source. Despite this, recommendations were made in both outbreaks to improve hygiene and food safety practices, which may reduce future cases of foodborne disease. Following these investigations, new information sheets on specimen provision have been proposed for country WA Public Health Units to improve specimen provision rates in future outbreaks.

Background

Foodborne gastroenteritis has a significant impact on the health and wellbeing of Australians. It is estimated that 4.67 million cases of foodborne gastroenteritis occur each year in Australia, with an associated cost of $2.1 billion, primarily from lost productivity(5). Illness transmitted through food has hundreds of possible sources, and can be prevented by improvements in food production and food service at both commercial and household levels(6).

In WA, outbreaks of suspected foodborne illness are investigated by the WA OFN within the Department of Health's Communicable Disease Control Directorate. OFN conducts these investigations in order to determine the outbreak cause, control the outbreak, and to inform public health responses(7). OFN works in partnership with local PHUs, the Environmental Health Directorate of the WA Department of Health, and PathWest Laboratory Medicine WA to recommend and implement control measures. In 2021, WA OFN investigated 21 foodborne outbreaks that caused 172 cases of illness(7).

Gastroenteritis may be caused by a range of pathogens, which have varying incubation periods, symptoms, duration and transmission routes [Table 1].

Table 1. Characteristics of common gastroenteritis-causing pathogens

Pathogen	Incubation period	Symptoms	Duration	Typical transmission route
Bacterial				
Bacillus cereus(8)	1 – 16 hours	Nausea, vomiting, abdominal cramps, watery diarrhoea	~1 day	Foodborne
Camopylobacter(9)	2 – 5 days	Fever, nausea, abdominal cramps, diarrhoea	1 – 2 weeks	Foodborne
Clostridium perfringens(10)	6 – 24 hours	Abdominal cramps, watery diarrhoea, nausea	~1 day	Foodborne
Escherichia coli(11)	2 – 10 days	Bloody diarrhoea, abdominal cramps	5 – 10 days	Foodborne
Salmonella(12)	6 – 72 hours	Headache, fever, abdominal cramps, diarrhoea, vomiting, nausea	4 – 7 days	Foodborne
Shigella(13)	1 – 3 days	Diarrhoea, fever, nausea, vomiting, abdominal cramps	~One week	Faecal-oral
Vibrio parahaemolyticus(14)	4 – 96 hours	Nausea, vomiting, abdominal cramps, diarrhoea	~3 days	Foodborne or waterborne

Pathogen	Incubation period	Symptoms	Duration	Typical transmission route
Viral				
Hepatitis A(15)	2 – 4 weeks	Abdominal pain, nausea, vomiting, fever, fatigue	Several weeks – six months	Foodborne or faecal-oral
Norovirus(16)	1 – 2 days	Fever, nausea, vomiting, abdominal cramps, diarrhoea	1 – 2 days	Foodborne, person-to-person or fomites
Rotavirus(17)	1 – 3 days	Vomiting, diarrhoea, fever	Up to one week	Person-to-person

Outbreak 1: Gastroenteritis following a Christmas lunch

Introduction

On 15 December 2022, a not-for-profit (NFP) organisation contacted the WACHS South West PHU to report that seven attendees of their office Christmas lunch the previous day had developed symptoms of gastrointestinal illness. South West PHU notified OFN, who confirmed the presence of an outbreak and commenced an outbreak investigation. The aim of the investigation was to identify the source of infection and prevent any further transmission from occurring.

The Christmas lunch, held at 12pm on 14 December, was attended by approximately 45 staff members, clients and their family members. The lunch was buffet-style, with dishes provided by an external home-based catering business.

Methods

Epidemiological investigation

Case finding was conducted via a survey containing questions on symptoms, onset time and foods eaten at the lunch, which was developed in REDCap and sent to lunch attendees via a representative of the NFP on 16 December(2,3). OFN liaised with the NFP representative to ensure lunch attendees received several reminders to complete the questionnaire. The outbreak case definition was as follows:

Case: Any lunch attendee reporting vomiting AND/OR diarrhoea with onset within 72 hours from 12pm on 14 December 2022.

A case series study was conducted to describe symptoms and exposures among all cases identified through the REDCap survey. All analysis was conducted in Stata/SE version 17(18).

Environmental investigation

Local government EHOs attended the home-based kitchen of the catering business on 20 December. EHOs collected environmental swabs from kitchen surfaces and cooking utensils, and two food samples from pre-prepared desserts used by the caterer for other events. No leftover food from the Christmas lunch was available for testing. EHOs did not collect environmental or food samples from the office where the event was held.

Laboratory investigation

Despite encouragement and reminders from OFN, no cases submitted a stool sample for testing. Environmental swabs and food samples collected from the caterer were tested at the PathWest Food Hygiene Laboratory in Perth. Aerobic plate count and *Escherichia coli* tests were conducted for all environmental swabs. The food samples were tested for aerobic plate counts, *E.coli*, Coagulase-positive staphylococci, *Clostridium perfringens*, *Bacillus cereus*, Salmonellae and *Listeria monocytogenes*.

Ethics Approval

This investigation was covered by the Australian National University (ANU) Human Research Ethics Committee umbrella approval for outbreak investigation projects (2017/909).

Results

At the lunch, guests ate a range of foods including turkey, pork, potatoes, pumpkin, carrots, peas, corn, gravy, sauces, pudding, custard, pavlova, and a range of drinks. These foods were provided by a home-based catering business. The caterer prepared the majority of foods at the office, except a roast pork that was prepared at their home kitchen and transported to the office for the lunch. In addition, a ham was purchased commercially and prepared by staff at the NFP.

Epidemiological Investigation

Of approximately 45 attendees at the Christmas lunch, 28 (62%) completed the survey. There were no reports of illness prior to the event among attendees or their household members. Of the 28 respondents, 11 (43%) met the outbreak case definition. The incubation period was short, with eight of 11 cases (73%) reporting symptom onset within 24 hours [Figure 1].

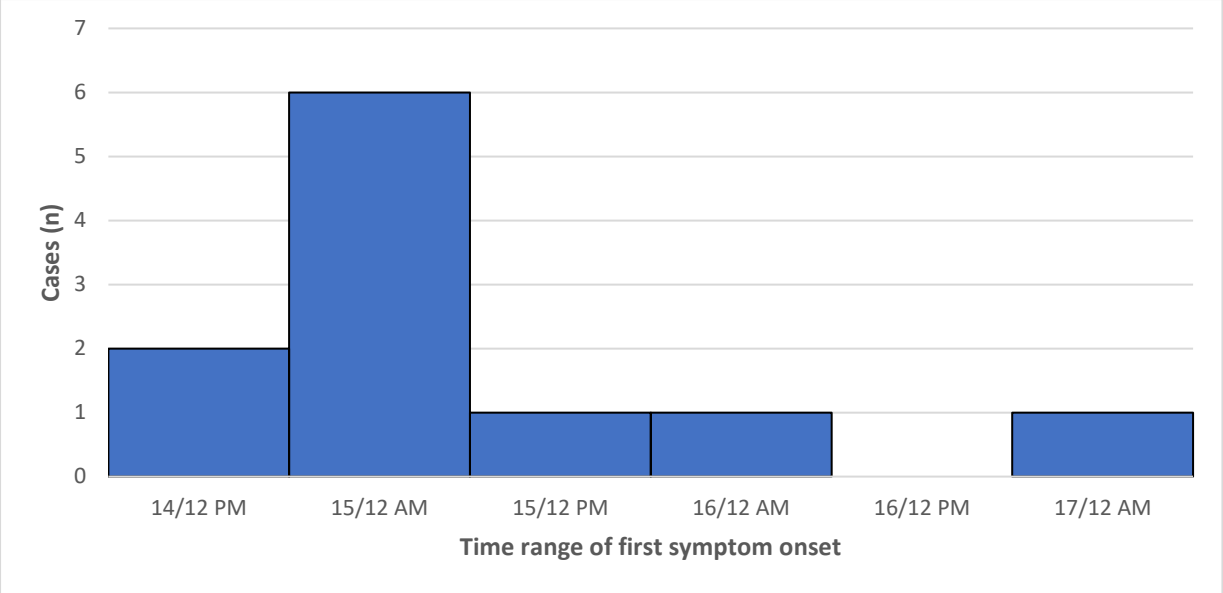

Figure 1. Symptom onset time among Christmas lunch outbreak cases, December 2022

The illness experienced was mild and relatively consistent across cases [Table 2]. All 11 reported experiencing abdominal pain, and all reported diarrhoea. Diarrhoea was short in duration, and did not extend beyond one day for any case. Nausea was reported by five of 11 cases, but none reported vomiting. One case sought medical attention from a General Practitioner (GP) but did not provide a stool sample.

Table 2. Gastroenteritis symptoms among Christmas lunch outbreak cases, December 2022

Symptom	Cases affected (%)
Any	11 (100%)
Diarrhoea	11 (100%)
Blood in diarrhoea	0 (0%)
Fever	3 (27%)
Abdominal pain	11 (100%)
Nausea	5 (45%)
Vomiting	0 (0%)
Headaches	5 (45%)
Lethargy	5 (45%)
Joint and muscle pain	2 (18%)
Other symptoms	0 (0%)

The demographic profile of respondents indicated that females were more likely to become ill. Of 23 female respondents, 10 (43%) reported illness, compared to just one of five (20%) male respondents. While the median age among cases (65 years) was older than among non-cases (57 years), their ranges were similar (25–72 years among cases and 25–79 years among non-cases).

Survey respondents ate widely from the available foods [Table 3]. Turkey, pumpkin, carrots, and peas were consumed by 11 cases (100%), corn and potatoes by 10 (91%), and pork by nine (82%). Among

non-cases, the most frequently consumed foods were pumpkin (76%), turkey and pork (71%), and carrots and pavlova (65%). Statistical comparison between cases and non-cases was deemed inappropriate given the small sample size and the high rate of exposures across both cases and non-cases. As a result, no clear relationship between illness and an individual food item could be identified.

Table 3. Exposures among Christmas lunch outbreak survey respondents, by outcome, December 2022

Food item	Cases exposed (%)	Non-cases exposed (%)
Any	11 (100%)	17 (100%)
Turkey	11 (100%)	12 (71%)
Pork	9 (82%)	12 (71%)
Ham	9 (82%)	6 (35%)
Potatoes	10 (91%)	9 (53%)
Pumpkin	11 (100%)	13 (76%)
Carrots	11 (100%)	11 (65%)
Peas	11 (100%)	10 (59%)
Corn	10 (91%)	10 (59%)
Pudding	7 (64%)	9 (53%)
Custard	7 (64%)	5 (29%)
Pavlova	6 (55%)	11 (65%)

Environmental and Laboratory Investigation

The results of microbiological testing are shown in Table 4. Low levels of *C. perfringens* and *B. cereus* were found in the carrot cake and apple pie samples. These are both toxin-producing bacteria commonly implicated in foodborne outbreaks of gastroenteritis(8,10). Coagulase-positive staphylococci are also potentially able to cause foodborne illness and were detected in low levels(19). *C. perfringens* is commonly associated with cooked meats, gravies, stews and soups, especially after periods of cooling and reheating(19). *B. cereus* is similarly associated with rice, potato, pasta, meat and vegetable dishes, and grows when food is kept outside temperature-controlled conditions(19). However, the levels of bacteria identified in this investigation lie within Food Standards Australia New Zealand's (FSANZ) satisfactory limit for pre-prepared foods of <100 colony-forming units (CFU) per gram, with no follow-up actions recommended for levels of bacteria identified in this range(19).

Table 4. Concentrations of detected organisms in samples, Christmas lunch outbreak, December 2022

Location of sample	Organisms detected	Concentration	FSANZ rating
Hand basin tap; sink tap; microwave handle; exhaust fan buttons; cupboard handle; knife handle; fridge handle; peeler	*E. coli*	<10 CFU/item	N/A
Roast pan; benchtop; cutting board	*E. coli*	<0.1 CFU/item	N/A
Carrot cake; apple pie	*E. coli* Coagulase-positive staphylococci *C. perfringens* *B. cereus*	<1 CFU/g <100 CFU/g <100 CFU/g <100 CFU/g	Satisfactory Satisfactory Satisfactory Satisfactory

Discussion

No causative organism or food vehicle was identified for this outbreak of gastroenteritis among attendees at a Christmas lunch in December 2022.

The clinical nature of the illness reported by attendees supported a hypothesis that the causative agent was a toxin-producing bacteria such as *B. cereus* or *C. perfringens*, including the short incubation time and duration of illness. As outlined in Table 1, the incubation periods of *B. cereus* and *C. perfringens* are 1–16 hours and 6–24 hours respectively(8,10), and both pathogens cause diarrhoea and abdominal cramps that typically last for 12–24 hours(19). The nature of the symptoms described in this outbreak, and the fact that similar types of food are often implicated in outbreaks caused by these pathogens are also suggestive of a toxicogenic bacterium causative agent. However, laboratory evidence could not confirm this hypothesis, as neither stool nor food specimens from the lunch were provided for testing, which was a major limitation of the investigation. The collection of food samples was complicated by the delay between the onset of illness and the attendance of EHOs to the catering business six days later, which was caused by business closure and limited EHO capacity, and resulted in a lack of available leftover food from the event. Further, EHOs were unable to attend the office itself to collect food samples, because this was under the jurisdiction of another local government and coordination between the two agencies was limited over the Christmas period. The lack of stool specimens provided, despite reminders from OFN, also hampered the investigation, and is discussed in more detail later in this chapter.

The epidemiological investigation did not produce evidence to support a particular food vehicle as the source of the outbreak. A range of foods were consumed by all cases, raising the index of suspicion for these exposures, but these were also consumed by a high proportion of non-cases. It is possible that one of these foods contained the causative pathogen, and that likelihood of illness was affected by exposure dose, immune responses of attendees, or dispersion of the pathogen throughout the dish. However, this could not be confirmed. While attendees were asked to report prior illness among themselves and their household members, the possibility of a non-foodborne pathogen such as norovirus or rotavirus was not thoroughly explored. This was a limitation of the investigation and may have resulted in additional hypotheses.

The public health response to this outbreak included the provision of standard infection prevention advice to the NFP, including exclusion of sick attendees from the workplace for 48 hours following resolution of their symptoms. Following microbiological testing, EHOs provided advice to the catering business, including a recommendation that their equipment sanitation processes be reviewed. No further cases of illness were reported after 17 December.

Outbreak 2: Gastroenteritis at a residential boarding school

Introduction

On Friday 10 March 2023, a residential boarding school contacted WACHS South West PHU to report gastroenteritis symptoms among 34 students, with onset from the previous evening. South West PHU notified OFN, who confirmed the presence of an outbreak and initiated a joint outbreak investigation. The aim of the investigation was to identify the source of infection and prevent any further transmission from occurring.

Approximately 160 students between Years 10 and 12 are enrolled at the school, including 120 boarders and 40 non-boarders. The school employs 70 teaching, administration and operational staff. The school kitchen provides meals that are available to all staff and students, but some choose to bring their own food. The school operates a teaching farm, which includes dairy and vegetable production, and rearing of cattle, sheep, pigs and chicken. Fresh produce produced by the farm is used in the school kitchen.

Boarding accommodation at the school is split by gender, with groups of 16 students from mixed year groups sharing dormitory and bathroom facilities. These facilities are not used by non-boarder students, but during the day all students use shared gender-specific bathrooms. Staff bathrooms are mostly separate but occasionally staff may use the same bathrooms as students.

Methods

Epidemiological Investigation

Case finding was conducted via a survey containing questions on symptoms, onset time and foods eaten on 8 and 9 March, which was developed in REDCap and sent via email to all students and staff by the school administration on 13 March(2,3). Case finding also involved examination of the school's daily line list of absent staff and students. School administrators were provided with a standard template to use for the outbreak line list(20). However, they did not provide information on specific symptoms, instead recording "gastro" alongside the names of those affected and the date of their first absence. The outbreak case definition was as follows:

Case: Any student or staff member of the school who reported vomiting AND/OR diarrhoea with onset from 8 March onwards via the online survey.

Probable case: Any student or staff member of the school who was recorded as absent due to gastroenteritis by the school administration from 8 March onwards, but did not report vomiting or diarrhoea via the survey.

A case-control study was conducted among survey respondents who reported vomiting and/or diarrhoea (cases) and those who did not report illness (controls). Other than inclusion in the epidemiological curve, probable cases were excluded from the analysis because there was no information available on their symptoms or exposures. The aim of the study was to determine which food items were associated with the gastroenteritis outcome. Survey respondents who reported symptoms that did not include vomiting or diarrhoea were excluded from the analysis. A descriptive analysis of demographics, symptoms and exposures was conducted, and univariate odds ratios and 95% confidence intervals were calculated for each food item in the survey. Chi squared tests were used to determine p-values, except where cell counts were <5, where Fisher's exact tests were used. A multivariate logistic regression model was used to calculate adjusted odds ratios. The first iteration of the regression model included all food exposures that had a univariate p-value of 0.3 or lower, as well as categorical variables for age and gender. Non-significant covariates were then excluded iteratively until only covariates with p-values of 0.05 or lower and potential confounders remained. Covariates were included as potential confounders if their removal from the model changed resulting odds ratios by more than 30%. A Hosmer-Lemeshow goodness of fit test was used to assess the fit of the final model.

Contact details for the case with the earliest onset, who was a staff member, were provided by the school and a follow-up telephone interview was conducted.

Environmental Investigation

EHOs attended the school kitchen on 10 March and collected a range of food samples from dishes served in the previous two days. Samples taken included pork noodles, custard, broccoli salad, spaghetti bolognese, cauliflower cheese, mixed vegetables, lamb chops, sausages, raw eggs and school-produced milk. EHOs returned to the school kitchen on 15 March to collect swabs from kitchen surfaces and equipment, and again on 16 March to collect a further sample of school-produced milk.

Laboratory Investigation

PHU staff visited the school on 10 March to deliver specimen collection kits, which included an instruction sheet, gloves, specimen container, larger plastic container, plastic ziplock bag and paper bag. These were distributed to the parents of unwell students. In addition, PHU staff spoke directly with several unwell students to emphasise the purpose and importance of stool samples to the outbreak investigation, and provided detailed instructions and demonstrations of how to collect and return a sample. A further visit and provision of additional specimen kits was conducted on 13 March, and several reminders were sent to students and parents by the school administration. Despite these efforts, no stool or vomitus samples were submitted for testing.

Food samples were delivered to the Food Hygiene Laboratory at PathWest in Perth for testing. Samples were tested for aerobic plate counts, *E. coli*, coagulase-positive staphylococci, *C. perfringens*, *B. cereus*, Salmonellae and *Listeria monocytogenes*.

Ethics Approval

This investigation was covered by the ANU Human Research Ethics Committee umbrella approval for outbreak investigation projects (2017/909).

Results

Epidemiological Investigation

Overview

Throughout the investigation, 32 cases and 37 probable cases were identified through the use of the survey and the school absence roll. The outbreak was declared over by the South West PHU on 28 March, seven days after the final case was reported by the school. Figure 2 demonstrates the incidence of cases and probable cases across the two-week outbreak period. Date of first absence was used as a proxy for symptom onset among probable cases.

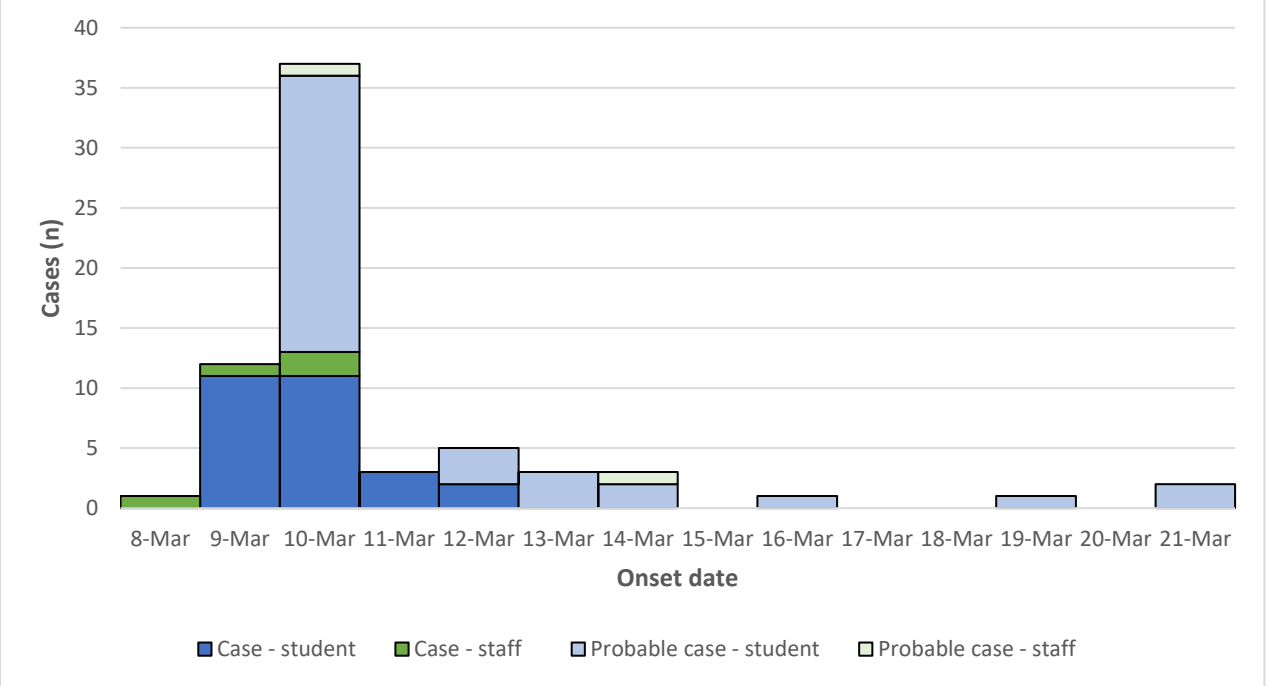

Figure 2. Symptom onset date among school outbreak cases and probable cases, March 2023

Of 102 respondents to the survey, 32 (31%) met the case definition. All cases reported symptom onset between 8 and 12 March, with the majority of these (n=25, 81%) becoming unwell between 9 and 10 March. Among probable cases identified through the school absence list, the majority were first absent on 10 March (n=24, 65%), although the true onset of their symptoms may have occurred prior to this. Between 11 March and 21 March, cases continued to occur but slowed significantly, with five

cases (16%) and 13 probable cases (35%) identified during this period. Students were overrepresented among cases and probable cases. Cumulatively, 91% of cases and probable cases were students, and 9% were staff, compared to 70% and 30% of the overall school population respectively. No illness was reported among staff involved in food handling or kitchen duties.

Case Control Study — Descriptive Analysis

Of 102 respondents to the survey, 32 were included as cases and 67 were included as controls in the case-control study. Three were excluded from analysis after reporting symptoms other than vomiting and diarrhoea. Characteristics of study participants are included in Table 5.

Table 5. Demographic characteristics of case-control study participants, school outbreak, March 2023

Characteristic	Cases (%)	Controls (%)
Total	32 (100%)	67 (100%)
Gender		
Female	14 (44%)	31 (46%)
Male	18 (56%)	36 (54%)
Age		
Median	16 years	16 years
0–19 years	28 (88%)	48 (72%)
20–39 years	0 (0%)	3 (4%)
40–59 years	4 (13%)	12 (18%)
60+ years	0 (0%)	4 (6%)
Person type		
Non-boarder student	4 (13%)	14 (21%)
Boarder student	24 (75%)	34 (51%)
Staff	4 (13%)	19 (28%)

Of 32 cases, 14 were female (44%) and 18 were male (56%), which was similar to the gender of controls (46% female, 54% male). The median age among both cases and controls was 16 years. A higher proportion of cases were students compared to controls, and a lower proportion were staff.

Table 6. Gastroenteritis symptoms among school outbreak cases, March 2023

Symptom	Cases affected (%)
Any	32 (100%)
Diarrhoea	17 (53%)
Blood in diarrhoea	1 (3%)
Fever	18 (56%)
Abdominal pain	23 (72%)
Nausea	25 (78%)
Vomiting	28 (88%)
Headaches	16 (50%)
Lethargy	20 (63%)
Joint and muscle pain	14 (44%)
Other symptoms	3 (9%)

The most common symptoms reported by cases were vomiting (88%), nausea (78%), abdominal pain (72%) and lethargy (63%) [Table 6]. Of the cases, 17 reported diarrhoea (53%), with most saying this resolved within 24 hours (47%), but four reported that diarrhoea lasted for two days (24%) and one reported blood in their stool (6%). Medical attention was sought by one case, but did not provide a stool or vomitus sample.

Liaison with school administrators confirmed that meals served in the two days before illness was reported to OFN included pancakes, pork noodles, roast chicken, cauliflower cheese, eggs and sausages, tandoori chicken, lamb chops, and a range of snacks, salads and desserts. Survey respondents were asked to answer questions about 36 food exposures. Foods consumed most frequently by cases were cheese balls (72%), pork noodles (72%), and roast chicken (63%) on Wednesday; and scones (63%) and lamb chops (53%) on Thursday. Of the cases, two reported nil food exposures through the survey, with one indicating in free text comments that they do not eat food from the school kitchen at all. Both of these cases were staff members. Among controls, common foods consumed included pork noodles (56%), cheese balls (51%), scones (51%), and tandoori chicken (45%).

Case-control study — Comparative Analysis

Table 7 outlines the analytic results of the case-control study. Of 36 food exposures, two were significantly associated with the gastroenteritis outcome in univariate analysis, braised lamb chops (unadjusted OR=2.95, 95%CI:1.12–7.84, p=0.01); and custard (unadjusted OR=4.70, 95%CI=1.23–19.48, p=0.01). Both food items were consumed on the evening of Thursday 9 March by 53% and 28% of cases respectively.

The final multivariate logistic regression model included five food exposures as covariates, after age, sex and the remaining 31 exposures were excluded iteratively due to non-significance. The relationships identified in the univariate analysis persisted, with only lamb chops (OR=5.87, 95%CI=1.22–28.34, p=0.03) and custard (OR=7.55, 95%CI=1.46–39.06, p=0.02) significantly associated with the outcome. Caesar salad, black forest cake and steamed vegetables were included as potential confounders. The high p-value (>0.5) resulting from the Hosmer-Lemeshow test demonstrated a good fit between the data and the final model.

Table 7. Exposures among school outbreak case-control participants, by outcome status, March 2023

Exposure	Cases exposed (n=32)	Controls exposed (n=67)	Univariate OR (95%CI)	Multivariate OR (95%CI)
Wednesday 8th March				
Pancakes	16 (50%)	24 (36%)	1.79 (0.70–4.59, p=0.18)	n/a
Carrot cake	14 (44%)	28 (42%)	1.08 (0.42–2.75, p=0.85)	n/a
Cheese balls	23 (72%)	34 (51%)	2.41 (0.90–6.78, p=0.06)	n/a
Pork noodles	23 (72%)	37 (56%)	2.00 (0.75–5.67, p=0.13)	n/a
Rice salad	8 (25%)	11 (16%)	1.69 (0.52–5.30, p=0.31)	n/a
Caesar salad	15 (47%)	22 (33%)	1.76 (0.68–4.56, p=0.19)	1.22(0.46–3.21, p=0.69)
Fresh fruit	10 (31%	24 (36%)	0.81 (0.29–2.16, p=0.65)	n/a
Crackers, cheese, tomato (afternoon)	12 (38%)	19 (29%)	1.48 (0.55–3.94, p=0.38)	n/a
Roast chicken	20 (63%)	27 (41%)	2.41 (0.93–6.32, p=0.04)	n/a
Gravy	16 (50%)	27 (41%)	1.44 (0.57–3.68, p=0.40)	n/a
Cauliflower cheese	13 (41%)	22 (33%)	1.40 (0.53–3.63, p=0.45)	n/a
Beans	6 (19%)	12 (18%)	1.06 (0.29–3.47, p=0.92)	n/a
Black forest cake	7 (22%)	4 (6%)	4.34 (0.98–21.69, p=0.04)	0.82(0.31–2.15, p=0.68)
Biscuits	5 (16%)	6 (9%)	1.85 (0.41–7.96, p=0.34)	n/a
Cake	4 (13%)	5 (8%)	1.74(0.32–8.74, p=0.47)	n/a
Crackers (evening)	3 (9%)	6 (9%)	1.03 (0.16–5.26, p=1.00)	n/a
Thursday 9th March				
Eggs	11 (34%)	22 (34%)	1.02(0.37–2.71, p=0.96)	n/a
Sausages	11 (34%)	16 (25%)	1.60(0.57–4.41, p=0.31)	n/a
Beans and spaghetti	7 (22%)	14 (22%)	1.02(0.31–3.13, p=0.97)	n/a
Scones	20 (63%)	33 (51%)	1.62(0.63–4.25, p=0.28)	n/a
Crackers, cheese, tomato (morning)	14 (44%)	26 (40%)	1.17(0.45–2.99, p=0.72)	n/a
Tandoori chicken	16 (50%)	29 (45%)	1.24(0.49–3.16, p=0.62)	n/a
Rice	13 (41%)	28 (43%)	0.90(0.35–2.32, p=0.82)	n/a
Cous cous salad	8 (25%)	11 (17%)	1.64(0.50–5.12, p=0.35)	n/a
Watermelon	10 (31%)	14 (22%)	1.66(0.56–4.72, p=0.30)	n/a
Rockmelon	4 (13%)	10 (15%)	0.79(0.17–3.05, p=1.00)	n/a
Fresh fruit	8 (25%)	17 (26%)	0.94(0.31–2.71, p=0.90)	n/a
Crackers, cheese, tomato (afternoon)	6 (19%)	13 (20%)	0.92(0.26–2.98, p=0.88)	n/a
Braised lamb chops	17 (53%)	18 (28%)	2.95 (1.12–7.84, p=0.01)	5.87(1.22–28.34, p=0.03)
Mashed potato	9 (28%)	21 (32%)	0.82(0.28–2.25, p=0.68)	n/a
Gravy	13 (41%)	19 (29%)	1.66(0.62–4.37,p=0.26)	n/a
Steamed vegetables	15 (47%)	21 (32%)	1.85(0.71–4.80, p=0.16)	0.29(0.05–1.60, p=0.16)
Pudding	9 (28%)	7 (11%)	3.24(0.94–11.44, p=0.03)	n/a

Exposure	Cases exposed (n=32)	Controls exposed (n=67)	Univariate OR (95%CI)	Multivariate OR (95%CI)
Custard	9 (28%)	5 (8%)	4.70(1.23–19.48, p=0.01)	7.55 (1.46–39.06, p=0.02)
Biscuits	5 (16%)	5 (8%)	2.22(0.47–10.45, p=0.23)	n/a
Cakes	4 (13%)	2 (3%)	4.50(0.59–51.57, p=0.09)	n/a

Phone Interview

A follow-up interview was conducted with the case with the earliest reported onset time on the afternoon of 8 March, who was a staff member. They ate meals from the school kitchen on 8 and 9 March. They reported collecting food from a buffet-style setup common to both staff and students, but eating separately in a staff area. They were not involved in food handling or preparation and their contact with students was limited to a formal classroom setting. Reported symptoms were very mild.

Environmental Investigation

The majority of food samples collected returned satisfactory microbiological results [Table 8], including the samples from lamb chops and custard. However, an initial sample of milk produced in the school dairy and collected from the kitchen on 10 March had a high level of *E. coli* detected, above the satisfactory limit of 1000 CFU/g for ready-to-eat foods(19). As a result, EHOs collected a further milk sample on 16 March, which again returned an unsatisfactory level of *E. coli*, and a marginal result for *B. cereus*, indicating that the process controls were compromised. Shiga-toxin producing *E.coli* were not detected in either sample of school-produced milk.

Table 8. Concentrations of detected organisms in school outbreak, by sample type, March 2023

Location of sample	Organisms detected	Concentration	FSANZ rating
Taps, cutting boards, bain marie, benches, plate, cutlery, utensils, door and equipment handles, food handler hands [all collected 15/3/23]	*E. coli*	<10 CFU/item	N/A
Pork Noodles; Custard; Broccoli salad; Spaghetti Bolognese; Cauliflower Cheese; Mixed Vegetables; Lamb Chops; Sausages; Raw Eggs [all collected 10/3/23]	*E. coli* Coagulase positive staphylococci *C. perfringens* *B. cereus*	<1 CFU/g <100 CFU/g <100 CFU/g <100 CFU/g	Satisfactory Satisfactory Satisfactory Satisfactory
School-produced milk [collected 10/3/23]	*E. coli* Coagulase-positive staphylococci *C. perfringens* *B. cereus*	18000 CFU/g <100 CFU/g <100 CFU/g <100 CFU/g	Unsatisfactory Satisfactory Satisfactory Satisfactory

Location of sample	Organisms detected	Concentration	FSANZ rating
School-produced milk [collected 16/3/23]	*E. coli*	>25000 CFU/g	Unsatisfactory
	Coagulase positive staphylococci	<100 CFU/g	Satisfactory
	C. perfringens	<100 CFU/g	Satisfactory
	B. cereus	350 CFU/g	Marginal

Discussion

The epidemiological and environmental investigations following this gastroenteritis outbreak at a residential boarding school in March 2023 failed to identify a causative pathogen, food vehicle or likely transmission route.

Some epidemiological evidence collected throughout the investigation supported a hypothesis of foodborne transmission of gastroenteritis in this outbreak. Primarily, the spike in cases and probable cases between the evening of 9 March and the morning of 10 March was suggestive of a point-source outbreak. However, while the lamb chops and custard consumed on Thursday evening were statistically associated with illness, they were consumed by a low proportion of cases (56% overall), and returned satisfactory microbiological results. Furthermore, eight of the 32 cases (25%) reported initial symptom onset before 7pm on Thursday 9 March, indicating that if infection was foodborne, their exposure occurred earlier than Thursday dinnertime. Unfortunately, the outbreak questionnaire focused on exposures on 8 and 9 March because initial information from the school was that the first cases were on Friday 10 March, with earlier cases only identified after the survey had been disseminated. Additional information on earlier food exposures, for example a seven-day food recall survey, may have aided the identification of a responsible food vehicle, but time and logistic constraints prevented this.

The continued identification of probable cases following the initial spike suggested that person-to-person transmission of gastroenteritis may have also occurred. Several early cases reported excessive vomiting via the free text section of the survey, which in the context of shared bathroom facilities and potentially poor hygiene practices among teenagers, could have resulted in transmission of a viral gastroenteritis pathogen such as norovirus or rotavirus. Possible person-to-person spread was also suggested by survey results indicating that some staff members who experienced illness do not consume food from the school kitchen. However, without the identification of a causative pathogen via a stool or vomitus specimen, a viral agent could not be confirmed, and the person-to-person transmission pathway remained hypothetical. Alternatively, the tail of cases could also be explained by ongoing exposure to a food vehicle containing the causative pathogen.

The environmental investigation identified unsatisfactorily high levels of *E. coli* in the two samples of school-produced milk, but further testing confirmed that neither sample contained shiga-toxin producing *E. coli*, the strain most commonly associated with gastroenteritis(21). Five other strains of *E.coli* may cause bacterial gastroenteritis, including enterotoxigenic, enteroaggregative, enteroinvasive and diffusely adherent *E.coli*, each of which primarily cause diarrhoea lasting a minimum of three days(22). It is possible that one of these *E. coli* strains was the causative pathogen in this outbreak, although the clinical profile of cases indicates that this was unlikely given that only 53% of cases experienced diarrhoea and this generally resolved within 24 hours. Development of gastroenteritis in this outbreak could not be linked to milk as a food vehicle because it was not included as a standalone exposure in the outbreak survey. Unfortunately, this could not be investigated via universal follow-up interviews, as contact details of cases were not readily available and no cases were diagnosed with a notifiable condition.

Despite the absence of a confirmed causative pathogen and transmission source in this outbreak, public health actions were taken to control the spread of infection. These included rigorous twice-daily cleaning of student rooms and bathrooms, and exclusion of unwell students and staff from school for 48 hours following resolution of symptoms. Additionally, while the milk could not be confirmed as a food vehicle, the microbiological results alone were enough to warrant a response. EHOs conducted further investigation of the school's approach to milk production and processing, including examining the results of a recent food safety audit. Several recommendations were made to the school to improve the milk production process, including a review of milk pasteurisation time and temperatures, submission of further milk samples to PathWest for testing, and implementation of alkaline phosphate testing for each milk batch. Follow-up with the school in April 2023 confirmed they had serviced and calibrated pasteurisation equipment, purchased new testing equipment, and ceased using school-produced milk in the kitchen until further testing could confirm satisfactory levels of *E. coli*. A further audit is planned for November 2023 to confirm that these changes resulted in improved microbiological results. These actions may result in prevention of future cases of foodborne disease at the school.

Specimen collection in gastroenteritis outbreaks

Identifying a causative pathogen is a key element of outbreak investigation and response, and is often useful in determining appropriate control measures(4). While descriptive or analytical evidence may suggest a likely pathogen, laboratory testing is required to confirm this(23). As a result, outbreak investigation guidelines routinely emphasise the importance of timely specimen collection(4,23).

Australian jurisdictional guidance on gastroenteritis outbreaks consistently includes stool specimen collection as an early step, with some outlining numerical targets for this(24-28).

The identification of a causative pathogen in both outbreak investigations described in this chapter was significantly limited by the lack of stool or vomitus specimens provided by cases. Without a laboratory diagnosis, discussion of causation in both outbreaks remained hypothetical, and control measures could not specifically address the outbreak source. In addition, this constrained the ability of the investigations to contribute to pathogen-specific public health and epidemiological knowledge. In either outbreak, identification of a pathogen in even one stool or vomitus specimen may have enabled greater certainty in the investigation and guided a more thorough response.

Discussion with South West PHU staff indicated that difficulty obtaining stool specimens is a common problem in gastroenteritis outbreaks. Similarly, research studies from Australia and the United States have reported that a large proportion of outbreaks with unknown aetiology had no stool specimens collected(29,30). Annual OFN reports from New South Wales indicate challenges collecting specimens may be increasing, with just 19% of institutional gastroenteritis outbreaks having a stool sample collected in 2020(31) compared to 28% in 2019(32) and 33% in 2018(33), although this decrease may also be attributable to COVID-related constraints in 2020.

PHU staff hypothesised that outbreak cases may be unwilling to provide a stool or vomitus sample because they find the process of collecting the sample unappealing; because they may find it logistically difficult to collect and/or return the sample to a collection centre; or because they are not experiencing severe symptoms and therefore perceive it to be unnecessary. These barriers align with the results of a survey of American public health professionals, which reported that transport, storage, staff capacity, patient embarrassment, inconvenience, and patients not understanding the reason for or value of providing a sample were reasons for limited stool sample provision in gastroenteritis outbreaks(34). Research in non-outbreak settings reports similar patient-level barriers to providing stool specimens, and suggests that individuals may be motivated to provide a sample if they understand the benefit of doing so, whether this applies to their own clinical care or to others'(35,36). Research on stool and/or vomitus specimen provision in Australian outbreak settings, specifically examining the attitudes of cases, is currently lacking and would add important knowledge to this area.

In each of the outbreaks described in this chapter, OFN and PHU staff stressed the importance and purpose of stool specimen provision in initial communication to the institution's contact person. For the Christmas lunch outbreak, this would have required cases to have an appointment with a GP and inform them that a stool specimen had been requested. The requirement to actively visit a health service may have acted as a barrier, especially as this occurred in the busy Christmas period and cases

experienced only mild symptoms. Previous research has found that providing stool specimen kits, rather than requiring cases to actively seek healthcare, significantly increased provision of stool specimens in gastroenteritis outbreaks(37). However, the provision of specimen kits to cases in the school outbreak did not result in any specimens being collected. Additional efforts by PHU staff, including face-to-face discussions and demonstrations, also failed to prompt any specimen provision. Staff suggested that disgust was likely a strong motivator against providing a sample in this instance, and that reluctance to provide a sample was likely affected by the age of cases, who were predominately teenagers. This corresponds with previous research reporting that willingness to submit a stool sample was associated with increasing age(38).

Despite findings from international research and anecdotal evidence suggesting the difficulty of obtaining stool samples is common across Australia, existing government documents provide no guidance on how to encourage stool specimen provision during outbreaks. Queensland's guidelines contain a public fact sheet for how specimens are to be collected(26), but do not extend to how to approach this conversation with cases or overcome embarrassment and other barriers. WACHS PHUs also provide information sheets to outbreak cases, with practical guidance on how to collect a stool specimen. These text-based information sheets do not include pictures, or information on why stool specimens are useful in outbreak investigations. However, Australian research on bowel cancer screening has indicated that the use of simple pictorial instructions regarding stool sample collection is preferred to text-heavy instructions(39). While most resources focus on the collection of stool specimens, vomitus specimens can also provide useful information in gastroenteritis outbreaks, and may be easier and more palatable to collect than stool specimens.

Following the conclusion of the two outbreak investigations described in this chapter, a proposal for the development of a new WACHS patient information sheet on specimen provision during gastroenteritis outbreaks was progressed and approved. The information sheet will include concise and simple messaging about the purpose and value of specimen provision, alongside text and pictorial instructions and details of local pathology collection centres. The intent behind these changes is to reduce barriers by providing clear reasons for cases to submit specimens, including for their own health and to protect others, and by normalising and simplifying specimen collection through the use of visual instructions. At the time of writing, the proposed information sheet was with WACHS graphic designers for finalisation. Once completed, the information sheet will be provided to regional PHUs for dissemination to outbreak cases alongside PathWest specimen collection kits. The introduction of this information sheet is intended to improve the rate of stool and vomitus specimen collection in future gastroenteritis outbreaks, thereby aiding in the identification of causative pathogens.

Conclusion

Both of the gastroenteritis outbreaks described in this chapter were hampered by the lack of specimens provided by cases, ultimately resulting in no causative pathogen being identified in either outbreak. In the Christmas lunch outbreak, while descriptive epidemiological evidence indicated likely foodborne transmission and a toxin-mediated bacterial pathogen, this could not be confirmed via laboratory evidence. In the school outbreak, epidemiological evidence suggested possible foodborne and/or person-to-person transmission, but this could not be determined without a confirmed food vehicle or causative pathogen. Although it could not be implicated as the source of this outbreak, the identification of unsatisfactory levels of *E. coli* and *B. cereus* in the school-produced milk prompted an environmental health response and led to improved food production practices at the school. While the failure to identify causative pathogens in these two outbreaks limited the immediate public health actions taken in response, standard infection prevention guidance was provided, and both outbreaks resolved within two weeks.

While the identification of a disease aetiology is central to outbreak investigation guidelines, these two investigations demonstrate that public health actions to improve hygiene and food safety remain possible without a causative pathogen. Targeted actions to address the specific causes of each outbreak were limited, but the actions taken as a result of each investigation were valuable and may prevent foodborne disease transmission in the future. Further, changes to WACHS patient information on specimen collection have been recommended to improve specimen provision in future gastroenteritis outbreaks.

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Chapter 3: Preparation of country Western Australia notifiable disease reports, 2022–2023

Contents

Prologue

I prepared the two reports described in this chapter for the Western Australia (WA) Country Health Service (WACHS), *Notifiable Disease in Country Western Australia 2022* and *WACHS Notifiable Disease Quarterly Update – Quarter 2 2023* between May and September 2023. This work was completed to fulfil the Master of Philosophy in Applied Epidemiology (MAE) core competency to analyse a public health dataset, and the minor competency to prepare a summary report for a non-scientific audience.

My role

I had primary responsibility for preparing the two reports, which included managing data extracts, data cleaning, descriptive analysis, preparation of tables and figures, writing and formatting the reports. Based on a need identified by WACHS executive for more timely reporting, quarterly snapshot reports were prepared for the first time in 2023, and the quarter two (Q2) report was the second in this series. While the annual report was part of standard reporting, I updated the structure for the 2022 report to focus on key conditions to inform action.

I prepared and submitted an ethics application to the Australian National University (ANU) Human Research Ethics Committee, and submitted data requests to WA Health data custodians. On advice from the WA Department of Health's Epidemiology Directorate, I calculated 2022 population estimates for country WA. I consulted previous WACHS and Metropolitan Communicable Disease Control (MCDC) reports to plan methodology and content.

For both reports, I extracted and cleaned notification data from the WA Notifiable Infectious Diseases Database (WANIDD), and compiled this in Excel with additional notification, immunisation and population data. I conducted a descriptive analysis for each notifiable condition, including calculation of notification rates, and selected key conditions for focus in consultation with the WACHS Central Office Public Health team. For the Q2 report, I compared disease counts and rates with the previous quarter. For the 2022 annual report, I compared notifications by calculating notification rate ratios compared to the 2021 period, the 2017–2021 average, and the state and national rates for 2022. I drafted and compiled each report, and incorporated feedback from the Public Health team and Public Health Physicians. I progressed the annual report to WACHS' Executive Director of Clinical Excellence for review and approval and prepared a one-page summary for circulation to external stakeholders [Appendix 3].

I also developed two Excel templates with instructions so that public health staff can easily replicate the descriptive analyses for future quarterly and annual reports. These templates were based on an initial version made by Dr Ashish Yadav, a WACHS public health registrar who prepared the 2021 annual report.

Lessons learnt

My experience preparing these notifiable disease reports was a great opportunity to develop a broad level of subject matter knowledge on notifiable disease patterns in WA, especially regarding current priorities and conditions of interest. It also enabled me to develop a greater understanding of the role of WACHS Public Health Units (PHUs) in responding to public health issues.

Engaging with stakeholders to prepare the reports enhanced my understanding of the public health landscape in WA. To obtain data, I engaged with staff from the Communicable Disease Control Directorate (CDCD), including Immunisation, Sexual Health, COVID-19, Surveillance and Disease Control, and OzFoodNet teams, as well as the rheumatic heart disease (RHD) Control Program team at WACHS, and the Epidemiology Directorate at the Department of Health. I liaised with WACHS's Central Office Public Health team and five regional Public Health Physicians on the content of the reports, and also sought advice from staff at MCDC. It was valuable to have the opportunity to connect with so many stakeholders and rewarding to have brought together their input.

My experience working on these reports also taught me an important lesson about the difference between epidemiology in theory and in practice. From my exposure to epidemiological scholarship so far, I am aware of a perception that Microsoft Excel is too laborious and unreliable for best-practice epidemiology. However, Excel was the preferred tool for this project because it enabled the results to be used and interrogated by other WACHS public health staff, including replication for future reports. While it would have likely been much faster for me to conduct the analyses in a statistics program, I was not conducting this work in a private research capacity, but in a real-world office environment as part of an operational team. My development of a template for use in the future aims to minimise Excel's shortcomings, including by producing calculations and figures automatically and ensuring a consistent methodology.

Public health impact

The preparation of the notifiable disease reports described in this chapter form part of WACHS' routine reporting on notifiable disease. The reports disseminate key messages about notifiable disease activity and trends, and aim to support decision-making around public health resourcing and programs. The addition of quarterly reports in 2023 has added value by providing more timely summary information on notifiable diseases in an accessible and convenient format for regional stakeholders. For the annual report, I updated the structure to focus on key diseases in more detail than previous reports, increasing its relevance and utility. To aid in descriptive analysis of notification data in the future, I developed Excel templates that can be used for both the quarterly and annual reports. The templates will reduce the workload required for future reports, allowing public health staff to focus on data interpretation and explanation.

Acknowledgements

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Abstract

Background

Dissemination of notifiable infectious disease data is an important part of public health management in country Western Australia. This information is used by public health stakeholders to guide decision-making, including resource allocation to reduce disease transmission. WA Country Health Service staff have prepared annual reports since 2017 to describe disease distribution by region and demographic characteristics. In 2023, quarterly reports were introduced to provide timely snapshots of notification counts and highlight key diseases. This chapter describes the preparation of the annual report *Notifiable Disease in Country Western Australia 2022* and the *WACHS Notifiable Disease Quarterly Update* for the second quarter (Q2) of 2023.

Methods

For both reports, notification data were extracted from the WA Notifiable Infectious Disease Database in July 2023, and descriptive analyses conducted. Notification counts and rates were compared with previous periods and state and national data. Key conditions of interest were identified based on contextual information, and described by age, sex, Aboriginal status, vaccination status and place of acquisition as relevant. Analysis was conducted in Microsoft Excel.

Results

There were 226,257 infectious disease notifications in 2022, including 213,498 COVID-19 notifications and 12,759 non-COVID notifications. The non-COVID notification rate of 2,399.7 notifications per 100,000 persons was an 80% increase on the notification rate in 2021, largely driven by increases in influenza and respiratory syncytial virus notifications, after an unusually low transmission year in 2021. There were 10,627 infectious disease notifications in the second quarter of 2023, including 5,952 COVID-19 notifications and 4,675 non-COVID notifications. Non-COVID notifications increased by 79% compared to the previous quarter, again largely driven by increases in seasonal respiratory viruses.

Discussion

The 2022 annual and 2023 Q2 notifiable disease reports were distributed to WA Health stakeholders between August and October 2023 and were well-received. Improvements could be considered to increase the impact of future reports, including the incorporation of additional testing data and wider publication of the annual report. However, changes made to reporting practices, including the addition of quarterly reports, and the shift to a shorter and more focused annual report, have improved the utility of the reports for their intended audiences.

Background

The notification of cases of infectious disease to a government authority is a cornerstone of public health activity in Australia and globally. Analysis of notifiable infectious disease data allows responsible agencies to track disease trends, informs outbreak response, guides policy on necessary public health interventions, and enables resources to be allocated efficiently to areas of highest need, both in the short and long term(1). In Australia, populations at higher risk of infectious disease include those living in rural and remote areas, and Aboriginal and Torres Strait Islander people(2). Other groups at risk include children and people aged over 65, who experience higher relative disease burden from infectious diseases compared to other age groups(3), and pregnant people, who are at higher risk of complications from vaccine-preventable diseases(4). People living in rural and remote areas experience disadvantage in employment, income and education compared to their metropolitan counterparts, which places them at higher risk of poor health outcomes, compounded by challenges accessing healthcare services(5, 6). Aboriginal and Torres Strait Islander people living in rural and remote areas face additional challenges that increase their risk of infectious disease, including high rates of household crowding, and culturally-specific barriers to accessing health services (7, 8). Examining notifiable disease trends among these populations is necessary to inform appropriate interventions and reduce disease occurrence.

There are 81 notifiable infectious diseases and related conditions in WA, including 70 that are nationally notifiable and an additional 11 that are notifiable in WA(9). As per WA's *Public Health Act 2016*, any medical practitioner, nurse practitioner or responsible pathologist who identifies a patient with a notifiable disease must notify this to the WA Chief Health Officer(10). Most notifications are recorded in WANIDD, a database managed by CDCD. This excludes COVID-19 notifications, which are recorded in the Public Health Operations COVID-19 Unified System (PHOCUS), also managed by CDCD, and acute rheumatic fever (ARF) and RHD notifications, which are recorded in the WA RHD Register and managed by the RHD Control Program at WACHS Central Office.

Data on notifiable diseases in WA are available from a range of sources. In August 2023, CDCD introduced a new online notifiable infectious disease dashboard, which provides a statewide overview of disease data(11). The dashboard extends on previously available information on notification counts and rates over time, to include notification patterns by Aboriginal status, age, sex, and region, and is filterable by disease and calendar year. It is automatically updated regularly with WANIDD data.

In addition to this online database, weekly surveillance reports on COVID-19 and other notifiable diseases are prepared by CDCD and published on the WA Health website(12, 13). The general notifiable disease weekly report provides statewide counts of infectious disease notifications by week,

comparison with previous periods, and a regional breakdown of notifications. The COVID-specific weekly report includes an in-depth analysis of statewide notification trends, and also provides information on reinfections, hospitalisations, deaths and testing. Detailed reports are also available on a quarterly and annual basis for sexually-transmissible diseases and blood-borne viruses(14), enteric infections(15) and healthcare-associated infections(16) across WA.

While statewide notifiable disease reporting includes regional counts, country-WA-specific reporting is needed to investigate notification data in detail, given that contextual factors are likely to result in distinct patterns in regional areas. Sex, age and Aboriginal status variables are analysed at a statewide level in the aforementioned sources, masking potential differences between metropolitan and regional WA.

Since 2017, WACHS has prepared an annual report, *Notifiable Diseases in Country Western Australia*, to address this gap. The report provides detailed information on notifiable diseases data in country WA, including describing the distribution of notifications by age, sex, and Aboriginal status; comparing notification rates in country WA to state and national rates; and describing the role of regional PHUs in responding to infectious diseases of concern. It also includes information on notifications not generally included in statewide reporting, such as Human Immunodeficiency Virus (HIV), ARF, and RHD, and describes country WA immunisation coverage under the early childhood and school-based immunisation programs. Given the incorporation of multiple datasets and the time taken to prepare the report, it is usually disseminated in the second half of the subsequent calendar year.

Rather than informing immediate responses to infectious disease outbreaks and notifications, the annual WACHS report aims to provide a longer-term view of important notifiable disease trends in country WA, in order to inform health service planning and delivery, and to summarise key PHU activity. The report is targeted at WACHS personnel, who can access it via the WACHS intranet, and is also distributed to WA Health stakeholders including the Chief Executives of five of the WA Health Service Providers and the Director of CDCD.

In 2022, WACHS executives identified a need to produce a quarterly notifiable disease report for regional PHUs and other health stakeholders, in addition to the more in-depth annual report. The preparation of quarterly reports by WACHS Population Health was planned for 2023, with the intent that these reports would provide more timely information on notifiable disease activity and PHU responses.

This chapter describes the preparation of the *Notifiable Diseases in Country Western Australia* 2022 annual report, and the *WACHS Notifiable Disease Quarterly Update* for Quarter 2 (April – June) 2023.

Methods

Data sources

Notification data

A line list of infectious disease notifications in 2022 was extracted from WANIDD on 31 July 2023. A line list of infectious disease notifications in the second quarter of 2023 was extracted from WANIDD on 24 July 2023.

For both reports, the majority of notifications were selected if they had an optimal date of onset (ODOO) within the reporting period (1 January 2022 – 31 December 2022 for the annual report and 1 April 2023 – 30 June 2023 for the quarterly report). For some diseases with a typically long delay between onset and notification, notifications were selected if the date of receipt (DOR) was within the reporting period, in line with existing national and CDCD methodology(17, 18). These included non-infectious syphilis, tuberculosis, leprosy, Creutzfeldt-Jakob disease, hepatitis B (unspecified) and hepatitis C (unspecified).

For both reports, notifications among residents of Christmas Island and Yongah Hill Immigration Detention Centres were excluded, in line with existing WACHS reporting processes, as were notifications among people who had a residential address outside of country WA.

Aggregate HIV notification data for 2022 were provided by CDCD in July 2023. HIV notifications were grouped into southern (Great Southern, Midwest, South West, Wheatbelt) and northern/remote regions (Goldfields, Kimberley, Pilbara) to protect confidentiality. HIV notifications were not included for analysis in the Q2 2023 report due to small numbers. Aggregate ARF and RHD notification data for 2022 and Q2 2023 were provided by the WA RHD Control Program team in July 2023. COVID-19 notification data were extracted from PHOCUS and provided by CDCD in a line list in July 2023.

Population data

Appropriate 2022 Australian Bureau of Statistics population figures were not available at the time these reports were prepared. Therefore, an estimated 2022 population for country WA was forecasted based on population estimates from 2017–2021. Estimates were stratified by 5-year age group, sex, region and Aboriginal status. The population estimates for 2017–2021 were provided by the WA Department of Health Epidemiology Directorate in July 2023. Forecast functions were calculated for each population stratum in Microsoft Excel, and summed to estimate totals.

Immunisation data

Immunisation coverage data were provided by CDCD in July 2023. These data are sourced from the Australian Immunisation Register (AIR), which records all vaccines administered under the National

Immunisation Program, school programs and privately in Australia. Coverage data were provided in aggregate and were unlinked to line-listed notification data.

Data analysis

Variables

Notification data in WANIDD were entered by CDCD and PHU staff following notification by either a medical or nurse practitioner, or a responsible pathologist. Table 1 presents the variables extracted from WANIDD for analysis of notification data.

Table 1. Variables extracted from WANIDD for each notification in the reporting period, 2022–2023

Variable	Type	Definition	Values
Optimal date of onset	Date	Either date of onset provided by notifying practitioner; or date of specimen collection for laboratory identified cases; or if neither of these is available, date of notification. Used to filter the majority of notifications.	01/01/2022 – 31/12/2022 (annual report); 01/04/2023 – 30/06/2023 (Q2 2023 report)
Date of receipt	Date	Date the notification was received by CDCD, used to filter select diseases as above.	01/01/2022 – 31/12/2022 (annual report); 01/04/2023 – 30/06/2023 (Q2 2023 report)
Region	Categorical	WACHS region in which the case was a resident at the time of notification	Goldfields; Great Southern; Kimberley; Midwest; Pilbara; South West; Wheatbelt
Sex	Categorical	Sex of case	Male; female; indeterminate; unknown
Age group	Categorical	Case's age at disease onset	Five-year age groups from 0–4, 5–9 etc.
Ethnicity	Categorical	Indigenous status of case	Aboriginal (includes underlying values of Aboriginal; Torres Strait Islander; Aboriginal and Torres Strait Islander); Non-Aboriginal (includes underlying values of non-indigenous and unknown)
Disease	Categorical	Disease for which the notification was made	Numeric codes assigned to 81 notifiable conditions
Infection acquired	Categorical	Place where the notifiable condition was acquired	WA; interstate; overseas; unknown
Serogroup/type	Categorical	Serogroup, type or strain information of organism causing disease	Drop-down list specific to each disease
Vaccination status	Categorical	Vaccination status of the case for the notified condition, available only for vaccine preventable disease notifications	Fully vaccinated; partially vaccinated; not vaccinated; not applicable; unknown

Line list data on notifications of COVID-19 included region, sex, ethnicity, age group, and date of receipt, with definitions as per Table 1. This dataset also included information on test type, a categorical variable with two possible values of 'Antigen Detection' (RAT) and 'Nucleic acid testing' (PCR). Aggregate data on ARF and RHD notifications included region, age group, and ethnicity with definitions as per Table 1.

Statistical analysis

A simple descriptive analysis was conducted for notifications of each infectious disease and related condition, in country WA overall and then stratified by region. A crude notification rate was calculated for each disease by dividing the number of notifications by the relevant population estimate and multiplying by 100,000. Notification counts and rates were compared to the previous reporting period by calculating percentage increases. For the annual report, a historical mean of both notification counts and rates between 2017 and 2021 was calculated based on the data provided in previous reports. Crude rate ratios (RRs) were calculated to compare the 2022 country WA notification rate with the 2017–21 mean rate, 2022 state and 2022 national rates, by dividing the 2022 rate by each relevant comparison rate.

For both quarterly and annual reports, several conditions were selected for further descriptive analysis, based on notable changes in the notification rate; organisational priorities; or contextual factors including public health importance, or national and global trends. This included calculation of disease counts and proportions by time, age, sex, Aboriginal status, place of acquisition, serogroup/type, and/or vaccination status, depending on the relevant disease and factors of interest. Where relevant, crude notification rates and RRs were calculated by age, sex, region and Aboriginal status, or combinations of these strata. Tables and figures were developed to highlight key trends and provide summaries of notification characteristics.

Analyses were conducted in Microsoft Excel. Quality assurance checks were built into the analysis spreadsheet to ensure accurate calculations, for example by using conditional formatting to highlight cells with incongruous values. Template spreadsheets and step-by-step instructions were developed to facilitate consistent and efficient data analysis for future reports. In the future, the spreadsheets will automatically generate disease counts, rates and figures when notification data and population data are inputted in the instructed format.

Ethical Considerations

Approval for the use of notification and immunisation data for this project was sought and obtained from each of the relevant data custodians. The project was granted ethics approval by the ANU Human Research Ethics Committee in June 2023 (2023/294).

Results

WACHS Notifiable Disease Quarterly Update, Quarter 2 2023

Summary

A copy of the *WACHS Notifiable Disease Quarterly Update* for Quarter 2 2023 is available in Appendix 1. There were 10,627 infectious disease notifications during the reporting period, including 5,952 COVID-19 notifications and 4,675 non-COVID notifications. Non-COVID notifications increased by 79% compared to the first quarter of 2023 (n=2,607). Diseases highlighted in the report included: syphilis; Murray Valley encephalitis; legionellosis; COVID-19, influenza and respiratory syncytial virus (RSV).

Data Completeness

All variables analysed for the Q2 report had completeness of 95% or higher [Table 2]. Only two key variables, sex and ethnicity, had completeness less than 100%. For the sex variable, all missing values were from COVID-19 notifications, and no sex metrics were included for COVID notifications in the report. Both COVID and non-COVID notifications had missing values for ethnicity, although this was more pronounced for COVID notifications (4.6% compared to 3.2%).

Table 2. Completeness of key variables analysed for report, Q2 2023

Variable	Total relevant notifications	Relevant notifications with analysable value (%)	Relevant notifications with unknown or blank value (%)
Optimal date of onset	4,675 (all non-COVID notifications)	4,675 (100%)	0 (0%)
Date of receipt	10,627 (all notifications)	10,627 (100%)	0 (0%)
Region		10,627 (100%)	0 (0%)
Sex		10,495 (98.8%)	132 (1.2%)
Age group		10,627 (100%)	0 (0%)
Ethnicity		10,201 (96.0%)	426 (4.0%)
Disease		10,627 (100%)	0 (0%)
Test Type	5,952 (all COVID notifications)	5,952 (100%)	0 (0%)

Notifiable Diseases in Country Western Australia 2022

Summary and Key Trends

Appendix 2 presents an extract of the full *Notifiable Diseases in Country Western Australia 2022* report, as examples of the work conducted for this report. It includes the in-focus sections of the report related to COVID-19, influenza and invasive Group A streptococcal disease (iGAS), and the full section on sexually transmissible infections. Other conditions highlighted in the report included Japanese encephalitis, RSV, tuberculosis, ARF and RHD. The report also included a summary of early childhood and school-based immunisation coverage.

There were 226,257 infectious disease notifications during the reporting period, including 213,498 COVID-19 notifications and 12,759 notifications of non-COVID infectious disease. Non-COVID notifications increased by 81% compared to 2021 (n=7,039), largely driven by increases in influenza and RSV. Compared to the 2017-21 average, notifications in the 'vaccine-preventable' and 'other' categories rose markedly [Figure 1], again due to notifications of influenza, which increased following COVID-related decreases in previous years, and RSV, which became notifiable in 2021. Sexually transmitted and enteric infections saw moderate rises, while blood-borne, vector-borne and zoonotic conditions all decreased compared to 2017-2021.

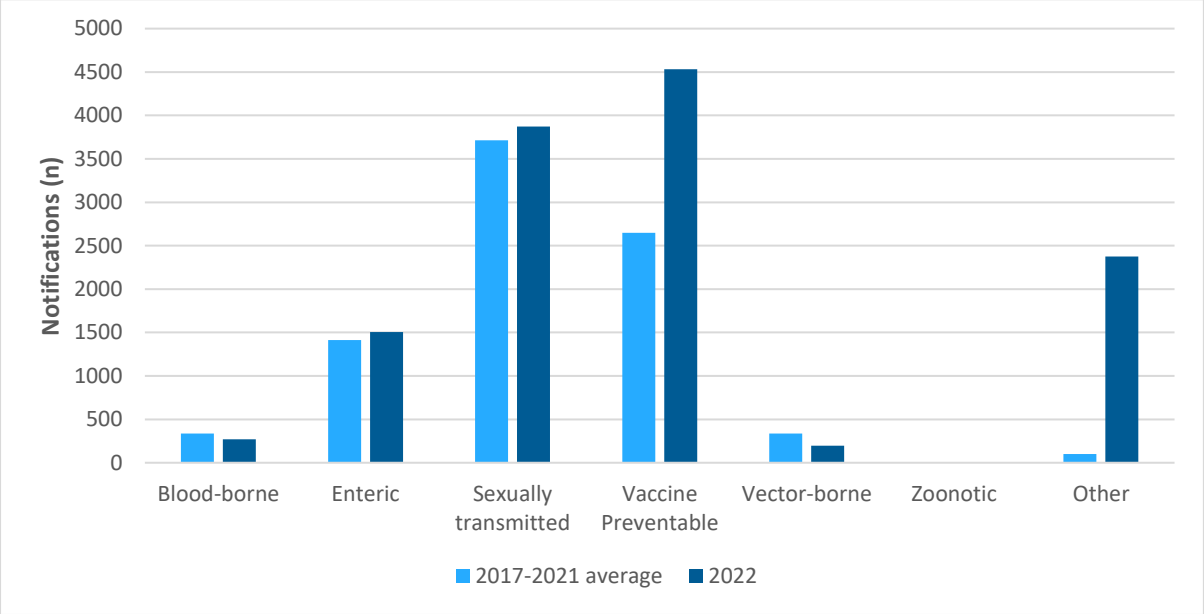

Figure 1. Notifications in country WA excluding COVID-19, 2022 compared to 2017-21 average, by category

The 81% increase in non-COVID disease notifications between 2021 and 2022 in country WA was consistent with, although smaller than, the 148% rise observed nationally (from 234,460 notifications in 2021 to 582,227 in 2022)(1). In both cases, influenza and RSV drove the overall increase in notifications, accounting for 97% of the increase in country WA (5,462 additional cases in 2022 compared to 2021) and 94% of the increase nationally (326,852 additional cases). Overall, country WA had a higher notification rate in 2022 (2,399.7/100,000 people) compared to the national notification rate (2,238.9/100,000), despite substantially higher influenza notifications nationally (897.4/100,000 compared to 637.4/100,000 in country WA). Notification rates were notably higher in country WA compared to nationally for iGAS (RR=3.56), shigellosis (RR=3.31), infectious syphilis (RR=2.26), invasive pneumococcal disease (RR=2.62), shingles (RR=3.70), Barmah Forest virus (RR=2.77), and Ross River virus (RR=2.68). Table 3 provides an overview of notifications in country WA in 2022, including comparison with historical, state and national notification rates.

Table 3. Summary of disease notifications in country WA, 2022, compared to 2017-21 average, 2022 state, and 2022 national notification rates

	Notifications (n)		Notification rate/100,000 population				
Notifiable disease	WACHS 2022	WACHS 2017-21 average	WACHS 2022	WACHS 2017-21 average	WACHS 2022: 2017-21 rate ratio	State 2022	National 2022
Blood borne viruses							
Hepatitis B	67	82	12.6	15.3	0.82	16.0	19.5
Hepatitis C	203	258	38.2	47.9	0.80	30.2	26.1
Enteric diseases							
Campylobacteriosis	886	666	166.6	123.6	1.35	152.4	162.5
Cryptosporidiosis	83	77	15.6	14.3	1.09	10.4	7.9
Hepatitis A	2	1	0.4	0.2	2.06	0.5	0.5
Salmonellosis	254	413	47.8	76.2	0.63	36.2	39.7
Shigellosis	95	114	17.9	21.1	0.85	7.3	5.4
Shiga-toxin producing *E.coli*	97	22	18.2	4.06	4.49	8.4	3.23
Yersiniosis	5	2	0.9	0.4	2.51	~	N/A
Sexually transmissible diseases							
Chlamydia	2371	2355	445.9	436.7	1.02	416.7	362.3
Gonorrhoea	1124	1104	211.4	204.7	1.03	124.5	127.6
Syphilis (congenital)	3	1	0.6	0.3	1.79	0.1	0.1
Syphilis (infectious)	285	208	53.6	39.0	1.37	30.3	23.7
Syphilis (non-infectious)	91	45	17.1	8.5	2.02	~	10.1
Vaccine preventable diseases							
Influenza	3389	1510	637.4	281.0	2.27	528.7	897.4
Measles	0	2	0.0	0.4	0.00	0.0	0.0
Meningococcal disease (invasive)	5	10	0.9	1.8	0.52	0.7	0.5
Mumps	1	5	0.2	0.9	0.22	0.0	0.2
Pertussis	11	199	2.1	36.2	0.06	1.2	1.8
Pneumococcal disease (invasive)	99	85	18.6	15.9	1.17	8.7	7.1
Rotavirus	81	112	15.2	20.7	0.74	14.0	24.8
Rubella	0	0	0.0	0.0	0.00	0.0	0.0
Tetanus	0	0	0.0	0.0	1.00	0.0	0.0
Varicella (chickenpox)	99	162	18.6	29.9	0.62	16.4	7.0
Varicella (shingles)	787	668	148.0	124.3	1.19	90.8	40.0
Varicella (unspecified)	144	38	27.1	7.1	3.82	95.1	70.5
Vector-borne diseases							
Murray Valley encephalitis	1	0	0.2	0.0	5.33	0.0	0.0
Japanese encephalitis	0	0	0.0	0.0	1.00	0.0	0.2
Barmah Forest virus	19	22	3.6	4.1	0.88	1.0	1.3
Chikungunya virus	2	2	0.4	0.3	1.28	0.4	0.2
Dengue virus	5	19	0.9	3.6	0.26	2.7	2.1
Malaria	2	4	0.4	0.8	0.49	1.5	0.8

	Notifications (n)		Notification rate/100,000 population				
Notifiable disease	WACHS 2022	WACHS 2017-21 average	WACHS 2022	WACHS 2017-21 average	WACHS 2022: 2017-21 rate ratio	State 2022	National 2022
Rickettsial disease (typhus)	11	10	2.1	1.8	1.14	0.7	N/A
Ross River virus	158	278	29.7	50.9	0.58	16.7	11.1
Zoonotic diseases							
Leptospirosis	2	2	0.4	0.3	1.27	0.1	0.8
Q Fever	2	4	0.4	0.7	0.51	0.2	1.8
Other diseases							
Creutzfeldt-Jakob disease	1	2	0.2	0.3	0.64	0.2	N/A
Legionellosis	13	13	2.5	2.4	1.02	2.4	2.6
Melioidosis	4	4	0.8	0.7	1.13	0.2	.
Tuberculosis	13	12	2.5	2.2	1.11	3.7	5.0
Invasive Group A streptococcus	85	N/A	16.0	N/A	-	7.8	4.5
Acute post-streptococcal glomerulonephritis	11	9	2.1	1.8	1.19	0.5	N/A
Respiratory syncytial virus	2242	N/A	421.7	N/A	-	267.7	368.3

As described in Appendix 2, notification rates for influenza, iGAS, chlamydia, gonorrhoea and syphilis were higher among Aboriginal than non-Aboriginal people in country WA. The disparity was particularly high for infectious syphilis, with the notification rate among Aboriginal people 63.2 times as high as the rate among non-Aboriginal people.

Data Completeness

Across the key variables analysed for the 2022 annual report, data completeness was relatively high, with the majority above 95% [Table 4]. The sex and age group variables had 3.9% and 0.5% missing values respectively, with all these attributable to COVID notifications. Completeness for the ethnicity variable was at 97%, comprising 97.8% completeness among non-COVID notifications and 96.9% completeness among COVID notifications. Infection acquired, which was only available for non-COVID notifications, had a completeness of 67.1%, noting that this variable relies on information provided from the patient. The serogroup/type variable had the lowest completeness at 40.5%, although for notifications of influenza, hepatitis B and hepatitis C (for which it was included in the report), completeness was much higher at 99.3%. Vaccination status, which is only relevant for vaccine-preventable diseases, had completeness of 92.3%. Among notifications of COVID-19, over 99.9% had a recorded test type.

Table 4. Completeness of key variables analysed for 2022 annual report

Variable	Total relevant notifications	Relevant notifications with analysable value (%)	Relevant notifications with unknown or blank value (%)
Optimal date of onset	12,759 (all non-COVID notifications)	12,759 (100%)	0 (0%)
Date of receipt	226,257 (all notifications)	226,257 (100%)	0 (0%)
Region		226,257 (100%)	0 (0%)
Sex		217,523 (96.1%)	(3.9%)
Age group		225,066 (99.5%)	1,191 (0.5%)
Ethnicity		219,468 (97.0%)	6,789 (3.0%)
Disease		226,257 (100%)	0(0%)
Infection acquired	12,759 (all non-COVID notifications)	8558 (67.1%)	4201 (32.9%)
Serogroup/type	12,759 (all non-COVID notifications)	5173 (40.5%)	7586 (59.5%)
Vaccination status	4,531 (all notifications of vaccine-preventable diseases)	4181 (92.3%)	350 (7.7%)
Test type	213,498 (all COVID notifications)	213,469 (>99.9%)	29 (<0.1%)

Discussion

The Q2 2023 report was circulated to regional PHUs in August 2023 and shared by PHUs with their local government and Aboriginal community-controlled health sector partners as appropriate. The intention of the report was to provide a brief snapshot of notifiable disease counts and key issues for consideration by relevant stakeholders. The addition of quarterly notifiable disease reports in 2023 was received positively by regional PHU staff, who reported that the Q2 2023 report was a useful snapshot of WACHS-wide communicable disease activity and an important avenue to improve information sharing with regional health stakeholders. Feedback on the report indicated that PHUs would benefit from a region-specific rather than WACHS-wide report, which would better inform regional communicable disease control priorities and highlight areas for further attention. This approach was implemented from the third quarter of 2023.

The 2022 annual report was sent to Chief Executives of five WA Health Service Providers and the Director of CDCD in October 2023, and was uploaded to the WACHS intranet for information and use by internal staff. Trends described in the 2022 annual report reflect existing research that demonstrates higher rates of infectious disease among rural and remote populations and Aboriginal and Torres Strait Islander peoples in Australia(2, 5). By describing notifiable disease trends across and within country WA regions, the 2022 WACHS report enables a better understanding of how disease notifications differ within and between these regions and population groups. The intent is that this

information can then be used by WACHS and other WA Health stakeholders to inform resource allocation, for example by providing evidence for the introduction of new or altered public health programs, funding for additional staff, or establishment of collaborative responses to public health issues.

WACHS' annual notifiable disease reports between 2017 and 2021 included descriptive sections on 35 notifiable diseases. The structure of the 2022 annual report was updated, to highlight trends for nine key notifiable diseases and include only summary information for the remaining conditions. The intention of this structural change was to make the report more easily digestible and operationally relevant, and to make its style more consistent with a similar annual report prepared for metropolitan WA. The new structure was well-received by stakeholders, who reported that it was comprehensive but appropriately succinct.

A challenge of preparing the quarterly and annual notifiable disease reports is the amount of information included in the analysis, especially given the limited resources available. Notifiable disease reports are ordinarily prepared by a single public health staff member, for whom data analysis is a small part of an expansive portfolio of program and policy work. Across 81 notifiable conditions, the analysis includes calculation of overall notification counts and population rates, comparison with previous periods and state and national rates, as well as calculation of seven regional counts and population rates. For conditions of interest, further variables such as Aboriginal status, age, sex, vaccination status, place of acquisition and disease sub-type are examined and described as relevant. While straightforward in a statistical sense, this analysis is time-consuming and resource-intensive, particularly because WACHS public health staff do not have access to or expertise in statistical programs such as R Studio or Stata. This limits the addition of more complex analysis, for example, age-standardised notification rates such as those included in national reporting on notifiable diseases(17). The use of age-standardised rates would allow for more accurate comparison between notification rates among Aboriginal and non-Aboriginal people and reduce the impact of any confounding based on age. However, a key strength of the WACHS reports is the incorporation of situational and disease-specific knowledge from public health staff, which helps to contextualsie trends and provide possible explanations. The development of an Excel template to automate much of the descriptive analysis for future reports will reduce the time required for this work, and allow public health staff to focus more resources on the explanatory sections of the reports.

While the WACHS notifiable disease reports already incorporate data on notifications, immunisation, and population estimates, the addition of further testing data in future reports would enable greater understanding of notifiable disease trends. Without testing information, it is difficult to know whether

apparent increases or decreases in notification rates represent true changes in transmission patterns, or whether these changes are affected by surveillance artifacts such as changes to testing criteria, the use of a more sensitive or specific test, or changes in test-seeking behaviour. For the 2022 annual report, testing counts for syphilis, chlamydia and gonorrhoea were obtained from CDCD and added important context to this section of the report, especially because notification rates for sexually transmissible infections are particularly vulnerable to changes in testing practices and behaviour over time(17). For future reports, consultation with PathWest Laboratory Medicine and CDCD could be considered, to provide more comprehensive testing data and contextual information on how relevant testing changes may have affected notification trends.

At present, the WACHS annual report is shared with a limited audience, including internal WACHS staff and select stakeholders within other WA Health Service Providers. As outlined above, this enables the report to inform public health knowledge and resource allocation within WACHS. However, publishing the report to a wider audience could increase its impact, for example by making it publicly available on the WA Health website. Annual notifiable disease reports published by MCDC are currently published online, so there is precedent to share this type of information with a public audience(19). While some data on notifiable conditions are publicly available, the analysis the annual report provides about disease trends within regions could provide value to external stakeholders who cannot otherwise access this information. For example, increased routinely available information about iGAS notifications, including distribution by Aboriginal status, has been called for by researchers who suggest that these data could support appropriate interventions and assessment of progress over time(20). Information described in the WACHS annual report may also provide the impetus for further, more in-depth research on infectious diseases and at-risk populations, that WACHS public health staff do not have the capacity to conduct.

Limitations

The notification data presented in these reports are likely to be underestimates of all cases of notifiable infectious diseases in country WA. Notifications can only be recorded for those cases who seek care or screening and receive an appropriate test, and this information must be then communicated to the Chief Health Officer. Care seeking behaviour may be affected by a range of factors, including access to health services, the nature of symptoms experienced, or knowledge of disease risk based on public health campaigns and media attention, and may affect population groups differentially. As outlined above, changing to testing practices can also affect notification data, as can clinician awareness and recognition of potential diseases. People with limited access to services, including those in remote regions or Aboriginal people, may therefore be underrepresented for some

conditions. Conversely, targeted screening for certain conditions may result in the overrepresentation of high-risk groups in notification counts.

While Excel was selected as the most appropriate tool for data analysis in the context of the WACHS operational environment, it is more vulnerable to user error and inaccuracy than formal statistical packages, and as a result calculations included in the report are subject to error. Quality assurance checks were used in the Excel template and notable trends discussed and verified with public health staff to ameliorate this risk, however inaccuracies may remain in the report.

Conclusion

The preparation of notifiable disease reports for country WA is an important aspect of communicable disease control and response. These reports provide useful information on infectious disease patterns across and within each of the seven WACHS regions, and enable regional PHUs and central decision-makers to appropriately target public health interventions. Improvements could be considered to increase the impact of future reports, including the incorporation of testing data and wider publication of the annual report. However, changes made to reporting practices in 2022 and 2023, including the addition of quarterly reports, and the shift to a shorter and more focused annual report, have improved the utility of the reports for their intended audiences.

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Appendix 1: WACHS Notifiable Disease Quarterly Update, Quarter 2 2023

Government of **Western Australia**
WA Country Health Service

WA Country Health Service Notifiable Disease Quarterly update

Issue 2 Quarter 2 2023

The WA Country Health service (WACHS) acknowledges the traditional custodians throughout Western Australia and their continuing connection to the land, waters and community. We pay our respects to all members of Aboriginal communities and their cultures; and to Elders both past and present.

Notifiable Diseases in Country WA, Q2 2023

WACHS Public Health Units (PHUs) have the responsibility for public health management of notifiable diseases across country WA including providing specialist advice to stakeholders and reducing community spread through the coordination of appropriate public health actions. WACHS Population Health teams work together and with health service partners to improve public health across country WA.

10627 notifications

5952 COVID-19*
2789 vaccine-preventable diseases
975 sexually transmitted infections

402 enteric diseases
71 blood-borne diseases
61 vector-borne diseases

Syphilis outbreak in country WA continues

Infectious syphilis cases continue to occur in high-risk groups including women of childbearing age and among Aboriginal people.

66 cases of infectious syphilis notified
33 cases in women aged 15-44
0 cases of congenital syphilis

Notifications decreased by 10% overall compared to Quarter 1. Crude notification rates were **3.9** times higher in the **Kimberley** and in the **Pilbara** compared to the overall WACHS rate.

Flavivirus transmission

No notifications of Japanese Encephalitis, but several cases of Murray Valley Encephalitis and unspecified flavivirus notified. In northern regions, JEV has been detected in sentinel chicken surveillance and vaccination of high-risk groups continues.

3 cases of MVE notified
1 case of unspecified flavivirus
2283 JEV vaccines administered to Kimberley and Pilbara residents

Uptick in Legionellosis notifications

Bacterial infection is transmitted via water droplets, air-borne particles, or by hand-to-mouth transfer from environmental sources. Disease is uncommon but severe.

13 cases of legionellosis
all cases aged **>40**
7x increase on Q1 notifications

COVID-19 notifications*

COVID-19 activity is difficult to measure due to likely underreporting of positive RATs and limited use of PCR testing, which is now restricted to within healthcare facilities or via GP referral. Available data indicates widespread transmission is continuing, with notification rates generally higher in older age groups.

5166 notifications via RAT
786 notifications via PCR
85+ age group had highest notification rate

*COVID-19 cases were not included in the 2023 Q1 report

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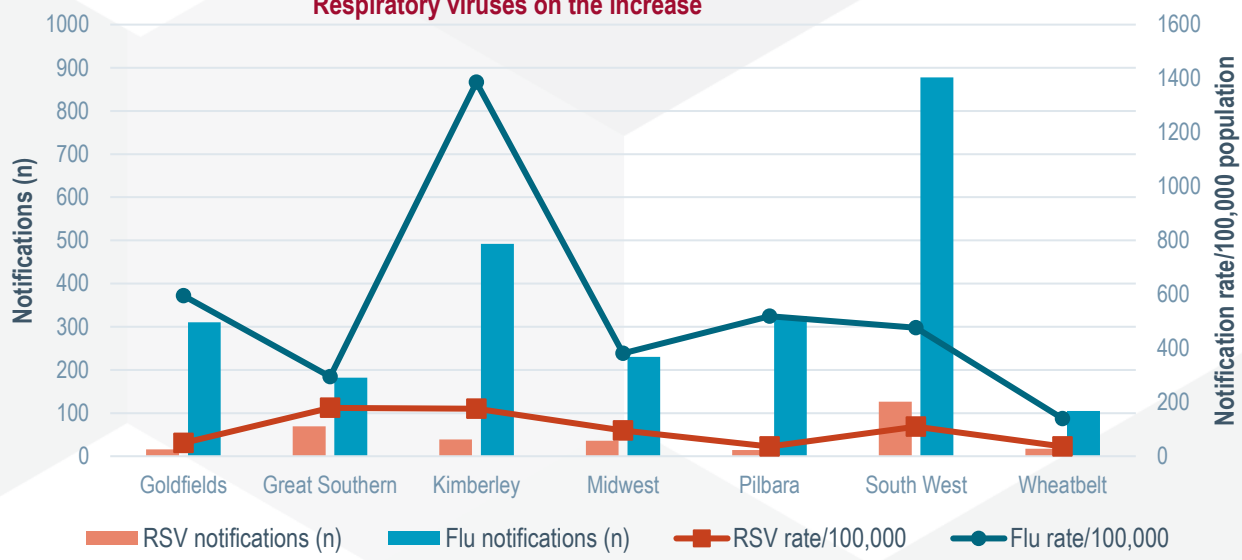
Consistent with changing seasons and transmission patterns, in Q2 Respiratory Syncytial Virus (RSV) notifications increased by **310%** and Influenza notifications by **520%** compared to Q1. There were **159** cases of RSV, and **369** cases of influenza, in children under 5 years.

Influenza and RSV notifications and rates, by WACHS region, Q2 2023

Respiratory viruses on the increase



Immunisation, Q1 2023 data

Early childhood immunisation coverage in country WA

Fully immunised children are those who have received the full schedule of according to their age at the end of Q1 2023.

1 year		90.6% 83.0%	non-Aboriginal children Aboriginal children	7.6% gap in coverage
2 years		89.7% 80.4%	non-Aboriginal children Aboriginal children	9.3% gap in coverage
5 years		92.2% 95.9%	non-Aboriginal children Aboriginal children	3.7% gap in coverage

School-based immunisation coverage in country WA

Fully immunised students are those who have received all recommended doses of the relevant vaccine in the school year in which immunisation was due. School-based immunisation programs continue to be administered throughout the year.

Human Papilloma Virus (HPV)	35.9% 13.5%	non-Aboriginal students Aboriginal students	22.4% gap in coverage
Diphtheria, Tetanus, Pertussis (DTP)	38.0% 14.7%	non-Aboriginal students Aboriginal students	23.3% gap in coverage
Meningococcal ACWY	7.2% 17.8%	non-Aboriginal students Aboriginal students	10.6% gap in coverage

Data Notes: Notification data sourced from WA Notifiable and Infectious Diseases Database, excluding ARF and RHD data sourced from WA RHD Register and COVID data sourced from Public Health Operations COVID-19 Unified System. Immunisation data sourced from Australian Immunisation Register via Communicable Disease Control Directorate, WA Department of Health. Immunisation data is compiled with a quarterly delay, so Q1 2023 is the most recent data available. Population rates calculated using forecasted 2022 population data from Epidemiology Directorate, WA Department of Health.

Appendix 2: Extract from Notifiable Diseases in Country Western Australia 2022

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Notifiable Diseases in Country Western Australia 2022 (extract)

SEPTEMBER 2023

COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

COVID-19 transmission dominates communicable disease landscape

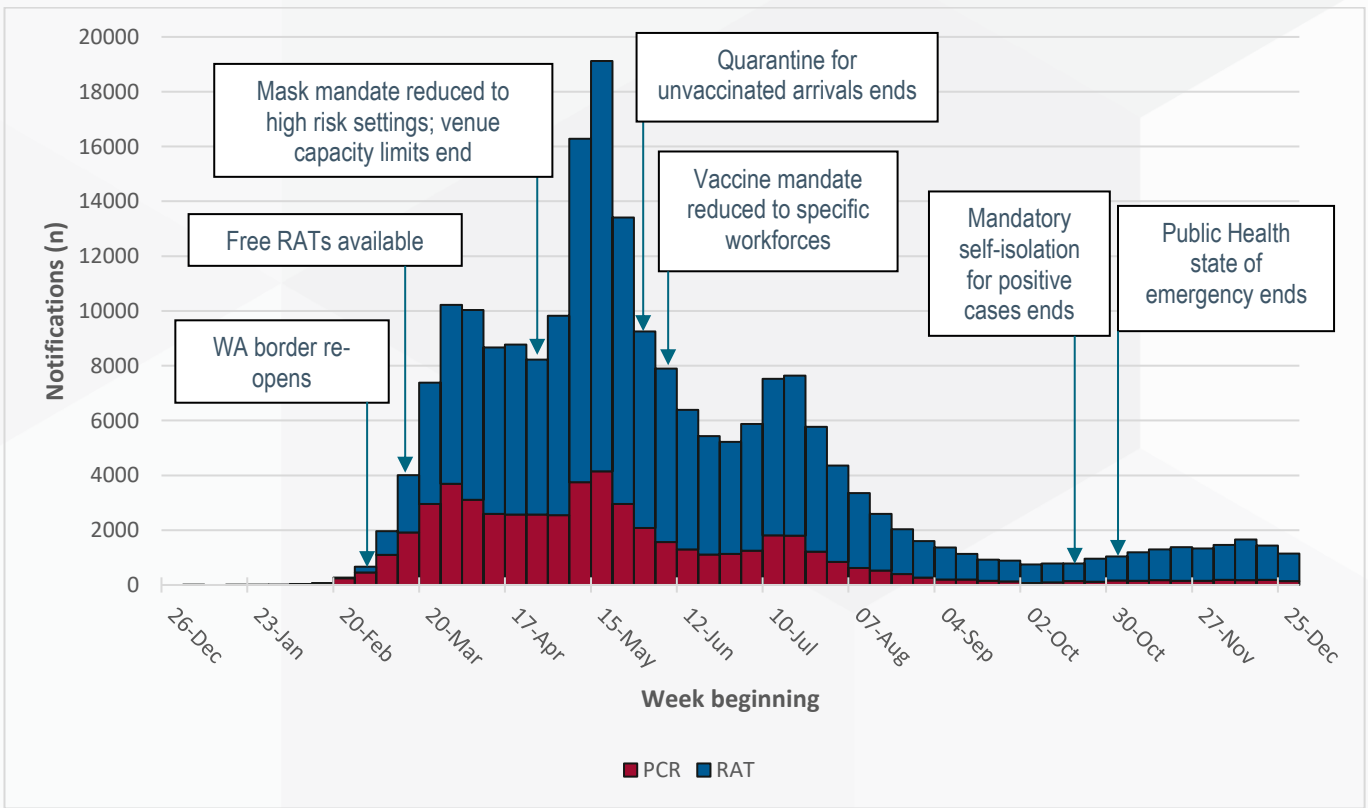
Although the COVID-19 outbreak was first declared a Public Health Emergency of International Concern by the World Health Organisation on 30 January 2020, it took two years for extensive community transmission of COVID-19 to occur in country WA. Prior to 2022, strict public health controls including domestic and international border closures, hotel quarantine requirements for incoming travellers, and biosecurity restrictions in many remote Aboriginal communities, prevented community transmission of COVID-19 and enabled widespread rollout of a comprehensive vaccination program. In 2021, 15 cases of COVID-19 were recorded among residents of country WA, but these cases all remained in hotel quarantine in Perth for the duration of their illness and were not counted as WACHS notifications.

The first cases of COVID-19 in country WA were notified in early 2022, and increased substantially following the removal of border restrictions on 3 March. There were over 200,000 notifications, more than 17 times the number of notifications for all other conditions combined. PHUs across country WA devoted significant resources to the COVID-19 response, including monitoring and managing outbreaks in high-risk settings, continued administration of the COVID vaccination program, overseeing point-of-care testing for COVID, and delivering education and health promotion campaigns to prevent further transmission.

Overview of COVID-19 notifications

COVID-19 notification data is sourced from reports of positive Polymerase Chain Reaction (PCR) and Rapid Antigen Tests (RATs). While the availability RATs for self-testing and point of care testing reduced the burden on public health laboratories, online self-reporting is vulnerable to incomplete data capture (1). As a result, the data presented in this section is likely to be an underestimate of all COVID-19 cases. RAT data are likely to be influenced by individual behaviour, decisions, access to tests and ability to report via the online portal.

Figure 1: COVID-19 notifications in country WA, 2022, by week and test type

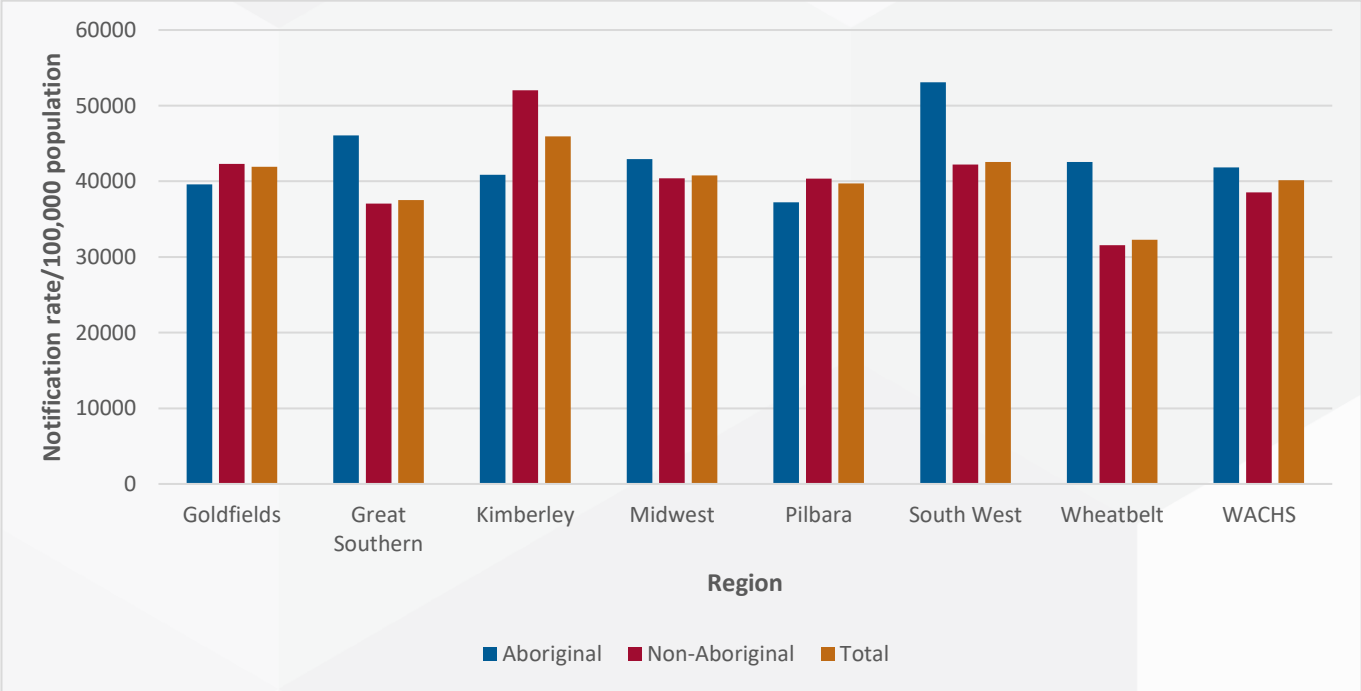


Overall, there were 213,498 notifications of COVID-19 in country WA in 2022, a rate of 40,154 per 100,000 people. This was slightly higher than the statewide COVID-19 rate of 38,355/100,000, but lower than the national rate of 41,692/100,000. The incidence of COVID-19 notifications throughout 2022 was characterised by three waves (Figure 1). The first peak of 10,221 weekly cases between 27 March and 2 April occurred three weeks following the removal of border restrictions. The second and overall highest peak of 19,125 weekly cases occurred between 15 and 21 May, following a reduced mask mandate and removal of venue capacity restrictions, and a final peak of 7,642 weekly cases occurred between 17 and 23 July. These notification patterns closely mirror that of statewide COVID notifications, which peaked between 20 and 27 March, 9 and 15 May, 11 and 17 July respectively. The drop in notifications from late July likely reflects respiratory virus seasonality, decreased PCR testing, and underreporting of positive RATs.

Regional COVID-19 notification trends

Figure 2 depicts COVID-19 notification rates across each of the seven WACHS regions. The highest total notification rate was 45,932/100,000 people in the Kimberley, followed by 42,560/100,000 in the South West and 41,916/100,000 in the Goldfields. The lowest regional notification rate was in the Wheatbelt (32,279/100,000).

Figure 2: COVID-19 notification rates in country WA, 2022, by region and Aboriginal status



Although the COVID-19 notification rate was higher among Aboriginal people across WACHS overall, this varied by region. In the Great Southern, Midwest, South West and Wheatbelt, notification rates were higher among Aboriginal people than non-Aboriginal people, with the greatest disparity evident in the Wheatbelt (Aboriginal/non-Aboriginal rate ratio=1.40). However, the Goldfields, Kimberley and Pilbara regions each saw higher COVID-19 notification rates among non-Aboriginal people, despite intensive testing and outreach to Aboriginal communities conducted during the first wave, reflected in significantly higher statewide notification rates among Aboriginal people between March and May (2). The lower rate in northern and remote regions overall may be related to testing fatigue following this initial push, among both healthcare workers and community members.

In each region, the highest notification rate was among either the 20-24 or 25-29 age group, and was upwards of 50,000 notifications/100,000 people in each instance. Across all regions, notification rates were consistently lower in older people, with each region having their lowest rate in an age group older than 70 years. In each region, females consistently had a higher COVID-19 notification rate than males. While these trends may reflect true COVID-19 transmission patterns, they are also likely to represent age and sex differences in testing and reporting behaviour.

Sexually transmissible infections

Summary

In 2022, there were 3874 notifications of sexually transmissible infections, accounting for 35.1% of all non-COVID notifications.

Chlamydia notifications increased by 7.7%, to 2371 from 2189 notifications in 2021, although tests declined by 8.8%. The notification rate was a 2.1% increase on the average rate between 2017 and 2021. The highest notification rate by age was in 20-24 year-olds (3468.5/100,000). Notification rates were higher in women than men (rate ratio = 1.54) and Aboriginal than non-Aboriginal people (rate ratio = 6.5).

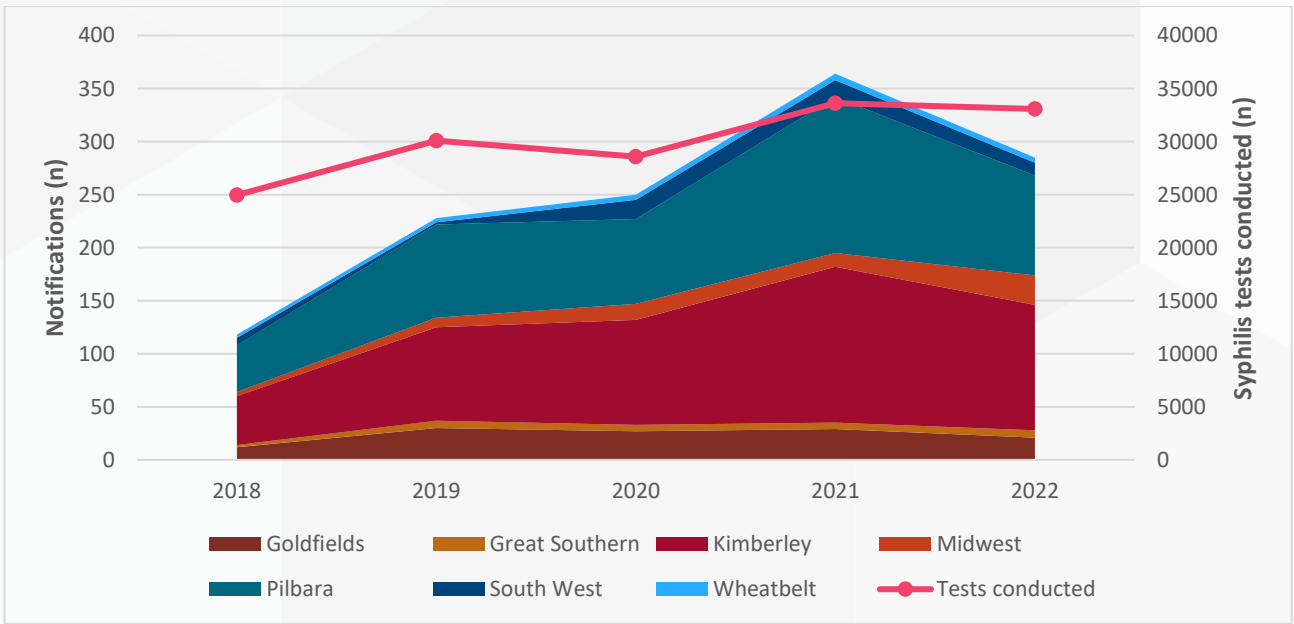
Gonorrhoea notifications increased by 7.4%, to 1124 from 1041 notifications in 2021, although tests declined by 8.8%. The notification rate was a 3.3% increase on the average rate between 2017 and 2021. The highest notification rate by age was in 20-24 year-olds (1287.6/100,000). Notification rates were slightly higher in women than men (rate ratio = 1.07) and substantially higher in Aboriginal than non-Aboriginal people (rate ratio = 44.7).

In focus: Syphilis notifications drop, but outbreak continues

A national multijurisdictional Syphilis Outbreak Working Group was formed in April 2015 to address increasing cases of syphilis among Aboriginal and Torres Strait Islander peoples largely living in rural and remote areas of northern Australia. In response to a sustained syphilis outbreak first identified in the Kimberley and then spreading to the Pilbara region, a WA-specific Syphilis Outbreak Response Group (SORG) was established in August 2018. The syphilis outbreak was subsequently identified in the Goldfields (2019) and South West (2020) regions. The WA Syphilis Outbreak Response Action Plan focusses on five priority areas: prevention and education; workforce development; testing, treatment and contact tracing; surveillance; and antenatal and postnatal care.

In 2022, there were 285 infectious syphilis notifications across WACHS, at a rate of 53.6 notifications per 100,000 people. Notifications decreased by 21.7% compared to 2021, despite a smaller 1.6% decrease in tests conducted. This decrease in infectious syphilis notifications contrasts with the 15.5% increase in metropolitan WA and the 7.1% increase nationally. However, the 2022 WACHS notification rate was 37.4% higher than the 2017-2021 average, 76.9% higher than the 2022 WA rate, and over twice as high as the 2022 national notification rate.

Figure 4: Infectious syphilis notifications and tests in country WA, 2018-2022, by region



Regional infectious syphilis notifications are displayed in Figure 4. The highest notification counts were recorded in the Kimberley (n=118) and Pilbara (n=94), which also had the highest notification rates. Compared to 2021, notifications dropped in all regions except for the Midwest, where they more than doubled from 13 to 28, and the Great Southern, where they increased from six to seven. In all regions, 2022 notification rates were higher than the 2017-2021 average.

Figure 5: Infectious syphilis notifications in country WA, 2022, by age group and Aboriginal status

Of the 285 infectious syphilis notifications, 89% were in Aboriginal people, at a rate of 404.5/100,000, compared to 6.4/100,000 among non-Aboriginal people. Among Aboriginal people, the highest notification rate was in the 20-24 age group (1129.1/100,000), followed by the 15-19 age group (935.5/100,000) and the 35-39 age group (816.9/100,000). Among non-Aboriginal people, the highest notification rate was in those aged 25-29 (33.5/100,000), followed by those aged 20-24 (28.3/100,000) and those aged 30-34 (16.1/100,000).

Congenital syphilis cases a cause for concern

Congenital syphilis occurs when syphilis is acquired by an infant from their mother during pregnancy. It has a range of potentially severe outcomes including stillbirth, prematurity, low birth weight, and neonatal death, and can cause ongoing damage to the organs, brain and nerves. Because congenital syphilis can be prevented by screening and treating syphilis in pregnant women, the occurrence of congenital syphilis is considered “a sentinel event reflecting potential missed opportunities for prevention in the public health, antenatal and primary health care systems” (3).

There were three congenital syphilis notifications in country WA in 2022, indicating the ongoing risk of poor outcomes from the outbreak, and contrasting with the apparent decrease in infectious syphilis notifications overall. These three cases follow another three in 2021, demonstrating a notable increase on the two total cases between 2017 and 2020.

Prevention of congenital syphilis is a key priority for regional PHUs, who devote considerable resources to detecting and treating syphilis in pregnant women. This includes promoting regular syphilis screening for pregnant women, which is recommended three times throughout pregnancy for most women, and five times for women in the Kimberley, Pilbara and Goldfields regions. The response to diagnoses of syphilis in pregnant women includes providing urgent treatment, managing partners, ongoing monitoring, collaborative work with other health providers including paediatric and obstetric teams, and follow up of mothers and babies after birth. The proportion of infectious syphilis notifications among women of childbearing age (15-44 years) remained stable between 2021 and 2022, at 47.5% (n=173) and 47.4% (n=135) of all cases respectively.

Vaccine preventable diseases

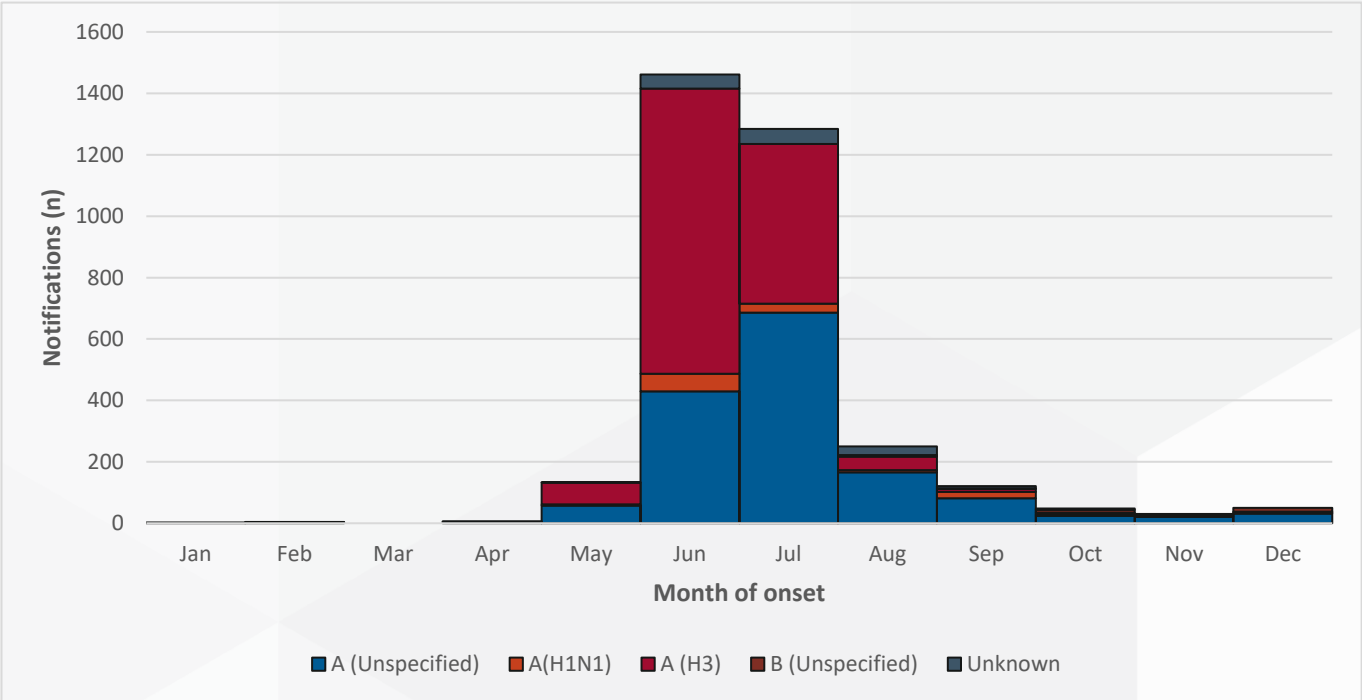
In focus: largest influenza season since 2019

In 2020 and 2021, country WA experienced a substantial drop in influenza cases, mirroring national and global trends and correlated with strict public health interventions to control the spread of COVID-19. There were 216 influenza notifications in 2020 and just 14 in 2021, compared to an average of 3325 notifications per year between 2017 and 2019.

In 2022, following the removal of border restrictions and relaxation of public health measures, country WA again experienced a large influenza season, with 3389 cases notified at a rate of 637.4 per 100,000 people. This rate was higher than the statewide WA rate of 525.8 notifications/100,000, but lower than the national rate of 897.4/100,000.

Figure 6 demonstrates the strongly seasonal nature of influenza, with 92% of all notifications occurring between May and August, and 81% in June and July alone. This trend reflected high influenza notifications across WA and nationally in winter, although state notifications peaked in July rather than June.

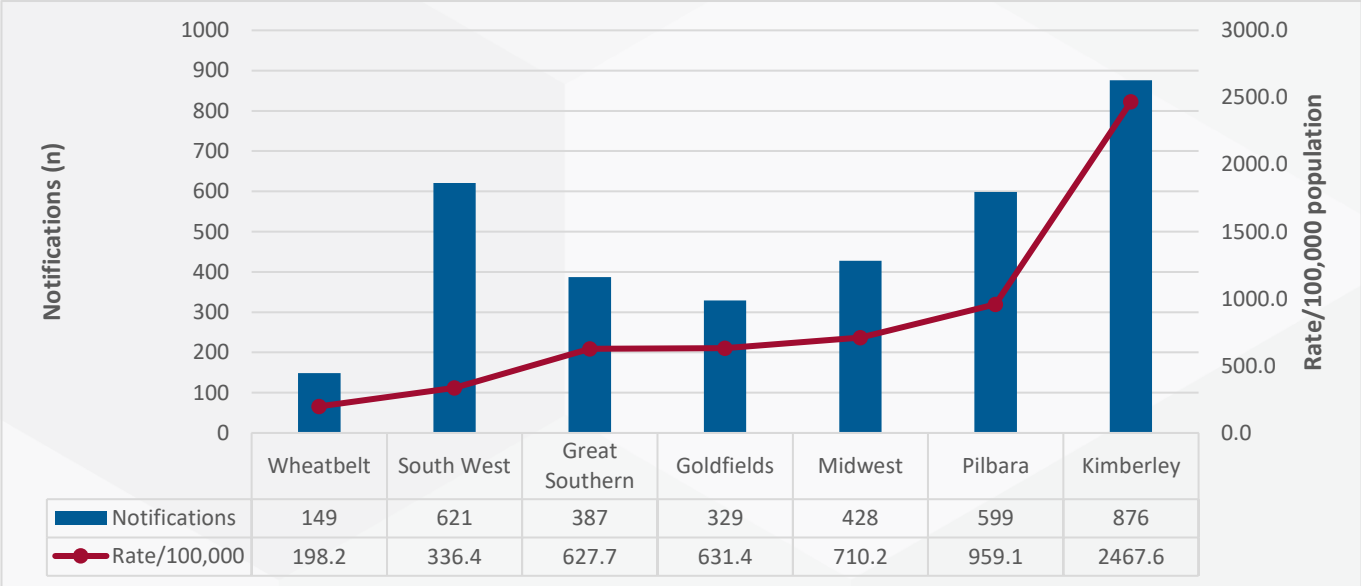
Figure 6: Influenza notifications in country WA, 2022, by month of onset and sub-type



In 2022, 96% of all influenza notifications had a recorded subtype. Subtype A comprised 95% of notifications, including 47% that were A (H3), 44% that were A (Unspecified), and 4% that were A (H1N1). Just 1% of notifications were subtype B, with all of these B (Unspecified). This differed from the 2019 influenza season, in which 25% of notifications were subtype B, but reflects a similarly low proportion of subtype B nationally in 2022 (4).

In 2022, several higher-risk groups were eligible to receive a government-funded influenza vaccine in WA, including those aged 65 and older; children from six months to five years; children in primary school; pregnant women; Aboriginal people aged six months and over; and people aged six months and older with certain chronic health conditions (5). Of 3389 notified influenza cases in 2022, 75% were not vaccinated for influenza, while 18% were recorded as fully vaccinated. Higher proportions of those who were fully vaccinated were non-Aboriginal (68%), female (60%), and aged over 65 (24%), compared to those who were not vaccinated (61%, 53%, and 4% respectively).

Figure 7: Influenza notifications in country WA, 2022, by WACHS region



As outlined in Figure 7, the Kimberley region had both the highest count of influenza notifications and the highest notification rate, followed by the Pilbara and the Midwest. The lowest notification rate was recorded in the Wheatbelt.

Across all regions, notifications were high in Aboriginal people, with notification rates among Aboriginal people more than twice as high as those for non-Aboriginal people in each region. The Kimberley had the highest notification rate among Aboriginal people (3310.4/100,000), followed by the Pilbara (2460.3/100,000) and Goldfields (1500.5/100,000). In each region, notification rates were higher in females than males.

Table 1: Age group with highest influenza notification rate in each WACHS region, 2022

	Goldfields	Great Southern	Kimberley	Midwest	Pilbara	South West	Wheatbelt
Age group	5-9 yrs	15-19 yrs	85+ yrs	0-4 yrs	20-24 yrs	15-19 yrs	20-24 yrs
Rate/100,000	1274.8	1417.7	4137.9	1396.2	4449.8	632.7	607.8

Table 1 demonstrates that age-based influenza trends differed across regions in 2022. In the Midwest, the highest notification rate by age was among children aged 0-4 years, and in the Goldfields it was among those aged 5-9 years, reflecting high rates in these age groups nationally. However, in most other regions teenagers and young adults were most affected, with those aged 15-19 having the highest rate in the Great Southern and South West regions, and those aged 20-24 having the highest rate in the Pilbara and Wheatbelt regions. In the Kimberley, the highest notification rate was among those aged 85 and over, although this represented a count of just six notifications.

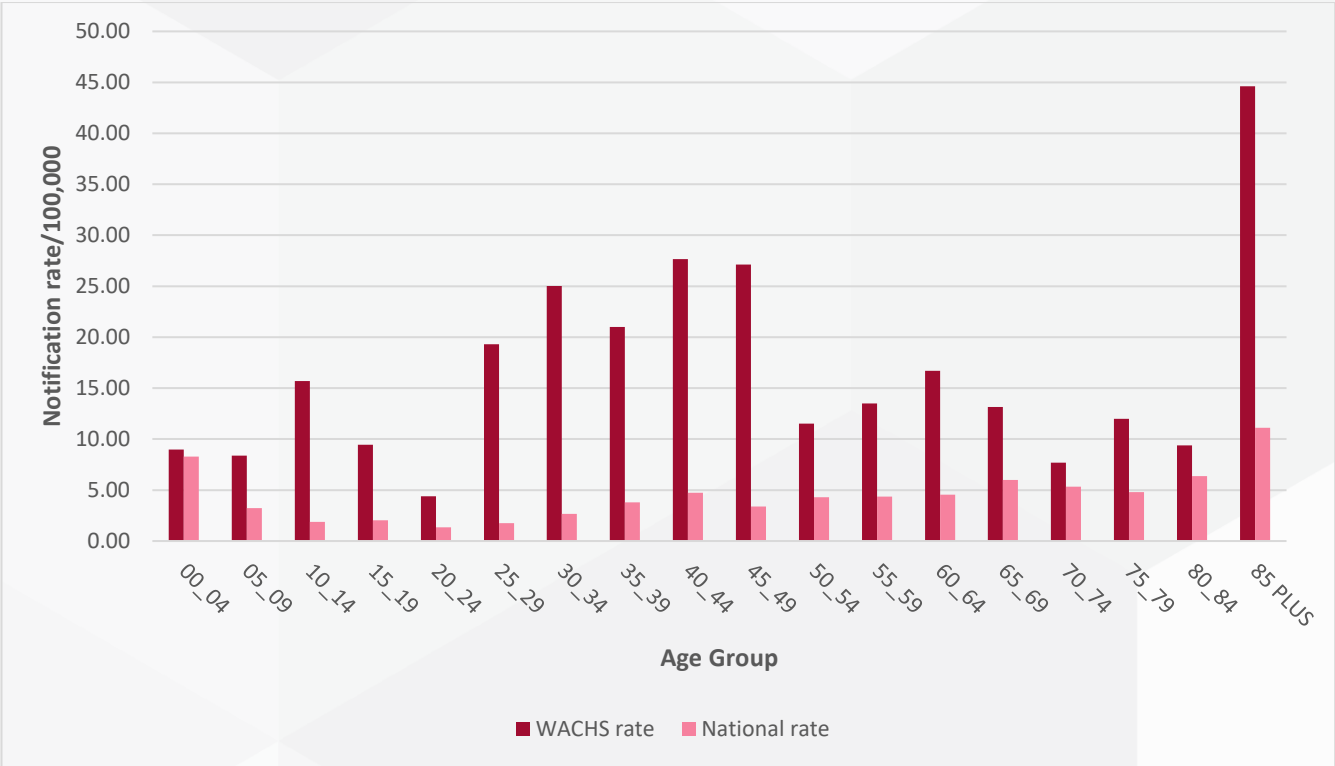
Other diseases

In focus: Invasive Group A Streptococcal disease newly notifiable

Invasive group A streptococcal disease (iGAS) became notifiable in WA in August 2021. iGAS is a severe and potentially life-threatening condition that is a rare outcome of a group A streptococcal infection, and can cause necrotising fasciitis and streptococcal toxic shock syndrome (6). While iGAS is newly notifiable in Australia, research using hospital admission data has demonstrated a significant increase in iGAS cases in Australian children in 2022 compared to 2020 and 2021, corresponding with similar spikes reported in the northern hemisphere (7).

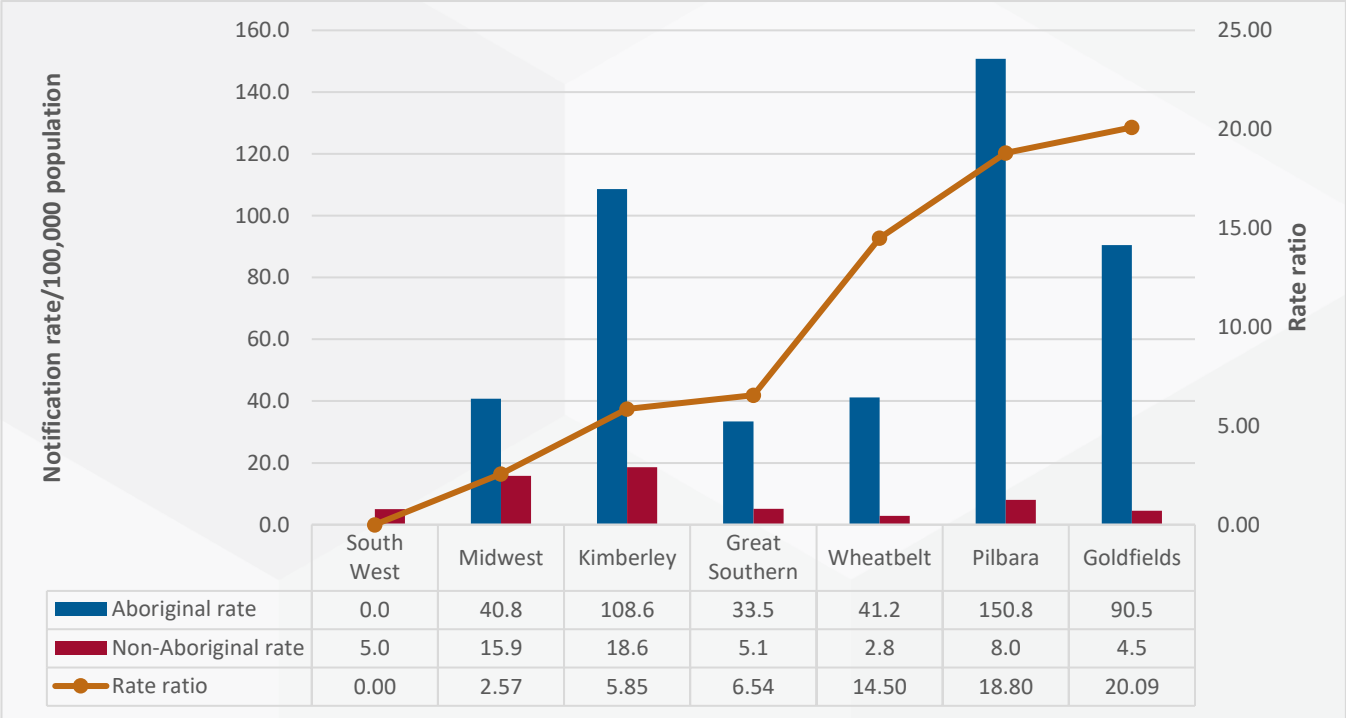
In country WA in 2022, there were 85 notifications of iGAS, at a rate of 16.0/100,000 people, which followed seven notifications between August and December 2021. The iGAS notification rate in country WA was more than twice as high as the statewide notification rate for WA, and more than 2.5 times higher than the national rate.

Figure 8: iGAS notifications in country WA and nationally, 2022, by age group



As demonstrated in Figure 8, the iGAS notification rate in country WA was higher than the national notification rate in every age group. In country WA, the highest notification rate by age was in those aged over 85 years (44.6/100,000), followed by the 40-44 age group (27.7/100,000), and the 45-49 age group (27.1/100,000). While national notification rates were also highest in the 85+ age group, they were second highest in those aged 0-4, and notifications in this age group comprised 12% of all notifications nationally. Contrastingly, the notification rate in 0-4 year-olds in country WA was relatively low compared to other age groups, and comprised just 4% of all notifications. Of the 24 iGAS cases reported in the Kimberley, which had the highest regional notification rate in country WA, (67.6/100,000), none were younger than 25, and 76% were 40 or older.

Figure 9: iGAS notification rates in country WA, 2022, by region and Aboriginal status



	South West	Midwest	Kimberley	Great Southern	Wheatbelt	Pilbara	Goldfields
Aboriginal rate	0.0	40.8	108.6	33.5	41.2	150.8	90.5
Non-Aboriginal rate	5.0	15.9	18.6	5.1	2.8	8.0	4.5
Rate ratio	0.00	2.57	5.85	6.54	14.50	18.80	20.09

Of the 85 iGAS notifications in country WA, 54 were among Aboriginal people (85.6/100,000 people), while there were 31 notifications among non-Aboriginal people (6.6/100,000). As outlined in Figure 9, the highest notification rate for Aboriginal people was in the Pilbara, followed by the Kimberley and the Goldfields. Among non-Aboriginal people, the highest notification rate was in the Kimberley, followed by the Midwest and the Pilbara. The notification rate among Aboriginal people was higher than that for non-Aboriginal people in every region except the South West, where there were no notifications in Aboriginal people. The largest difference in notification rates occurred in the Goldfields, where the notification rate among Aboriginal people was 20 times higher than among non-Aboriginal people, followed by the Pilbara and the Wheatbelt.

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Appendix 3: Summary – Notifiable Diseases in Country WA 2022

Government of **Western Australia**
WA Country Health Service

Notifiable Diseases in Country Western Australia 2022
Summary

The WA Country Health Service incorporates seven regional Population Health Units (PHUs), which respond to infectious disease notifications, and conduct health promotion and immunisation activities. This report aims to inform healthcare providers about notifiable disease trends in 2022 and assist in health service planning and delivery.

12,759 non-COVID notifications
81% ↑ from 2021

Increasing:
Influenza, respiratory syncytial virus

Decreasing:
Vector-borne diseases

Highest vaccination coverage
in Aboriginal 5-year-old children

COVID-19 notifications and outcomes

- Country WA recorded 213,498 cases of COVID-19 in 2022, at a rate of 40,154 cases per 100,000 people.
- There were 2030 COVID-19 hospital admissions, 31 intensive care admissions, and 155 COVID-19 deaths.
- PHUs responded to COVID-19 by managing outbreaks in high-risk settings, supporting COVID vaccination, overseeing point-of-care testing, and delivering education and health promotion to prevent transmission.

Sexually transmissible infections

- Infectious syphilis notifications decreased to 285 from 364 in 2021, but remained higher than 2022 state and national rates. Notifications were 63.2 times as high in Aboriginal people than non-Aboriginal people.
- The three cases of congenital syphilis indicate the importance of a continued outbreak response, including screening, detecting, and managing syphilis in pregnant women.
- Chlamydia increased by 2.1%, and gonorrhoea by 3.3%, compared to the 2017-2021 notification rate.

Vaccine-preventable diseases

- The 3389 notifications of influenza marked the largest influenza season since 2019. Notifications peaked in June, and rates were highest in the Kimberly, Pilbara and Midwest regions.
- The decrease in pertussis and rotavirus, and nil reported cases of measles, rubella or tetanus, emphasise the effectiveness of the childhood immunisation program in country WA.

Vector-borne diseases

- While there were no cases of Japanese encephalitis reported, a comprehensive public health response, including rollout of vaccines to high-risk populations, was launched to address this potential threat.
- Vector-borne disease notifications decreased overall, reflecting reduced numbers of Ross River and Barmah Forest viruses compared to previous years.

Other diseases

- Respiratory syncytial virus notifications peaked in September, contrasting with the national winter peak, and mainly affected children aged 0-4 years.
- There were 85 invasive Group A streptococcal notifications, disproportionately affecting Aboriginal people and those in northern and remote regions.
- Local transmission of tuberculosis in the Midwest prompted a thorough response from Midwest PHU and partners, including targeted community screening and health provider education.

Chapter 4: Establishing a family and domestic violence indicator for Emergency Departments in country Western Australia

Contents

Terminology

This chapter will characterise family and domestic violence (FDV) in line with the definition provided in the Western Australia Country Health Service's (WACHS) policy on FDV identification and management(1):

> *FDV is not an isolated event but a pattern of ongoing, repetitive and purposeful use of behaviour towards a family member that is physically or sexually abusive; and/or emotionally or psychologically abusive; and/or economically abusive; and/or threatening; and/or coercive; and/or in any other way controls or dominates the family or household member, and causes that person to feel fear for their safety or wellbeing or that of another person.*

This chapter uses the term 'victim-survivor' to describe people who have experienced violence from a partner or family member. This term acknowledges that FDV causes significant harm, while also recognising the strength of those who have experienced it.

Prologue

This chapter describes my involvement in the creation of a system to record Emergency Department (ED) presentations in country Western Australia (WA) related to FDV. This work was undertaken to fulfil the Master of Philosophy in Applied Epidemiology (MAE) core competency to establish or evaluate a surveillance or other public health information system. It also outlines the preparation of a lay summary for a non-scientific audience.

My role

I worked on the establishment of the FDV indicator system for the majority of my field placement at WACHS, alongside Senior Project Officer for Family Safety, Jade Lyons, who oversaw the project. The indicator functions as a standalone field in WACHS' ED records system, and has dual purposes to a) alert ED clinicians to the need for FDV screening and response and b) assist in health service planning for EDs by enabling the measurement of FDV-related ED presentation trends across WACHS.

I co-led a Quality Improvement (QI) Activity with Jade to establish the FDV indicator system. I conducted a quantitative analysis to determine which type of presentations should trigger a mandatory response to the FDV indicator, which included designing a case-control analysis, extracting and cleaning a dataset of ED presentations, matching cases to controls, and conducting both descriptive and comparative analyses. I also presented a summary of results to several internal stakeholders and committees. In parallel to this, Jade and I undertook a series of face-to-face consultations at WACHS sites to determine how the introduction of the FDV indicator would impact ED staff. My focus was on how FDV was documented in the ED setting, how this information was used and by whom, and how the incoming indicator could function effectively with these processes. I was responsible for recording the responses of staff during sessions and summarising the results of each session in visual products.

In addition to the quantitative analysis and the QI Activity, Jade and I met with a range of stakeholders within WACHS to progress the implementation of the indicator. My role in these consultations was focused on how the data collected by the indicator could be verified and used effectively. This involved planning for an audit tool, recommending metrics and audiences for data reporting, and drafting and confirming a data dictionary entry for the indicator. Alongside Jade, I also presented the results of our work, including explaining the rationale of our recommendations for the system, to health information managers, ED decision-makers, and the state-wide body responsible for funding the indicator.

Lessons learnt

My involvement in this project was a significant learning experience and one of the highlights of my placement at WACHS. The process of designing and conducting the quantitative analysis was

technically challenging for me, due to my limited prior experience with quantitative analysis and statistics programs. It was sometimes frustrating, and I made many mistakes, having to re-conduct the analysis three times. However, I was proud of what I achieved in this analysis, and glad to receive positive feedback from colleagues and executives about the work.

The travel I undertook for this project was an invaluable opportunity to meet frontline health professionals working in WACHS facilities, and to understand the challenging nature of their work. I visited four separate regions, and had exposure to small health centres and large, bustling EDs. While I was aware of the importance of consulting data collectors when designing a surveillance system, I was surprised by how grateful ED staff were to have been genuinely involved in this process, and by how meaningfully they engaged with us, considering the time constraints they face within the workplace.

My experience working on this project also helped me to grasp the complexity of health information systems, and how difficult it can be to add a seemingly simple field to an existing system. I gained experience engaging with a range of stakeholders, each with different responsibilities for, interests in, and perspectives on the FDV indicator, and came to appreciate the amount of work that needs to be undertaken every time a change like this is made to a large system.

Public health impact

FDV has significant and potentially catastrophic health impacts for victim-survivors. A best-practice response to FDV-related presentations in the ED setting is essential to improve the safety of victim-survivors and to minimise further harm. At the time of writing, the FDV indicator has been approved, and a phased implementation began in July 2023. This will improve WACHS' ability to respond to FDV-related ED presentations. It will both enhance the real-time response during an ED presentation, and enable WACHS to measure time, regional and demographic FDV-related presentation trends. These data can then inform FDV decision-making, including regarding ED resourcing.

No previous Australian literature describes a systematic approach to recording FDV-related ED presentations. The Australian Institute of Health and Welfare has commented on the ongoing difficulty of measuring FDV-related ED presentations, and the fact that these data are not routinely collected in EDs in Australia (2). The implementation of the FDV indicator at WACHS is therefore an exciting move forward in the public health response to FDV. If effective, other health systems and jurisdictions may complete similar work to measure and improve the response to FDV in the ED setting.

Acknowledgements

Throughout this project I worked in close partnership with Jade Lyons, who was the most responsive, supportive and kind colleague I could have hoped for. Thanks Jade giving me the opportunity to be involved with this project, for the consistent moral support, and for the many hours of conversations we had throughout our travels. Thanks also to Kylee Cox, Sharon McBride, Karine Miller and Sylvia Lennon who oversaw various aspects of this project from a WACHS perspective. Thanks to Alex Xiao from the WA Department of Health who provided very patient advice on the case control study. Thanks to my MAE supervisors for their advice and support throughout this project. Finally, my deepest thanks to the ED staff who gave up their precious time to contribute to the design of the FDV indicator, and who continue to care for FDV patients in country WA with compassion and empathy.

Virginia outside Broome ED after a focus group, March 2023

Jade before the first focus group session at Bridgetown ED, October 2022

Abstract

Background

In country Western Australia (WA), family and domestic violence (FDV) causes significant morbidity and mortality, with a holistic health system response needed to prevent FDV harms. The identification of FDV-related Emergency Department (ED) presentations is an important aspect of this, but the busy and high-pressure nature of ED environments means that the need for FDV screening and response may be overlooked. In addition, current ED systems in country WA do not allow for the systematic recording of FDV information, resulting in a dearth of data on FDV-related presentations.

Methods

A Quality Improvement (QI) activity was undertaken to inform the design of a new health information system, known as the FDV indicator, for the WA Country Health Service (WACHS). A matched case-control analysis was conducted using a dataset of Kimberley ED presentations among women in 2019 and 2020, to determine presenting complaints and diagnoses positively associated with FDV. In parallel, targeted consultations with ED staff across country WA were carried out to inform the design of the FDV indicator, incorporating semi-structured focus groups at seven WACHS EDs between October 2022 and March 2023.

Results

Quantitative analysis found positive associations between FDV and three categories of presenting complaint and four categories of diagnosis, which were recommended to trigger a mandatory response to the indicator field. Staff consultations found inconsistency in the documentation of FDV information, demonstrating a need for ED-specific guidance on FDV response, and confirmed that prompts for FDV screening are necessary in the busy ED setting. Features of the FDV indicator system were designed in response to these findings. A phased implementation of the FDV indicator began in July 2023, with further enhancements expected in 2024. The system incorporates the addition of an FDV field to WACHS ED records system, WebPAS, and the establishment of supporting infrastructure to analyse, manage and disseminate data.

Discussion

The FDV indicator system will improve the response to FDV in WACHS EDs. In the real-time of an ED presentation, it will prompt ED staff to consider FDV screening, and connect staff with useful resources when FDV is indicated. It will also improve WACHS' longer-term FDV response by highlighting trends in FDV-related presentations and enabling responsive resourcing and education for ED staff. The strengths of the system lie in these dual uses, along with the incorporation of data collectors' feedback in its design, its use of existing data infrastructure, and the establishment of system supports to ensure that data is disseminated appropriately.

Background

While most measures of FDV incidence and prevalence in Australia are acknowledged to be underestimates, available data indicates a high rate of FDV throughout Australia. In 2023, the Australian Bureau of Statistics' Personal Safety Survey reported that 27% of adult Australian women and 12% of adult men have experienced violence from an intimate partner or family member(3). In WA specifically, this rises to 30% of adult women(3). Police data indicates similarly concerning trends. In 2021, 37% of all reported sexual assaults and 28% of all homicides in Australia were FDV-related(4). In WA, 63% of all reported assaults (n=22,880); 25% of homicides (n=12); and 26% of sexual assaults (n=909) were FDV-related in 2021(4).

People of all genders can experience FDV, but women are at significantly higher risk than men of experiencing FDV in Australia, and are more likely to experience severe, frequent, and protracted FDV than men(5, 6). Specific groups at higher risk of FDV include women living with disability; Aboriginal and/or Torres Strait Islander women; migrant and refugee women; women experiencing homelessness; women experiencing financial hardship; women in regional and remote areas; women with an experience of incarceration; and people who are LGBTQIA+(7, 8).

FDV has a range of short and long-term health impacts, is costly to the health and justice systems, and profoundly impacts the lives of victim-survivors and their families and communities. For women in Australia aged 15–44, violence from an intimate partner is the fourth leading risk factor for total disease burden, and is the tenth for women aged 45–64(9). Health impacts included in this burden include violent injuries, self-inflicted injuries, early pregnancy loss, depressive disorders, anxiety disorders, and alcohol use(10). Other documented health impacts of FDV include insomnia, chronic pain, physical exhaustion and reproductive health problems(11); an increased risk of unplanned pregnancies, sexually transmitted infections, HIV, and adverse birth outcomes(12); and higher risk of acquired brain injuries, disability and other chronic health conditions(13). Flow-on impacts to victim-survivors include effects on income, employment, education, housing security and general participation in social and civic life(2, 8, 12). In 2015, KPMG estimated that violence against women costs Australian society $22 billion annually, including $1.4 billion in direct costs to the health system. In WA, between 2009 and 2015 the total cost of FDV to WA Health was $51.9 million for people admitted to hospital for assault-related injuries(8).

The ED is a key part of a health system's response to, and management of, patients experiencing FDV. Identifying FDV-related presentations where possible and taking immediate steps to improve the safety of patients is vital to reduce FDV-related harm and prevent future violence. In general, victim-survivors are more likely to disclose their experience of FDV to a health professional than to law

enforcement or other community services(14). This provides health services with a unique opportunity to assist victim-survivors who may not have accessed any other form of support. ED in particular may be a preferable place for victim-survivors to disclose their experience of FDV, due to its perceived anonymity compared with other health services(15). Screening for FDV in the ED context is well-accepted as an effective method of identifying FDV, understanding and responding to the safety needs of patients, and referring to appropriate support services(15). A 2017 feasibility study conducted in New South Wales, in which 11% of eligible women were screened for FDV in the ED, found that screening was acceptable to staff, and the majority of staff agreed that the program improved women's safety(16).

The nature of medical records procedures in Australia makes capturing data on FDV-related ED presentations difficult. While data are available on hospital admissions related to FDV, information on 'external causes of injury' is not captured systematically at the ED level(2). As a result, the Australian Institute of Health and Welfare has recommended further research to examine trends in principal diagnoses for ED presentations in Australia, as well as "identification of potential types of cases to facilitate early intervention and/or flags for further investigation and assistance" in the ED setting(2).

WACHS' 'Identifying and Responding to Family and Domestic Violence Policy' guides clinicians in country WA on FDV response(1). This policy instructs clinicians to respond to disclosures of FDV with support and validation, to develop a safety plan including referrals to other services, and to identify children at risk of harm. Clinicians in a hospital setting are expected to screen, assess and make referrals for FDV with the guidance of standard forms, which are also used for documentation.

A new FDV indicator field for WACHS's ED patient administration system, WebPAS, was recommended in 2021 to allow for systematic recording of FDV-related presentations. This field would remind staff of the need for screening, allow for FDV-related presentations to be counted and tracked, and allow central office staff to ascertain ED clinicians' level of compliance with the policy. An initial version of the FDV indicator was approved and developed by the WebPAS vendor in 2022, but implementation was delayed until further work could be conducted to determine when the indicator should be mandatory for staff to complete; how the addition of the indicator would impact staff and whether they would need support to manage FDV presentations; and whether the indicator would work effectively within existing ED processes. A QI Activity entitled *Improving the identification and response to FDV in WACHS EDs* was commenced in October 2022 to address these questions.

Part 1: Determining mandatory triggers

Background

The placement of additional mandatory requirements on ED staff, who already experience a high workload, needs to be considered carefully. As a result, WACHS Executives determined that the FDV indicator should be available to complete for every ED presentation, but mandatory for high-risk presentations only. Based on existing research demonstrating a higher risk of FDV among women, and existing WACHS processes for identifying and managing children at risk of FDV, it was determined that mandatory triggers for the FDV indicator should be initially narrowed to presentations among females aged 16 years and older. Throughout the QI Activity, ED staff and other WACHS stakeholders frequently inquired about the rationale for selective mandatory triggers for the indicator, and how this would affect the indicator data. A short summary was developed to address these questions and was circulated to stakeholders upon request [Appendix 1].

Methods

A case-control analysis was conducted to determine which presenting complaints and diagnoses were positively associated with FDV among females aged 16 years and older. The aim of the analysis was to inform which ED presentations should trigger a mandatory response to the FDV indicator.

Study Population

The analysis was conducted using a dataset of ED presentations among women aged 16 years and over presenting to EDs in the Kimberley in 2019 and 2020, extracted from WACHS' Emergency Department Data Exploration Tool (EDDET) in July 2022. During this period, the Kimberley region adopted an enhanced case-finding approach, in which patient notes were retrospectively reviewed by a nurse practitioner and a 'FDV Stream' applied to FDV-related presentations. At the time the analysis was conducted this was the best information available on FDV-related ED presentations in WACHS.

Variables and Participant Selection

The exposure variables were 'presenting complaint' category and 'major diagnosis' category, and the outcome variable was 'FDV'. Presenting complaint is recorded in WebPAS at triage, with values grouped into 18 categories for analysis. Major diagnosis category is an automated variable derived from the patient's ICD-10 coded diagnosis, selected by a clinician at discharge. A case was defined as a presentation with the 'FDV Stream' selected, and a potential control was defined as a presentation without the 'FDV Stream' selected. Aboriginal status, age and residential address are collected from the patient by ED staff following triage, but these values are automatically filled if the patient has an existing WA Health record. Socioeconomic Indexes for Areas (SEIFA) quintile was derived from a patient's residential postcode. Presenting quarter was derived from the automatic timestamp associated with the patient's arrival at ED.

Presentations at small health centres and those with a residential postcode outside of WA were excluded. Two unique controls were matched to each case on Aboriginal status; 5-year age group; presenting quarter; and SEIFA quintile.

Data Analysis

A conditional logistic regression model was used to calculate adjusted odds ratios for each presenting complaint and diagnosis category, and a chi squared test was used to calculate p-values. Analysis was conducted in Stata/SE version 17(17).

Ethical Considerations

This analysis used de-identified record-level data on ED presentations. Data was stored in a WACHS-managed, multifactor authentication-protected Office 365 folder, with access limited to the project team only. Following the completion of analysis, data were saved in a secure folder on WACHS' records management system and will be destroyed after seven years. This analysis was covered by the Australian National University (ANU) Human Research Ethics Committee umbrella approval for surveillance system projects (2017/909).

Results

Descriptive Analysis

A total of 58,775 presentations were included in the original data extract. After data cleaning and matching was conducted, 2,527 cases and 5,049 controls were included in the analysis. Table 1 presents an overview of their matched characteristics.

Table 1. Characteristics of FDV ED cases and matched controls, Kimberley region, 2019–2020

Characteristic	Cases	Controls
Total	2,527	5,049
Age Group		
16–19	214 (8%)	427 (8%)
20–29	792 (31%)	1584 (31%)
30–39	779 (31%)	1557 (31%)
40–49	583 (23%)	1163 (23%)
50–59	143 (6%)	286 (6%)
60–69	16 (1%)	32 (1%)
Aboriginal	2437 (96%)	4869 (96%)
Non-Aboriginal	89 (4%)	178 (4%)
SEIFA Quintile		
1 —Most disadvantaged	2314 (92%)	4628 (92%)
2	28 (1%)	53 (1%)
3	118 (5%)	236 (5%)
4	19 (1%)	36 (1%)
5 — Least disadvantaged	48 (2%)	96 (2%)
Presenting Quarter		
Q1 2019	407 (16%)	812 (16%)
Q2 2019	292 (12%)	583 (12%)
Q3 2019	267 (11%)	532 (11%)

Characteristic	Cases	Controls
Q4 2019	279 (11%)	558 (11%)
Q1 2020	321 (13%)	642 (13%)
Q2 2020	271 (11%)	542 (11%)
Q3 2020	273 (11%)	546 (11%)
Q4 2020	417 (17%)	834 (17%)

As per the matching criteria, there was no difference between cases and controls in terms of age distribution; presenting quarter; Aboriginal status; or socioeconomic status. Of presentations included, 70% were among those aged below 40 years, 28% among those aged between 40 and 59, and just 1% were aged 60 or over. Presentations were relatively consistent across the eight presenting quarters included in the study, although higher proportions of presentations occurred in the first (Q1 2019) and last (Q4 2020) quarters. Aboriginal people comprised 96% of presentations, and 92% of presentations were among those in the lowest SEIFA Quintile.

All cases and controls had a value assigned for presenting complaint category. Among cases, the most common presenting complaint category was 'injury' (57%), followed by 'other' (14%) and 'pain' (13%). Among controls, the most common presenting complaint categories were 'pain' (25%), followed by 'other' (17%) and 'respiratory' (10%).

There was no assigned value for major diagnosis category in 10% of presentations, which were excluded from analyses for this variable. Cases (13%) were more likely than controls (9%) to have a missing diagnosis category. The most common diagnosis categories were 'Injuries, poisonings and the toxic effects of drugs' (29%), 'diseases and disorders of the skin, subcutaneous tissue and breast' (21%), and 'factors influencing health status' (9%). Among controls with a diagnosis category, the most common categories were 'factors influencing health status' (16%), 'diseases and disorders of the skin, subcutaneous tissue and breast' (12%), and 'diseases and disorders of the ear, nose, mouth and throat' (11%).

Comparative Analysis

Figures 1 and 2 below present the results from the conditional logistic regression models.

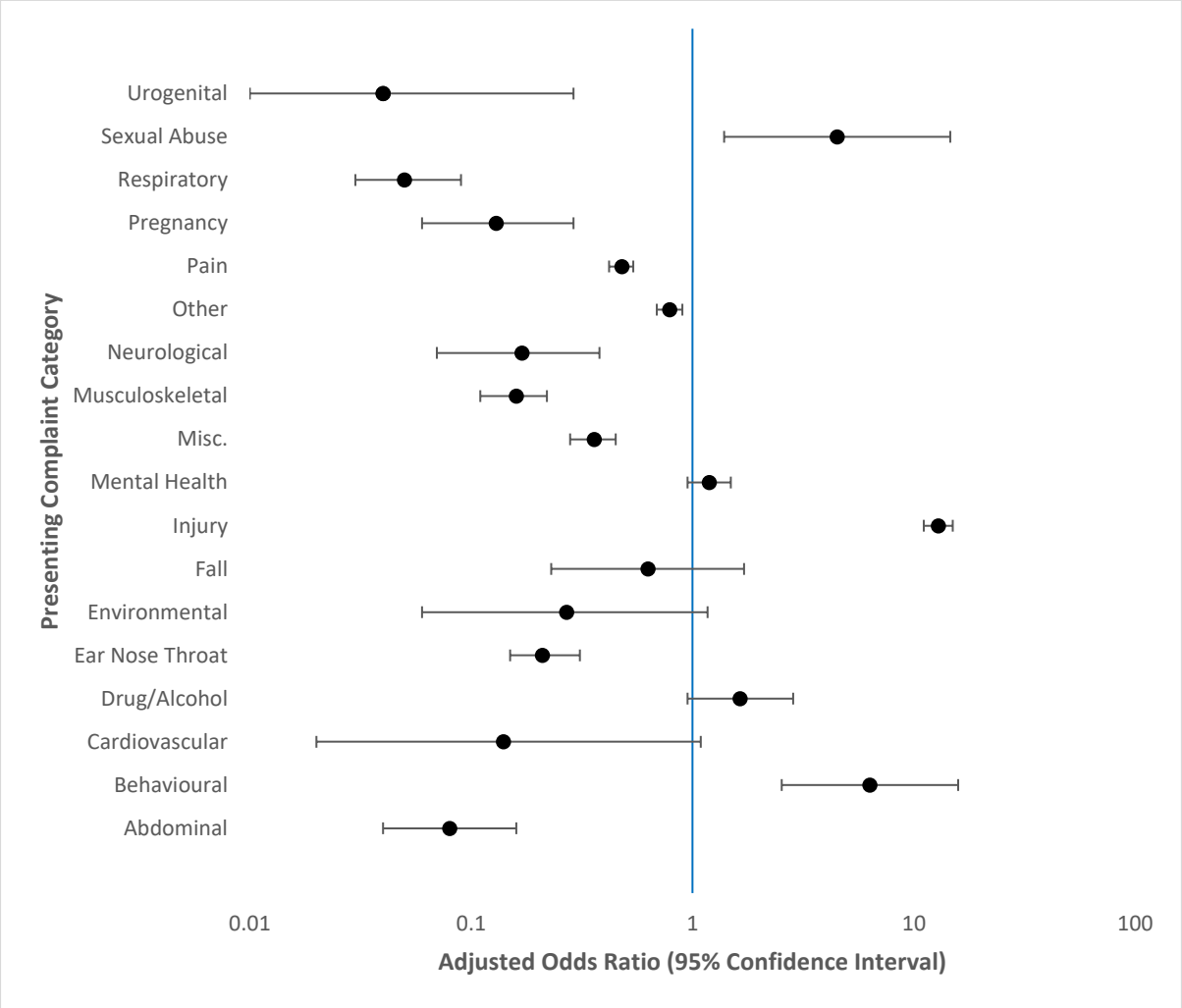

Figure 1. Adjusted Odds Ratios for FDV among women aged 16+ in the Kimberley, 2019–2020, by presenting complaint category

Of 18 presenting complaint categories, 'injury' had the strongest positive relationship with FDV (OR=12.90, 95%CI= 11.09–14.99, p<0.005), followed by 'behavioural' (OR=6.33, 95%CI=2.53–15.86, p<0.005) and 'sexual abuse' (OR=4.5, 95%CI=1.39–14.61, p<0.005). Presenting complaint categories for 'drug/alcohol', 'mental health', 'fall', 'environmental' and 'cardiovascular' each had a non-significant relationship with FDV. The remaining 10 presenting complaint categories were all negatively associated with FDV.

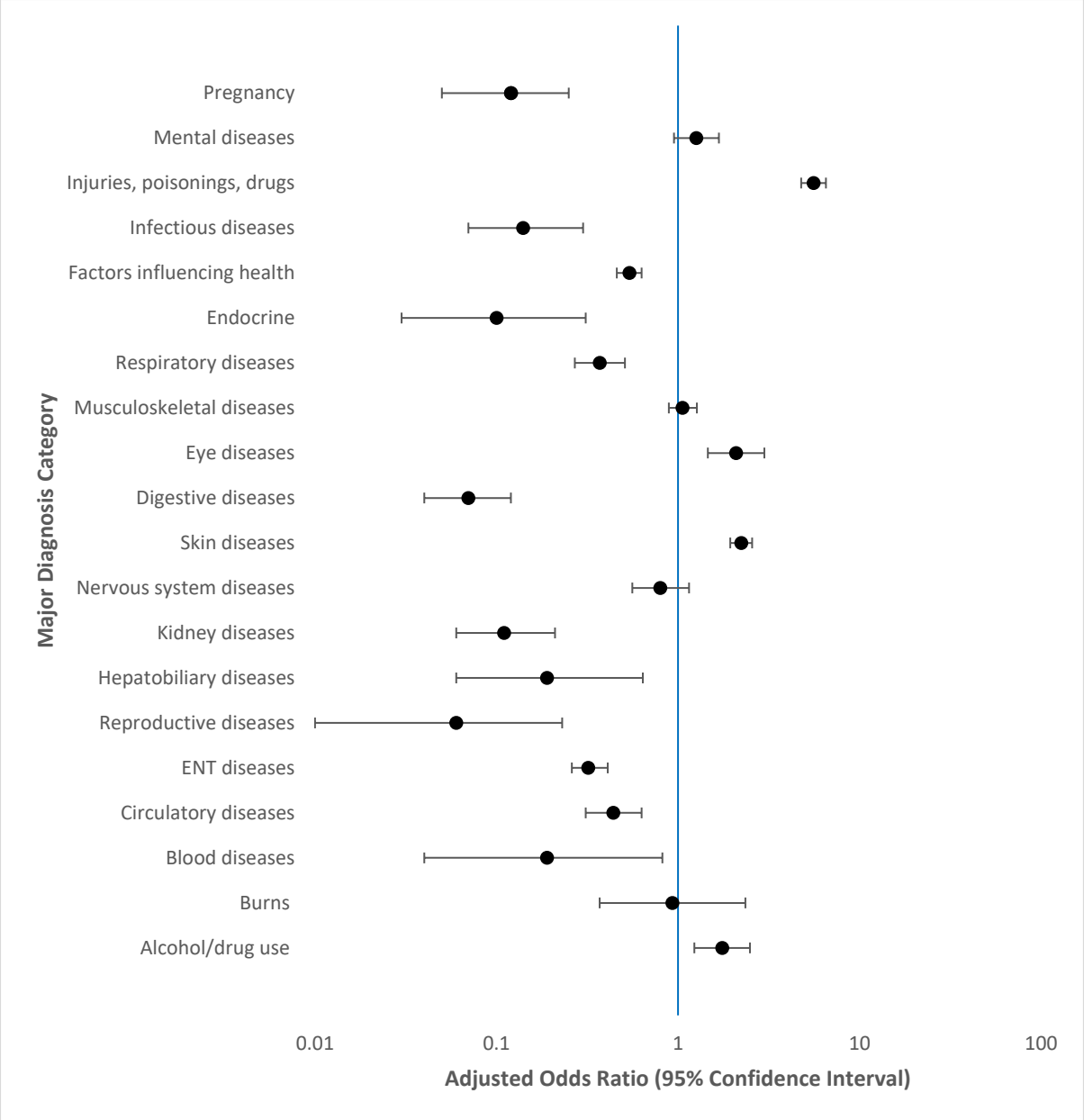

Figure 2. Adjusted Odds Ratios for FDV among women aged 16+ in the Kimberley, 2019–2020, by major diagnosis category

Of major diagnosis categories, 'injury, poisoning and the toxic effects of drugs' had the strongest positive relationship with FDV (OR=5.58, 95%CI=4.77–6.53, p<0.005), followed by 'diseases and disorders of the skin' (OR=2.23, 95%CI=1.94–2.56, p<0.005), 'diseases and disorders of the eye' (OR=2.09, 95%CI=1.46–2.99, p<0.005), and 'alcohol/drug use and alcohol or drug-induced organic mental disorders' (OR=1.75, 95%CI=1.23–2.49, p<0.005). Four major diagnosis categories had non-significant results, including 'mental diseases and disorders'; 'diseases and disorders of the musculoskeletal system and connective tissue'; 'diseases and disorders of the nervous system'; and 'burns'. The remaining 12 major diagnosis categories had a negative relationship with FDV.

Discussion

While limited data are available on FDV-related ED presentations in Australia, the descriptive results of the analysis correspond with research on FDV-related hospital admissions, which indicates that Aboriginal and Torres Strait Islander people, and younger women, are overrepresented among those hospitalised for FDV(2).

The finding of a strong relationship between injury-related presenting complaints and diagnoses and FDV in this analysis is unsurprising, as physical assault is one of the most well-recognised manifestations of FDV. Previous research conducted in the United States(18), nationally in Australia(2), and in WA specifically(19), has found head and neck injuries to be the most common reason for FDV-related hospitalisations.

The significant relationship between FDV and a diagnosis related to alcohol use agrees with Australian research that found an association between alcohol use and family violence, for both victims and perpetrators, including 30% of FDV victims reporting heavy drinking in the last year(20). In this analysis, presenting complaints in the alcohol and other drug category did not have a significant relationship with FDV, although the lower bound of the confidence interval was just below one.

Neither mental health presenting complaints nor mental health diagnoses were significantly associated with FDV in this analysis, although mental ill-health is a well-documented sequelae of FDV(21, 22). This may reflect potential measurement bias, as these manifestations of FDV can be harder to recognise and may not have been recorded as accurately as injury presentations, or may also reflect a high underlying incidence of mental ill-health in the study population.

The application of a mandatory response to the FDV indicator was recommended for presentations in the significantly associated presenting complaints and diagnosis categories based on the above results. Applying a mandatory trigger to these presentations aims to highlight the need for FDV screening and to improve data collection, while minimising the overall impact of the FDV indicator on ED operations and workload. Of the FDV-related presentations included in the analysis, 76% would have been captured by a mandatory trigger if this was in place. Applying the recommended mandatory triggers to WACHS-wide ED presentations in 2022 indicated that this would affect approximately 10% of all ED presentations. These results were presented to relevant WACHS executives in February 2023, who endorsed that these mandatory triggers be added to the FDV indicator's functionality.

Limitations

Data on FDV-related presentations was only available from the Kimberley region for this analysis. Country WA regions are distinct areas, with varying local contexts, population dynamics, economies, and geographic considerations, which may result in differing patterns in the manifestations of FDV.

Notably, the proportion of Aboriginal residents in the Kimberley is higher than that in other WACHS regions. The analysis controlled for population differences in FDV characteristics by matching cases and controls on age, Aboriginal status and socio-economic status, but as other unmeasured differences could not be controlled for, the results are still representative only of Kimberley presentations. Unfortunately, the dearth of data on FDV-related presentations in other WACHS regions meant that this was the best available evidence base for determining what the mandatory triggers should be. A review of data collected through the indicator is planned for 12 months following implementation, and WACHS will amend mandatory triggers based on the results if appropriate.

The 'FDV Stream' data used for this analysis relies on either an active FDV disclosure by the patient, or a disclosure following prompting or screening by ED staff. As a result, some truly FDV-related presentations are likely to have been misclassified as non-FDV in this analysis, i.e., some presentations included as controls may have truly been FDV cases. This misclassification is likely to have been differential between exposure groups, as non-physical forms of violence are less likely to be recognised and recorded by ED staff, and therefore constitutes potential measurement bias. This would have impacted the results by biasing the odds ratios among non-injury categories towards the null value. This is an inherent difficulty of studying a health issue that is self-reported only and cannot be ascertained with a diagnostic test. Implementation of the FDV indicator and mandatory triggers will be accompanied by resources and training for staff on how to recognise non-physical forms of FDV, and the importance of recording these presentations with the indicator will be emphasised.

Part 2: ED staff and stakeholder consultations

Methods

Project Design

In order to determine how the addition of the FDV indicator would impact staff, and whether it would work effectively within existing ED processes, a series of staff consultations at EDs across country WA was conducted as part of the QI Activity.

Selection of Sites

Sites were purposively sampled for participation in the QI Activity, with the aim of engaging with a cross-section of sites representing a diversity of regions and emergency care categories. Several sites were approached based on their existing work on FDV identification and management. Seven sites took part in the project, across five different regions. A total of 135 clinicians were consulted. The details of participating sites and staff are outlined in Table 2.

Table 2. QI Activity Participating Sites across WACHS, 2022–2023

Site	Region	Level of health service	Date of Visit/s	Number of staff consulted
Bridgetown	South West	Small Hospital	Oct and Dec 2022	20
Broome	Kimberley	Regional Resource Centre	Mar 2023	33
Geraldton	Midwest	Regional Resource Centre	Jan and Mar 2023	48
Jurien Bay	Wheatbelt	Health Centre	Nov 2022 and Feb 2023	12
Newman	Pilbara	District Hospital	Nov 2022	8
Pingelly	Wheatbelt	Health Centre	Oct 2022 and Mar 2023	14
Warren	South West	District Hospital	Oct and Dec 2022	20

Nature of Staff Engagement

Semi-structured focus group discussions were held at each site, with the project team visiting five sites twice and two sites once. The ED working environment is reactive and unpredictable, so sessions were designed to accommodate staff coming in and out as necessary. In some sites, discussions were held with one or two staff members at a time, with further staff contributions building on this. Topics of discussion included current processes for identifying and managing FDV, staff perceptions about these processes and how they could be improved, how the FDV indicator could integrate into existing processes, and what supports and resources staff need to better identify and respond to FDV.

Ethical Considerations

ED staff at each site were provided with information about the project team and aims of the project in advance of the face-to-face visits. Participation in the focus group sessions was voluntary. At the beginning of each session, staff were again provided with information about the project. Each session opened with an acknowledgement of the impact of FDV in the community and details of support services staff could access if required. Where possible, themes and ideas generated by ED staff were presented back to staff for sense-checking and verification. This work was covered by the ANU Human Research Ethics Committee umbrella approval for surveillance system establishment and investigation projects (2017/909).

Data Analysis and Reporting

Data from focus group sessions were organised via categorised sticky notes, which were confirmed with participants throughout the session. Gaps, barriers and solutions identified were then mapped using an overview chart in Excel, which allowed for comparison across sites. Summary products were created for each site and verified with participants at the second visit.

Findings from the project were described in an internal report and provided to WACHS decision-makers in June 2023. The report included a summary of key issues in the current processes for identifying and managing FDV in WACHS EDs, along with recommendations for how the FDV indicator and other supports could be used to address these.

Other stakeholder consultations

The process of establishing the FDV indicator also involved consultation with internal stakeholders and committees, as outlined in Table 3. This included exploratory discussions; presentations on the findings of the quantitative study and QI Activity; and meetings held to determine approvals or action items.

Table 3. Key internal stakeholder meetings on FDV indicator, 2022–2023

Stakeholder	Date/s consulted	Purpose
WACHS Executive project sponsors	February 2023; July 2023	Endorsement of mandatory triggers for indicator Endorsement of QI Activity results and recommendations
WACHS Health Information Managers committee	October 2022	Approval for indicator to require mandatory triggers
	March 2023	Presentation of results and approval for suggested changes to indicator following QI Activity
WACHS Data & Analytics	September 2022	Understanding current processes for reporting and tracking ED data
	April 2023	Flagging future introduction of Indicator and confirming information will flow through to ED database
	May 2023; July 2023	Establishing possibilities for and parameters of FDV ED dashboard
Statewide WebPAS User Forum	July 2023	In-principle approval for proposed enhancements to FDV indicator
Emergency Nursing Advisory Forum	July 2023	Presentation of QI Activity results and discussion of phased implementation of indicator
Emergency Medicine Leadership Group	August 2023	Presentation of QI Activity results and discussion of phased implementation of indicator
WACHS Safety & Quality Subcommittee	September 2023	Presentation of results and discussion of feasibility of introducing FDV ED audit

Results

A key finding from consultations was the inconsistency in what, where and how FDV information is recorded during an ED presentation. While practices differed across sites, staff generally reported that FDV screening and assessment forms are rarely used in the ED setting. Multiple reasons contribute to this, including the forms being too long and complicated for the ED environment, the separation of these forms from other information and record keeping systems, lack of knowledge about the forms' existence, and uncertainty about how to respond to a disclosure of FDV.

Without the guidance of these forms, the type of information recorded about FDV disclosures, if any, is variable and reliant on the initiative of individual staff members. If FDV information is recorded, it might include details of the disclosure, FDV suspicions of staff, or information about referrals or safety plans developed. This is typically recorded in free text notes, with the location of these notes varying depending on the site and staff preferences. Sites also have different procedures for communicating information about FDV between staff, including verbal discussions, hard copy notes and forms, or communication through WebPAS or other computer-based systems.

When asked about the FDV indicator specifically, staff confirmed that the indicator would be useful in reminding them of FDV screening and assessment forms, but emphasised that current forms are not appropriate for the ED. Staff noted that voluntary WebPAS fields are unlikely to be completed in a busy environment unless they are highly relevant, and that evidence-based mandatory triggers would be a good way to ensure the indicator provides meaningful data. The need for the FDV indicator result to be communicated to staff beyond the triage nurse was also emphasised.

Outcome: the FDV indicator system

Implementation of the FDV indicator into WebPAS ED has been approved and phased implementation began in July 2023. The first phase is a voluntary field with limited functionality. The second phase, planned for 2024, will include mandatory triggers and process improvements based on the QI Activity.

Description of the system

Flowchart of the system

A flowchart describing the FDV indicator system is included at Figure 3 below.

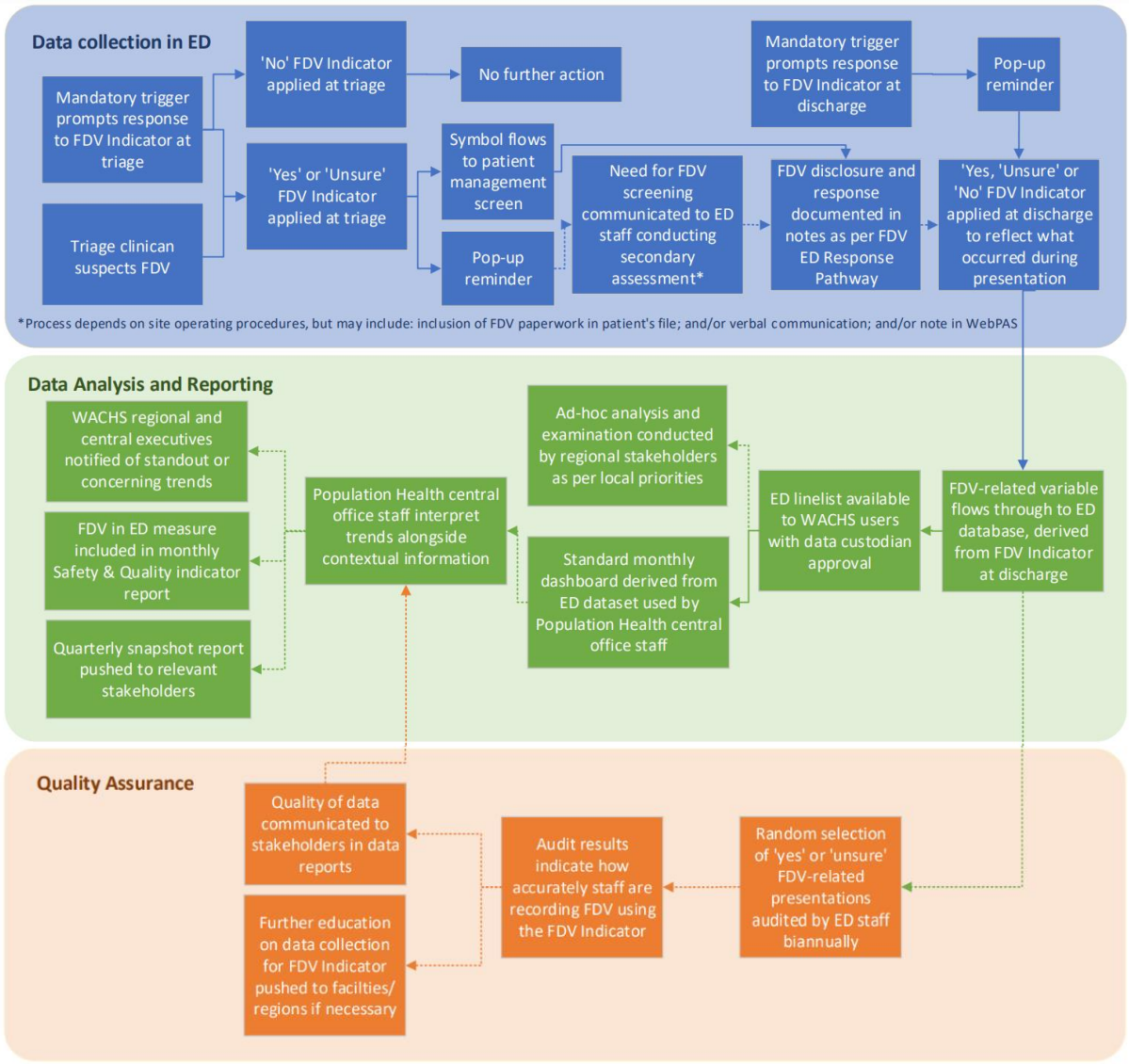

Figure 3. Flow of information through the FDV indicator system

Objectives of the system

The FDV indicator aims to improve the care delivered to FDV victim-survivors presenting to WACHS EDs. It will do this in the real-time of an ED presentation, by prompting ED staff to consider FDV, and by connecting staff with useful resources when FDV is indicated. It will also enable improvements in WACHS' FDV response in the long term, by highlighting where FDV presentations are occurring, the nature of these presentations, and informing decisions about resourcing, education and public health programs.

Legal Authority, Ethical and Confidentiality Considerations

The FDV indicator was developed with regard to the *Health Services Act 2016* (WA). Section 216 of the Act provides for the collection and use of health information for health service planning and research(23).

Like all health data, reports of FDV are inherently sensitive and care was taken throughout the establishment of the indicator to ensure that the collection of FDV data is ethical and remains appropriately confidential. The intent and proposed benefits of the indicator, including improved patient safety and organisational knowledge of and ability to respond to FDV trends, were determined to outweigh the potential risks of collecting this information systematically, although actions were taken to minimise these risks. For example, communications regarding the indicator emphasise that a 'yes' response requires an explicit disclosure from the patient or someone accompanying them, so that patients who choose not to disclose FDV will not have their presentation recorded as FDV-related. ED staff receive existing training on FDV screening and management, to help ensure that these conversations are conducted sensitively and minimise distress to the patient.

Like other data collected during ED presentations, the FDV indicator field is subject to WA Health information management laws and guidelines, including the State Records Act 2000(24), the Health Services Act 2016(23), the WA Health Information Access Use and Disclosure Policy(25), and the WACHS Health Record Management Policy(26). Access to WACHS Emergency Department data via the EDDET is governed by a strict approval process and staff accessing this information are obligated to abide by the aforementioned policies and laws, including by only accessing information where there is a requirement to do so for their job role, and by gaining express authorisation through appropriate approval channels when seeking to share information. Summary reports on FDV trends shared with key stakeholders will not include any identifying information and will consist only of aggregate counts and statistical information, which is allowed for in the WA Health Information Access Use and Disclosure policy(25).

Data collection method

Data for the FDV indicator will be collected by ED staff during an ED presentation, using a field in WebPAS. As per the flowchart above, staff will be able to record an answer to the FDV indicator (yes, no, or unsure) at both the triage and discharge screens of WebPAS. If 'yes' or 'no' is selected at triage, this value will automatically flow through to the discharge screen. If 'unsure' is selected at triage, the discharge field will be blank but mandatory to complete. While the two FDV indicator fields will be available for every ED presentation, some presenting complaints and diagnoses will trigger a mandatory response as per the quantitative analysis results.

Case definition

WACHS's EDDET, which contains data on all ED presentations in WACHS for the previous three years, is accompanied by a data dictionary. The data dictionary entry for the "FDV related" variable flowing from the indicator, and the information package prepared for ED staff to accompany the indicator's introduction, defines its values as follows:

- 'Yes' response to the FDV indicator: FDV has been explicitly disclosed either by the patient or someone accompanying them as the reason for their presentation to the ED, in line with the WACHS definition of FDV.
- 'Unsure' response to the FDV indicator: Either the ED staff member is unsure whether the reason provided by the patient for their presentation constitutes FDV; OR they suspect FDV has occurred, but it has not been disclosed by the patient; OR the possibility of FDV has not been ruled out.
- 'No' response to the FDV indicator: The reason given by the patient for their presentation is clearly unrelated to FDV and the ED staff member has no reason to believe it is FDV-related.

Transfer of information

A 'yes' or 'unsure' response to the FDV indicator at triage will prompt a pop-up reminder for staff to follow the ED-specific FDV Response Pathway, a resource that was developed as part of the QI Activity. This will be communicated differently between ED staff depending on facility operating procedures. A 'yes' or 'unsure' response will also activate a symbol to appear next to that patient's name on a further screen of WebPAS used for patient management and task delegation, allowing managing nurses to notify relevant staff of the need for screening.

WebPAS data flows to the EDDET database, which is based in Microsoft Power BI. A new 'FDV-related' variable has been added to the EDDET and will be derived from values of the FDV indicator at discharge. ED presentation data is available in the EDDET within 24 hours after an ED presentation has occurred, after data cleaning has been conducted.

Data analysis and dissemination of information

Data on FDV-related ED presentations will be available for analysis for anyone with custodian-approved access to the EDDET. Approved WACHS central office and regional staff will be able to conduct internal analyses on FDV on an as-needs basis. In addition, an automated Power BI dashboard has been developed to compile data on FDV trends on a daily basis, comprising aggregate data on FDV-related presentations, including patient and clinical characteristics. This dashboard will be used by Population Health central office staff to inform work priorities and areas for attention, alongside relevant contextual information. FDV ED measures are also planned to be included in actively disseminated reports, including the WACHS Safety & Quality Executive Committee monthly report, and a quarterly FDV snapshot report circulated to key stakeholders. Further details on the data reporting plan are provided in Appendix 2.

Quality Assurance

An audit of ED records is planned to assess the accuracy of data collected by the FDV indicator. At the time of writing, a trial audit tool is in development in RedCAP, and will be progressed for approval in late 2023. Auditors will use the audit tool to review a random selection of FDV indicator responses and cross check them against medical record notes to check accuracy and determine follow-up actions taken. The results of the audit will be assessed by Population Health Central Office staff, and sites with results indicating inaccurate use of the indicator field or suboptimal documentation of FDV response will be offered further support.

Attributes of the system

The process of establishing the FDV indicator involved consideration of how the indicator could best fulfill the best-practice attributes of a public health surveillance system(27). Table 4 provides a summary of the strengths and limitations of the FDV indicator system in relation to these attributes.

Table 4. FDV indicator strengths and limitations by surveillance system attributes

Attribute	CDC Definition(27)	Strengths	Limitations
Usefulness	Contribution of the system "to the prevention and control of adverse health events" and "understanding of public health implications of such events"	• Prompts FDV screening and response in real-time of presentation • Data informs health system resourcing	• Likely to miss some FDV cases
Acceptability	"Willingness of persons on whom the system depends to provide accurate, consistent, complete, and timely data"	• Developed in consultation with ED staff to fit with their needs and priorities	• Not all ED staff could be consulted on design • ED staff may use inaccurately

Attribute	CDC Definition(27)	Strengths	Limitations
Simplicity	Simplicity in system's "structure and ease of operation"; amount of resources required to operate	• Utilises existing data systems and infrastructure • Indicator field easy and quick for data collectors to use	• Requires human resources to interpret and communicate trends • FDV screening can be complex and time intensive
Data quality, PPV, sensitivity	Completeness and validity of collected data; proportion of cases detected; proportion of those identified truly cases	• Planned audit tool will allow for measurement of data quality • Targeted at high-risk presentations	• Underlying FDV rates inherently difficult to quantify • Likely to miss true FDV cases, especially where regional FDV trends differ from Kimberley
Timeliness	"Speed or delay between steps in the surveillance system"	• System prompts immediate action at the point of data collection • Data available for analysis within 24 hours	• FDV screening itself may take up significant time in ED
Flexibility	Adaptability to "changing information needs or operating conditions"	• Allows for updates to case definition and support resources • Potential to change mandatory triggers based on future analyses	• Specific to FDV, cannot easily be used for other health conditions
Representativeness	Accuracy in describing "occurrence of a health event over time" and its "distribution in the population"	• Available for use for all presentations in all WACHS EDs	• Data expected to be less accurate for non-mandatory presentations • Mandatory data collection based on Kimberley trends; may not represent other regions • Relies on patient disclosure

Usefulness

The FDV indicator system is intended to inform public health action to assist in the prevention of FDV-related morbidity and mortality. During relevant ED presentations, the system will prompt staff to undertake an ED-specific FDV Response Pathway, including screening, risk assessment, and intervention if necessary. The pathway instructs staff to help FDV patients develop a safety plan, and to direct them to local services if relevant. While the pathway will sit outside WebPAS, a 'yes' or 'unsure' response to the FDV indicator will trigger a pop-up reminder. This simple feature will help to avoid the pathway being overlooked in the busy ED environment.

Additionally, the introduction of the FDV indicator will allow WACHS to measure the incidence of reported FDV-related ED presentations, which is not currently possible. Inclusion of indicator data in the EDDET will enable further analysis, including measuring trends over time and across regions, and characterising FDV presentations by patient and clinical characteristics. These data can then be used to inform resourcing for EDs, including workforce planning and staff education, and may also assist with regional public health and prevention programs. A better understanding of the FDV patient cohort will also allow WACHS to cater their ED response appropriately.

Acceptability

The FDV indicator system was designed in consultation with ED clinicians that will use it to record data. The incorporation of staff feedback into the indicator design increases its acceptability, by ensuring that it fits well with existing processes. Features of the system, including the Response Pathway, the fact that the indicator will not be mandatory for all presentations, and the way the indicator response flows through WebPAS, were all designed to address concerns from ED staff.

The targeted consultation process meant that most WACHS sites were not able to participate. The addition of new requirements may be received poorly by some ED staff, especially if they do not understand the purpose of the indicator, which may result in the field being used inaccurately. To address this, communication products will focus on the benefits of the indicator. WACHS plans to conduct further consultations with ED staff to inform future enhancements to the indicator if necessary.

Simplicity

The FDV indicator is designed to be easy to use, for both people entering and analysing data. It is a simple drop-down field, and uses existing systems for data collection (WebPAS), data storage (EDDET), and data analysis (Power BI).

While the indicator field itself is relatively simple to complete, the conversation that an ED staff member may have with a patient in order to determine the answer could be complex. The translation of this information to the indicator relies heavily on the clinical expertise of ED staff, informed by existing WACHS education and training in this area. Interpretation of trends conducted by Population Health Central Office staff, and communication of this to executive, regional staff and other internal committees on an as-needs basis, will also add some complexity to the system. However, this is necessary to allow for the consideration of important contextual information alongside quantitative trends.

Data quality, positive predictive value, sensitivity

The sensitivity of the FDV indicator system will be impaired by the nature of FDV case ascertainment, which relies on both willingness from victim-survivors to disclose, and the skill and knowledge of ED staff in managing these conversations. This will likely result in underestimates of FDV cases, which will be exacerbated by expected lower rates of data completeness for presentations without a mandatory trigger. Because mandatory triggers were selected based on an analysis of Kimberley presentations alone, this may result in data from other regions being less sensitive and accurate, especially as FDV patterns and manifestations may differ in other regions compared to the Kimberley. These limitations to data quality were acknowledged throughout the project, and will be communicated to stakeholders receiving data reports.

The FDV indicator aims to maximise positive predictive value by targeting mandatory triggers at the presentations most likely to be related to FDV. This feature is intended to prompt ED staff often enough that it is useful and increases data collection, without becoming an imposition that staff complete quickly but inaccurately in order to fulfil the requirement.

The planned audit tool will enable comparison between the data collected through the indicator and more detailed information recorded in patient files. This will provide important insight into whether the data collected through the indicator is an accurate reflection of information disclosed by patients during their ED presentation. Further communication and education resources can then be targeted to sites and regions as necessary.

Timeliness

One of the key strengths of the FDV indicator is that it is designed to prompt an immediate response to FDV-related ED presentations. ED staff reported in consultations that the real-time functionality of the indicator, which links the indicator response with ED-specific advice, was an essential part of the system and would help to improve patient safety.

Data flowing from the FDV indicator will be available in the EDDET within 24 hours of a presentation, with the linked Power BI dashboard updated automatically. This will allow for timely consideration of any changes in FDV trends by Population Health staff. The timing of active reporting, including the quarterly snapshot report and monthly Safety & Quality measure, will be reviewed with stakeholders once the second phase of the indicator is implemented to ensure utility.

Flexibility

The flexibility of the FDV indicator is limited because it is designed specifically to record FDV-related presentations and cannot be used to capture information on other health events or conditions. However, other changes could be incorporated into the FDV indicator if required, including an updated FDV case definition, screening and/or intervention requirements, or changes to reporting practices. These would require updates to the supporting infrastructure of the indicator, including the EDDET data dictionary, the FDV Response Pathway, or the summary dashboard.

Representativeness

While the FDV indicator will improve the available data on FDV-related ED presentations across country WA, the data captured by the indicator will not be representative of all FDV-related presentations. The indicator is expected to be completed more frequently when it is mandatory to do so. Consequently, females with non-mandatory presenting complaints and diagnoses, and any presentations among males, are less likely to be identified by the indicator, as are presentations among people who are trans or non-binary, who cannot be clearly identified in WebPAS currently. This issue will be heightened in non-Kimberley regions, which have been assigned mandatory triggers based on the analysis of Kimberley presentations, but which may have differing FDV manifestations that will not be picked up by mandatory responses to the indicator. This was acknowledged as a limitation of the system throughout the project, and was balanced against the risks of making the indicator mandatory for every ED presentation (i.e. an undue administrative burden on busy ED staff, and the risk that the indicator would become meaningless to staff if triggered too frequently). This limitation will be managed via the distribution of comprehensive guidance for ED staff on additional groups at higher risk of FDV, and by encouraging staff to complete the indicator for every relevant presentation.

Conclusion

The FDV indicator and its supporting structures do not constitute a perfect public health surveillance system. The data collected by the system will have flaws, including that it is likely to underestimate the number of FDV-related presentations. The success of the system will be dependent upon ongoing work by WACHS, including consultations with ED staff and stakeholders receiving data reports, a

review of the mandatory triggers, and continuing education for ED staff on FDV identification and response.

When fully implemented, the FDV indicator will comprise a small part of a holistic and society-wide response to FDV. It will improve the service delivered to FDV patients in the ED, and inform resource allocation and program delivery in the longer term. The key strength of the FDV indicator system is its dual utility for both ED staff and WACHS decision-makers. This means it is likely to be highly acceptable to data collectors, who have been meaningfully consulted during the design phase. The indicator is integrated with existing systems where possible, to ensure simplicity and timeliness of data collection, analysis and dissemination. Supports to the FDV indicator, including the development of a data dictionary, the creation of a plan for data reporting, and the planned introduction of an audit of FDV indicator records, will help to ensure that it works effectively to achieve its aims.

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Appendix 1: Lay Summary — Rationale for FDV indicator mandatory triggers

Frequently Asked Questions: FDV indicator mandatory triggers rationale

Background

WACHS is implementing a new field in WebPAS ED called the 'FDV indicator'. The FDV indicator has two functions:

1. It will enable staff to record whether an ED presentation is related to family and domestic violence; and
2. It will prompt staff to consider FDV risk and screen for FDV in certain presentations.

The FDV indicator will be available for every ED presentation. It will sit on the triage, clinical and discharge screens of WebPAS. Feedback from ED staff indicates that making the indicator mandatory to complete will increase the chance that it is used for any given presentation.

The introduction of the FDV indicator has important benefits for country WA people including:

1. It will enable WACHS to analyse data on FDV trends that can be used to inform program changes to reduce FDV morbidity and mortality; and
2. It will improve the identification and response to patients presenting to EDs with FDV.

Why is the FDV indicator only mandatory to complete for some presentations?

FDV can happen to anyone. People presenting to ED because of FDV have diverse genders, ages and backgrounds, and may present very differently. Whilst evidence suggests people experiencing FDV attend EDs at a greater rate than the general population, FDV-related presentations are likely to comprise a small proportion of ED presentations overall.

The placement of additional mandatory requirements on ED staff, who already experience a high workload, needs to be considered carefully. Any mandatory requirements should therefore be evidence-based and proportional to risk. Given this context, it is not feasible to require completion of the indicator for every ED presentation. Doing so is likely to place an undue burden on staff and may result in the indicator being used incorrectly. So, while the indicator may be completed for any ED presentation, it will be mandatory for a selection of presentations, based on evidence-based criteria outlined below. This approach is similar to that taken by other public health programs in Australia, such as cancer screening programs that are targeted at high-risk population groups.

While this will likely result in some cases of FDV being missed, it is intended to maximise the value the indicator provides to staff while minimizing the resources required to use it. The costs and benefits of this approach have been carefully considered in the design of the indicator.

How were presentations requiring a mandatory response to the FDV indicator determined?

To determine when the FDV indicator should be mandatory to complete, WACHS Population Health conducted quantitative analyses of known FDV presentations in WACHS. Initial examination of these data found that females were 5.4 times as likely as males to present to ED with FDV between 2019 and 2022. This pattern aligns with the results of other Australian research, including that:

- Women are at higher risk of physical or sexual violence from an intimate partner, and emotional abuse from an intimate partner, compared to men.
- Between 2010 and 2019, 68% of those hospitalised for family and domestic violence in Australia were female.

- For each year between 2015 and 2022, females comprised the majority of family and domestic violence-related homicide victims.

Because WACHS has existing Child at Risk processes in place to identify and respond to children at risk of FDV, it was determined the FDV indicator does not need to target children as the primary patient. As a result of this analysis and contextual information, selection of mandatory triggers was narrowed to presentations among females aged 16 years and older. A case-control analysis was conducted to determine which presenting complaints and diagnoses were correlated with FDV and should prompt a mandatory indicator response[1]. The results of that analysis are outlined here.

Some known high-risk groups did not meet the threshold for mandatory triggers. These included females presenting with pregnancy, mental health or drug and alcohol related complaints. While FDV presentations among men are less common than in women, analysis showed that when men do present with FDV, they are most likely to present with injuries or mental health complaints.

What are the limitations of the data that will be collected by the FDV indicator?

The FDV indicator is more likely to detect FDV in presentations with a mandatory trigger, including presentations among females, compared to those without a mandatory trigger. This is understood as an inherent limitation of the system and will be clearly communicated to stakeholders receiving data reports.

Will the mandatory triggers be reviewed in the future?

WACHS Population Health plans to conduct further quantitative analyses using data collected through the FDV indicator after 12 months of operation, which will control for the effect of mandatory triggers on the data. This work will be used to inform any recommended changes to the FDV indicator functionality, including when it should be mandatory to complete.

Upcoming WebPAS changes, including a new gender identity field, will allow for the examination of additional risk factors.

How will staff be informed about using the FDV indicator?

Resources outlining recommended processes for identifying and responding to FDV in the ED context are being developed and will be available to ED staff.

As part of the implementation of the FDV indicator, communications to ED staff will emphasise that the indicator is available for all presentations and should be completed whenever relevant, regardless of whether a mandatory trigger is applied. As per the WACHS Identifying and Responding to FDV Policy, staff are advised to screen for FDV if they suspect a patient may be at risk of FDV or observe high risk signs such as: pregnant women; people presenting with mental health or drug and alcohol related complaints; people who have recently separated from their partner; and trans, gender diverse and other LGBTQIA+ people.

[1] This analysis was conducted by Virginia DeCourcy as part of her Master of Applied Epidemiology degree. Virginia undertook a field placement at WACHS while completing the degree through the Australian National University.

Appendix 2: FDV indicator data reporting plan

Family and Domestic Violence Indicator Data Reporting Plan

Background

The FDV indicator is a new field in WebPAS ED that enables staff to record whether ED presentations are related to family and domestic violence (FDV). The indicator was implemented into WebPAS on 1 July 2023 as a voluntary field on the triage and discharge screens. Enhancements to the indicator are planned for 2024, including addition of triggers to make the field mandatory to complete for some presentations. These enhancements are expected to increase data collection, and routine data analysis and reporting will commence following their implementation.

Ad-Hoc Requests

Internal ad-hoc requests regarding FDV ED data and trends can be directed to WACHS Senior Project Officer for Family Safety. They will manage and respond to requests in consultation with WACHS Population Health Central Office staff, WACHS Data and Analytics, and the WACHS Research Governance Unit as necessary.

WACHS Safety and Quality Executive Committee Report

A new indicator measure will be added to WACHS' Safety Quality Indicator Report, reported on quarterly to track incidence of FDV-related presentations across time and WACHS regions. This report is tabled for discussion at the monthly meeting of the WACHS Safety and Quality Executive Committee. The measure will report on the rate of FDV per 1,000 Emergency Department presentations, and will sit with other indicators of 'Comprehensive Care' as per the Australian Committee on Safety and Quality in Healthcare standards.

Snapshot Report on WACHS FDV Data

A two-page infographic report will be prepared at 6-monthly intervals and circulated to relevant stakeholders as outlined in Table 1. This report will provide an overview of FDV trends across the key FDV entry points including antenatal, child health, hospital admissions, and mental health. It will also have a section on FDV detected in the ED context will include information on the overall rate of FDV presentations in ED, FDV presentations and rates by region, timing of FDV presentations, and other variables as relevant.

WACHS FDV Dashboard

The FDV dashboard will be automatically updated daily and will include further detail on FDV-related presentations, including demographic and clinical characteristics of patients. This dashboard will be used by Population Health central office staff to inform work planning and areas for attention and follow-up.

Emergency Department Data Exploration Tool

The full set of available data on FDV-related ED presentations will be available in the EDDET for those with access to this database. The database includes over 180 variables for each ED presentation in a line list format, and is filterable. This will allow users to examine as much or little detail about FDV-related presentations as necessary for their purposes. The data dictionary linked to the dataset defines values for the FDV-related variable, allowing users to accurately interpret these data.

Table 1. Planned data reporting mechanisms for FDV indicator

	Format	Frequency	Audience	Purpose	Measures included	Responsible
Active Reporting						
Safety & Quality report	Row in Indicator table of PDF report, circulated in meeting papers via email	Quarterly	WACHS Safety and Quality Executive Committee	Measure WACHS performance against ACSQHC standards, enable recognition of changes in FDV ED presentation rates	• Rate of FDV presentations per 1,000 ED presentations, overall and by region	Senior Project Officer Family Safety, Population Health
FDV snapshot report	Two-page PDF infographic, circulated via email	Six monthly	• WACHS Executive Director Clinical Excellence • WACHS Regional Executive Directors • WACHS Regional Safety & Quality Managers	Increase awareness of FDV trends in country WA among key decision makers, provide baseline ED statistics for comparison in future time periods	• Rate of FDV presentations per 1,000 ED presentations • Count and rate of FDV presentations by region • % of FDV presentations outside of hours (9am-5pm weekdays)	Senior Project Officer Family Safety, Population Health
Passive Reporting						
FDV Dashboard	Online Power BI dashboard	Daily	WACHS Population Health team	Inform daily work and priorities of Family Safety portfolio, identify issues for escalation where necessary	Summary information: • Rate of FDV presentations per 1,000 ED presentations, by calendar month for last 12 months • Count of FDV presentations by calendar month for last 12 months Filterable by region and time period, aggregate counts of FDV presentations by: • Sex • Age group	Senior Project Officer (Data & Analytics), Population Health

					• Aboriginal status • Presenting complaint category • Major diagnosis category • Departure status • Time category of presentation	
ED Data Exploration Tool	As required	Daily	All WACHS personnel with data custodian approval	As needed	All 180+ variables included in dataset, including service-related, patient, clinical, quality indicator variables	WACHS Data & Analytics Services
Reactive Reporting						
Ad-Hoc requests	As required	As required	Specific stakeholders requesting information	Address internal or external research, reporting or briefing questions	As required	Senior Project Officer Family Safety, Population Health

Chapter 5: Investigating opportunities to prevent rheumatic heart disease-related mortality in Western Australia

Contents

Prologue

This chapter describes a mixed methods research project on rheumatic heart disease (RHD)-related mortality in Western Australia (WA), which I worked on for the majority of my field placement at the WA Country Health Service (WACHS). This work was completed to fulfil the Master of Philosophy in Applied Epidemiology (MAE) core competency to design and conduct an epidemiological study. Throughout the project I also completed work to fulfil the minor competencies to conduct a targeted literature review; present at a national or international scientific conference; and prepare an advanced draft of a paper for publication to a peer-reviewed journal.

This chapter comprises a structured literature review. An advanced draft manuscript describing the research results is included in Appendix 1.

My role

While this research project was conducted as part of my field placement at WACHS, I also worked in partnership with A/Prof Judith Katzenellenbogen, Dr Emma Haynes, and Ms Ingrid Stacey from the Cardiovascular Epidemiology Research Centre (CERC) at the University of Western Australia's (UWA) School of Population and Global Health, and Dr Daniel Hunt from the Derbarl Yerrigan Health Service.

At the outset of the project I formed an Aboriginal health advisory group, including Russell Simpson from WACHS, Melanie Robinson from the WA Child and Adolescent Health Service, and Lynette Dimer from the Heart Foundation, who provided guidance on the direction and scope of the study. I worked with the research team and the advisory group to develop a study question and design the mixed methods study. I then developed the study protocol and prepared and submitted two ethics applications, one to the WACHS Human Research Ethics Committee (HREC) and another to the WA Aboriginal Health Ethics Committee. I also applied to the Australian National University (ANU) HREC for recognition of prior approval. While I was waiting for ethical approval, I conducted a targeted literature review.

I was the Coordinating Principal Investigator for the study, which comprised three analyses. The first was an investigation of RHD-specific mortality rates in WA using data from the Australian Bureau of Statistics (ABS). With guidance from the research team, I liaised with the ABS to obtain this data, calculated age-specific and age-standardised mortality rates, and compared these across sex, time period and Aboriginal status variables. After an error in the ABS' processing of WA death certificates was revealed, I requested a revised dataset and conducted the analysis again. This analysis is outlined in Supplement A of the draft manuscript included in Appendix 1.

The second part of the study was a descriptive analysis of records from the WA RHD Register. I liaised with the RHD Register team in the WACHS Central Office to obtain this data, managed a data transfer

to UWA, cleaned the data and conducted the analysis. The third part of the study was a thematic qualitative analysis of RHD stakeholder interviews. With guidance from the research team and the Aboriginal health advisory group, I developed an interview guide, identified and contacted potential interviewees, organised and conducted nine interviews, developed transcripts, coded transcripts in NVivo, and developed a thematic framework to communicate findings.

Alongside Dr Daniel Hunt, I presented the results from the ABS mortality rates analysis and preliminary qualitative results from the interviews in a long oral presentation at the Communicable Disease and Immunisation Conference in Perth in June 2023. A copy of the slides from this presentation is included in Appendix 2 of this chapter.

I prepared an advanced draft manuscript for submission to the Australian Journal of Rural Health, focusing on the results from the RHD Register analysis and the qualitative interviews, which was edited and reviewed by the research team and the Aboriginal health advisory group, and also circulated to interview participants for checking. At the time of writing, the manuscript is in final review before submission to the journal. The advanced draft manuscript is presented in Appendix 1.

Lessons learnt

In terms of time and resources, this was the most significant field project I worked on during my MAE placement. I had limited prior subject matter knowledge of RHD before the project, which I had to develop quickly and build throughout. I learnt about RHD causality, epidemiology, prevention and treatment, the policy context of RHD, and the impact of RHD in Aboriginal communities. This project deepened my understanding of Aboriginal health, including the systemic drivers of ill-health, the ongoing impacts of colonisation, and the value of community-led programs and services.

During this project, I gained experience in academic research processes, including developing an ethics application, presenting at a scientific conference, and preparing a paper for a peer-reviewed journal. Working with a multidisciplinary research team from four institutions, I learnt the value of a diverse team, the skill of managing differing perspectives, and the importance of regular and clear communication. I also developed several technical skills throughout the project, including the design and conduct of a qualitative interview, the development of a thematic framework using qualitative data, and practical experience using age standardisation. I used two new software programs, NVivo and SAS. While I was challenged by multiple aspects of the project, I was glad to have had the opportunity to develop these skills, and expect that they will be useful throughout my epidemiological career.

Public health impact

RHD is a preventable disease that affects over 7000 Australians and has a disproportionate impact among Aboriginal and Torres Strait Islander peoples(1). While deaths from RHD are relatively rare, they have profound impacts on families and communities, and indicate shortcomings in the health system.

The study described in Appendix 1 makes several recommendations to prevent RHD deaths in WA in the future. It is the first study to focus on RHD-related mortality in WA specifically, and therefore makes an important contribution to Australian RHD scholarship, as well as providing evidence for policy and system change in WA. This study is also the first to use mixed methods to investigate RHD-related mortality in Australia. It demonstrates the value of employing both quantitative and qualitative methodologies to generate insights, especially in a complex and sensitive area of inquiry.

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Thanks to my three supervisors for your advice throughout this project, your many reviews of the manuscript and the contents of this chapter. Particular thanks to Marisa Gilles for suggesting the topic, helping me negotiate the WACHS processes, linking me up with Judy and the CERC group and for reviewing the manuscript while on holiday.

Thanks to Russell Simpson, Melanie Robinson, and Lynette Dimer, who provided advice on the design and framing of the study. Thanks to Melanie and Russell for reviewing the conference presentation and the manuscript. Your input was valued and much appreciated. Thanks also to those who helped with data extracts, especially Lauren Moran and the mortality data team from the ABS, and Jess de Dassel from the WA RHD Register team.

Finally, thanks to the stakeholders who gave up their valuable time to be interviewed for the research, and who provide vital and life-saving care to people with RHD in WA.

Literature Review

Background

RHD is characterised by valvular heart damage that develops following one or more episodes of Acute Rheumatic Fever (ARF), which is itself an immune reaction to a Group A Streptococcal infection(2). Progression through this disease pathway is associated with the social determinants of health, with global rises in living standards coinciding with a significant decrease in RHD mortality globally since 1900(3). Despite this, relatively high RHD morbidity and mortality rates persist in low and middle-income countries, and within particular, often indigenous, population groups in higher-income countries(4). In Australia, RHD contributes significantly to morbidity and mortality, especially among Aboriginal and Torres Strait Islander people and communities.

Most people who develop RHD will experience a long period of disease without any symptoms. When they do appear, symptoms can include breathlessness, reduced exercise tolerance, arrythmias, stroke, infective carditis and pregnancy complications(2). Other serious complications of RHD include heart failure, pulmonary hypertension, and atrial fibrillation(2). Screening via echocardiography can detect RHD early) and is encouraged in high-risk populations in Australia(2).

Recommended management for people with RHD in Australia is detailed in national guidelines(2). Follow-up recommendations differ depending on the severity of disease and the assigned priority level, but typically include regular secondary prophylaxis via penicillin injections, echocardiogram screening, and specialist, medical and dental review. Pregnant women, who are at higher risk of RHD complications, require careful monitoring and specialised treatment. For some patients, valvular surgery may be required, via a valve replacement (with either a mechanical or bioprosthetic valve) or valve repair procedure. All surgery patients will require ongoing follow-up, and those with a mechanical valve will require lifelong anticoagulation medication. As at December 2021, there were 6,869 prevalent RHD cases recorded by the five state-based RHD registers in Australia(1). The RHD rate across Queensland, South Australia (SA), WA and the Northern Territory (NT) (67/100,000 population) compares favourably with that estimated globally for countries with endemic RHD (444/100,000 in 2015), but is higher than the rate in non-endemic countries (3.4/100,000)(5). In these four jurisdictions, the RHD rate is notably high among Aboriginal and Torres Strait Islander people (1,083/100,000 population) compared to non-Aboriginal people(1).

All-cause mortality among RHD cases in Queensland, WA, SA and the NT was 595 deaths between 2017 and 2021, with higher proportions of deaths among females compared to males, Aboriginal and Torres Strait Islander people compared to non-Aboriginal people, and those aged 65 and over compared to younger age groups(1). Between 2017 and 2021, the median age at death among Aboriginal and Torres

Strait Islander people living with RHD was approximately 20 years younger than that for non-Aboriginal people.

Methods

I conducted a semi-structured literature review to answer the question: *according to existing research, what demographic, clinical and systemic factors are associated with RHD-related mortality?* I searched PubMed on 4 October 2022, using a combination of the search terms "rheumatic heart disease", "RHD", "mortality", "death", "severity", and "outcome". I searched for records published since 1 January 2000 and for search terms in titles only.

Of 115 articles meeting these criteria, 44 were excluded after screening of their title and/or abstract, four could not be retrieved, and 27 were excluded based on relevance. There were 11 reports and articles, including nine qualitative studies, included following reference list review, for a total of 50 sources included. A summary of the source selection process is included in Figure 1.

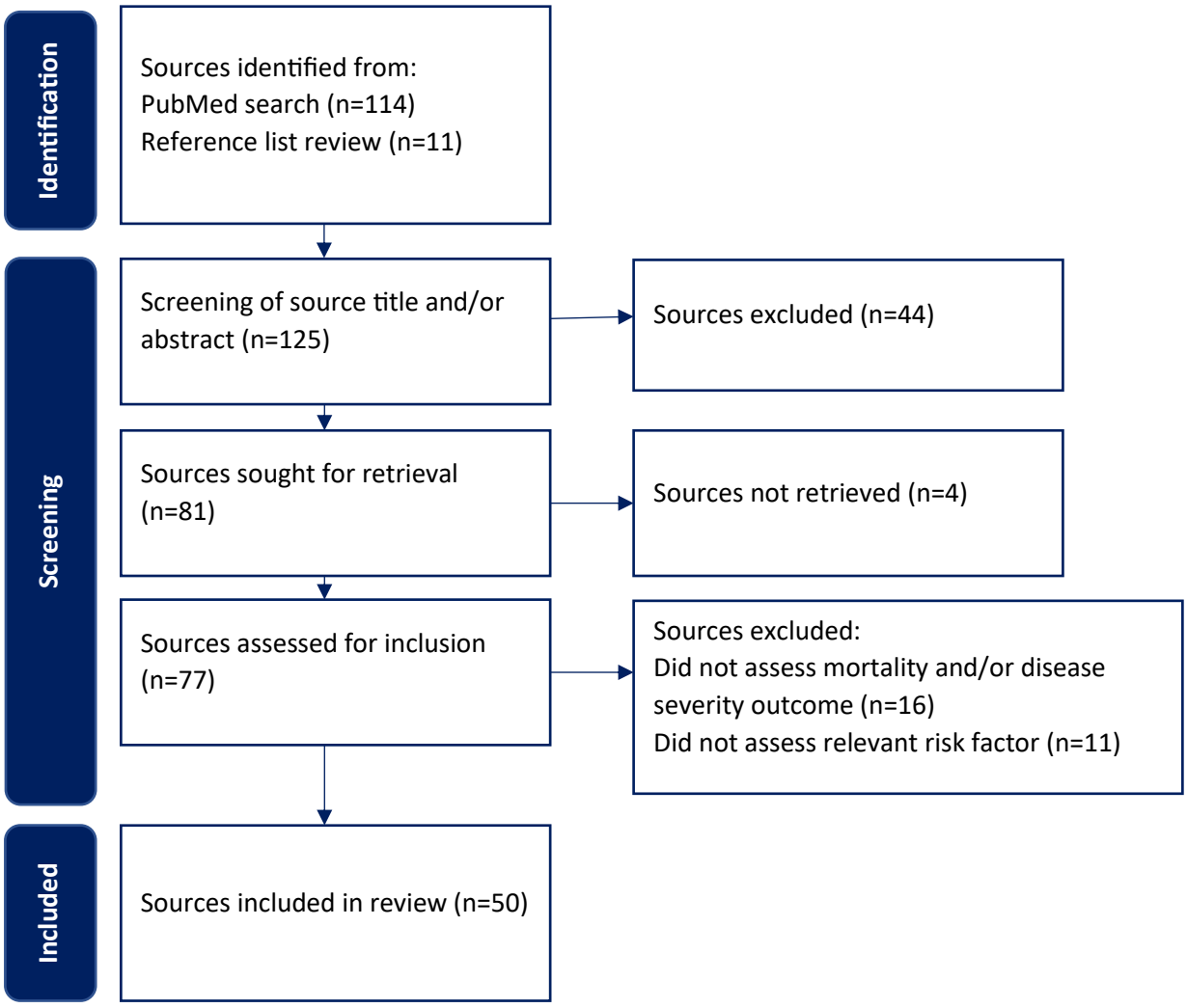

Figure 1. Selection of sources for targeted literature review, 2022

Results

A broad range of demographic, clinical and systemic factors were linked with RHD mortality and complications in quantitative studies [Table 1]. Most studies investigated all-cause mortality in people diagnosed with RHD, while others examined RHD-specific mortality or complications. In Table 1 below, a (+) indicates a finding of a positive or predictive link between the factor and outcome assessed; a (-) indicates a negative or protective link; and a (~) indicates no relationship was found. Studies conducted in Australia are in bold.

Table 1. Summary of findings among quantitative studies included in literature review

	Outcome assessed		
Factor assessed	**RHD complications or progression**	**RHD-attributable mortality**	**All-cause mortality**
Demographic Factors			
Male sex	(~) Murni 2021 (6)	**(-) Colquhoun 2015 (7)** (-) Cui 2022 (8) **(-) Davies 2014 (9)** (~) Fernandes 2014 (10) **(+) Hofer 2014 (11)** (+) Okello 2017 (12)	(+) Chang 2020 (13) **(+) He 2016 (14)** **(~) Kang 2021 (15)** (+) Parks 2015 (16) (~) Pillai 2021 (17) **(~) Stacey 2021** (-) Thomson 2014 (18) (~) Zimmerman 2022 (19) (+) Zuhlke 2016 (20)
Older age	(-) Beaton 2014 (21)	**(+) Colquhoun 2015 (7)** (+) Cui 2022 (8) (+) Fernandes 2014 (10) (+) Fu 2017 (22) (+) Yakub 2013 (23)	(+) Davarpasand 2015 (24) (+) He 2016 (14) (+) Kang 2021 (15) (+) Negi 2021 (25) (+) Stacey 2021 (26) (~) Thomson 2014 (18) (+) Zuhlke 2016 (20)
Aboriginal and/or Torres Strait Islander ethnicity		**(+) Alizzi 2010 (27)** **(+) Colquhoun 2015 (7)** **(+) Davies 2014 (9)** **(+) Hofer 2014 (11)**	**(~) Alizzi 2010 (27)** **(+) He 2016 (14)** **(~) Kang 2021 (15)** **(+) Lawrence 2013 (28)** **(~) Russell 2017 (29)** **(~) Stacey 2021 (26)**
Other indigenous ethnicity		(+) Milne 2012 (30)	(+) Parks 2015 (16) (~) Thomson 2014 (18)
Rural location		(+) Cui 2022 (8)	**(~) Kang 2021 (15)** **(-) He 2016 (14)** **(-) Stacey 2021 (26)**
Presence of comorbidities		(+) Debel 2020 (31) (+) Fernandes 2014 (10)	(+) Davarpasand 2015 (24) **(+) He 2016 (14)** **(+) Russell 2015 (32)**
Clinical factors			
Severe RHD rating or NYHA Class III or IV		(+) Fu 2017 (22)	**(~) Kang 2021 (15)** (+) Negi 2021 (25) (+) Sawhney 2003 (33) (+) Suri 2019 (34) (+) Zimmerman 2022 (19) (+) Zuhlke 2016 (20)

Factor assessed	RHD complications or progression	RHD-attributable mortality	All-cause mortality
Receipt of any valvular surgery			(+) Ali 2019 (35) (~) Hauge 2021 (36) (+) Mehta 2016 (37) (~) Parks 2015 (16) (-) Zimmerman 2022 (19)
Receipt of valve repair rather than replacement		(-) Fu 2021 (38) (-) Jiang 2021 (39)	(-) Fu 2021 (38) (-) Jiang 2021 (39) (-) Remenyi 2013 (40) **(~) Russell 2017 (29)** (~) Singh 2022 (41) (~) Thomson 2014 (18)
Receipt of bioprosthetic rather than mechanical valve		(~) Tamirat 2021 (42)	(+) Rusingiza 2018 (43) **(+) Russell 2015 (32)** (+) Tamirat 2021 (42)
Higher adherence to BPG prophylaxis	(~) Murni 2021 (6)	(-) Okello 2017 (12)	(-) Chang 2022 (44) (-) De Dassel 2021 (45) (~) Zuhlke 2016 (20)
System factors			
History of ARF; known to RHD control program			**(-) Stacey 2021 (26)** (-) Parks 2015 (16)
Severe RHD at diagnosis	(~) Murni 2021 (6)		**(+) Cannon 2017 (46)** **(+) Lawrence 2013 (28)**
Older age at RHD diagnosis	(+) Murni 2021 (6)		**(~) Cannon 2017 (46)**
Earlier or greater access to care			(-) Chang 2022 (44) (-) Gunther 2006 (47) (-) Suri 2019 (34)
RHD detection via screening vs clinical		(-) Engelman 2017 (48)	

Demographic factors

The relationship between RHD-related mortality or complications and sex was discussed in 16 sources, with variable results. Six studies described a positive link between male sex and all-cause or RHD-specific mortality. Most of these studies drew their participants from RHD registers, including the large multi-country REMEDY study, which assessed outcomes of over 3000 RHD patients from 14 low and middle-income countries(13,14,16,20). Conversely, four studies found a positive link between female sex and mortality, including two general population-based studies, although these results may reflect the higher underlying RHD incidence among females(7-9,18). A further six studies found no significant relationship between sex and RHD complications or mortality(6,10,15,17,19,26). The effect of gender on health-seeking behaviour was raised as an explanatory factor for the higher risk among both males(14) and females(18). Evidently, the relationship between RHD-related mortality and sex is not universal, and specific contextual factors may influence how this relationship plays out in different settings.

Included sources indicated that RHD-related mortality follows the expected pattern of increasing risk with increasing age. Older age was reported as a risk factor for RHD-specific or all-cause mortality in 11 studies, including two general-population based studies(7,8); five studies of RHD patients using register and hospitalisation data(14,15,20,25,26) and four studies among RHD patients undergoing valve surgery(10, 22-24). One study in surgery patients found no significant association between age and mortality, but the authors do not comment further on why this finding is inconsistent with other research(18).

Of the Australian studies, most discussed the relationship between mortality risk and Aboriginal and/or Torres Strait Islander status, reflecting the higher risk of RHD overall in this group. These included four studies demonstrating a higher risk of RHD-specific mortality among Aboriginal and Torres Strait Islander than non-Aboriginal people(7,9,11,27); and two reporting higher all-cause mortality in Aboriginal than non-Aboriginal people based on register data(14,28). Four studies found no difference in overall mortality risk between Aboriginal and non-Aboriginal people, but two of these noted that Aboriginal people were affected by RHD at younger ages, including a Queensland study which reported a 48-year difference in median age at death between Aboriginal and non-Aboriginal patients(15,26,27,29). Internationally, two studies reported higher mortality among indigenous compared to general population groups(16,30), while another found no relationship between ethnicity and mortality risk(18).

Despite evident health access disparities in rural compared to urban areas, most assessed studies did not report a higher RHD mortality risk in rural residents. Although one Chinese study found consistently higher mortality among RHD patients in rural areas(8), one Australian study found no relationship(15), and a further two Australian studies reported higher mortality risk among RHD patients residing in cities(14,26). Authors of one of the Australian studies proposed that the focus on RHD control in rural areas may contribute to urban cases being detected later or missed, leading to a higher risk of adverse outcomes, and emphasised that tertiary care access barriers are still relevant for urban residents despite their geographical proximity(26).

Several studies demonstrated a positive link between comorbidities and RHD mortality risk. These included studies linking diabetes(10), kidney disease(24,32), and comorbidity index score(14) with higher likelihood of RHD-related mortality. No studies reported a nil or negative relationship between comorbidities and mortality.

Clinical Factors

Unsurprisingly, evidence in the literature consistently demonstrated lower mortality risk among people with less severe RHD, with six studies in agreement(19,20,22,25,33,34). Disease intensity was

measured either with a 'mild, moderate, severe' rating, as generally used by RHD control programs, or as a functional New York Heart Association (NYHA) score, across different studies. Notably, in the large REMEDY cohort study, a 'severe' disease rating was the strongest predictor of mortality(20). However, one Australian study found no relationship between disease severity and mortality risk following multivariate analysis(15).

While valvular surgery is a well-accepted form of management for patients with severe RHD, just one study, conducted among Ugandan children, found that cardiac intervention was significantly protective from mortality(19). Three further studies found no reduced mortality risk in RHD patients who received surgery compared to those who did not(16,35,36), although authors suggested that the higher disease severity among surgery recipients is likely to have affected this relationship(35,36). Valve repair rather than replacement was protective against mortality in three studies, including a meta-analysis incorporating 16 studies(38-40), while a further three studies found no significant relationship between surgery type and mortality outcome(18,29,41). Among the three studies investigating outcomes in valve replacement patients, bioprosthetic valves were consistently associated with higher all-cause mortality, although one of these found no difference in surgical mortality between valve types(32,42,43).

The secondary prevention of ARF, generally via the administration of regular benzathine penicillin G (BPG) injections, is a cornerstone of RHD control programs globally(45). Of the included studies, three reported that receiving a higher number of BPG doses was protective against mortality, including a NT nested case-control study, which found that three measures of BPG non-adherence were significantly associated with mortality risk(12,44,49). Two studies found no significant relationship between secondary prevention and mortality or progression risk(6,20). The authors of the REMEDY study suggest this finding was likely affected by the late presentation of their cohort to health care services, limiting the preventative effect of BPG injections(20).

System factors

The findings of several quantitative studies indicate that contact with the health system lowers the mortality risk for RHD patients. A number of studies suggested benefits to the earlier detection of RHD, including two Australian studies reporting a higher mortality risk among those with severe disease at diagnosis(28,46), a study among Indonesian children that found older age at diagnosis a risk factor for disease progression(6), and a Fijian study that found that RHD patients who were detected via screening were less likely to die than those who were diagnosed clinically(48). Three studies conducted in low and middle-income countries reported a negative relationship between access to care and mortality, including a large Ugandan cohort study finding that those "retained in care" were less likely to die than those who were not(34,44,47). The authors of an Australian study that found lower

mortality and complications among those with a recorded ARF diagnosis propose that this could be attributable to improved monitoring and delivery of prevention in this group(26).This corresponds with the results of a Fijian cohort study, which demonstrated that those who were known to the RHD control program had a lower risk of death than those who were not(16).

These quantitative results were supported by the findings of Australian studies that examined the structural and systemic barriers to care for Aboriginal and Torres Strait Islander people with RHD. The failure of Australian health systems to adequately incorporate Aboriginal knowledge systems and perspectives into health messaging, resulting in limited access to services by Aboriginal people with RHD, was highlighted in three studies(50-52). The Australian RHD Guidelines and two further studies on care-seeking among Aboriginal and Torres Strait Islander cardiac patients also emphasise this point(53,54). Fear was reported as a barrier to seeking care, and may stem from knowledge of or personal experience of racism in a health setting(51,53,55,56). The tendency of mainstream health services to characterise RHD progression as the fault of the individual or family rather than examining structural disadvantages was also discussed as a disincentive to care seeking(51,52,54). Provision of culturally safe care, including acknowledging the impact of colonisation and socioeconomic inequity on health outcomes, was reported as an enabler of access for Aboriginal and Torres Strait Islander people with RHD(50,53,54). Ensuring a stable, culturally competent mainstream health workforce(50,51,56-58); involving family and community in care discussions and decisions(52,53); and appropriate resourcing of the Aboriginal and Torres Strait Islander health workforce(2,15,56) were suggested to improve access to care for Aboriginal and Torres Strait Islander people with RHD.

Conclusion

The available literature on mortality in people with RHD indicates that a broad range of factors may contribute to, or protect from, the risk of death. Literature suggests that older age, Aboriginal and Torres Strait Islander or other indigenous ethnicity, severe disease, valve replacement rather than repair, lower BPG adherence, presence of comorbidities, and limited access to RHD care, contribute to higher mortality risk in people with RHD. However, the relationship between mortality risk and other factors, including sex and location, is less clear – with contextual factors likely affecting these relationships in different settings. What is clear from the literature is that RHD progression, complications and mortality occur in a complex environment in which drivers of outcomes are multifaceted and inter-related.

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Appendix 1: Advanced Draft Manuscript (Restricted)

Opportunities for reducing rheumatic heart disease-related mortality in Western Australia: a mixed methods study

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Abstract

Introduction

Preventable rheumatic heart disease (RHD) deaths continue to occur in Australia, with Aboriginal people disproportionately affected. Despite research into structural drivers and the lived experience of people with RHD, and national guidelines focusing on RHD prevention and treatment, recent coronial inquests have highlighted that systemic failures are ongoing. Few studies describe RHD service delivery and/or mortality within the Western Australian (WA) context.

Objective

This study aimed to integrate quantitative information regarding RHD-related deaths in WA between 2012 and 2021 with qualitative interview data, to identify system-level opportunities for the prevention of RHD-related mortality in the WA health care setting.

Design

Using quantitative data from the WA RHD register, descriptive analysis of the clinical and demographic characteristics of RHD patients aged <65 years was conducted, stratified by vital status. Thematic qualitative analysis of RHD stakeholder interviews was conducted in parallel, capturing systemic factors perceived to prevent or contribute to RHD-related mortality in WA.

Findings

Limited health service contacts were documented for the 60 register-recorded deaths among people with RHD. Interviewees emphasised that access to appropriate care was vital to prevent mortality. Passionate healthcare providers can and are connecting patients with care by fostering trusting relationships, but logistic, socio-cultural and care quality barriers continue to present challenges.

Conclusion

Systemic change is needed in WA to support motivated providers, and ensure that efforts to reduce RHD mortality do not rely on individual initiatives. This study strengthens the evidence base for the design of RHD control and management efforts in WA.

Summary Box

What is already known on this subject

- RHD mortality rates, although declining, remain significantly higher in Aboriginal and Torres Strait Islander people in Australia compared to non-Aboriginal people.
- Aboriginal and Torres Strait Islander peoples face a range of complex barriers to accessing high-quality healthcare, including for RHD treatment and management.

What this paper adds

- In WA, RHD register data demonstrates limited health service contact among people who have died with RHD, including low utilisation of echocardiography, specialist, and secondary prophylaxis services.
- The WA health system is strengthened by motivated RHD health providers who are committed to building relationships with RHD patients to overcome access barriers ensure access to best-practice care. Frontline providers can benefit from more support and training.
- This study is the first mixed methods analysis investigating RHD mortality in Australia and the first to examine RHD-related mortality in WA.

Introduction

Rheumatic heart disease (RHD) is valvular heart damage that can develop after acute rheumatic fever (ARF), itself an immune reaction to a group A streptococcal infection. Australian rural and remote residents are disproportionately affected by RHD burden, and face challenges accessing health care compared to urban residents(1,2). RHD-related mortality rates are declining globally, however in Australia, preventable RHD deaths continue to occur and are particularly high among Aboriginal and Torres Strait Islander peoples (hereafter, respectfully, 'Aboriginal')(3-5). Consequently, considerable Australian research in the last decade has investigated RHD acquisition and progression in Aboriginal communities(6-8), to reduce RHD-associated morbidity and mortality.

Examination of the structural drivers of ill-health has emerged as a clear priority for RHD prevention, notably as an alternative to deficit discourse, in which behaviours of Aboriginal people are blamed for poor health outcomes(9,10). Guiding documents, including the Australian ARF and RHD Guidelines(11) and the RHD Endgame Strategy(12), outline recommendations to avoid RHD harms. Central to these documents is the importance of health system improvements such as cultural safety, embedding environmental health in primary care, and building the Aboriginal health workforce. These recommendations stem from research into the lived experiences of people with RHD, who face

significant barriers to accessing best-practice RHD care(13,14). The impact of health system failures is highlighted in several publications and recent high-profile coronial inquiries, including the RHD Doomadgee cluster in Queensland and the death of Mr Yeeda in Western Australia (WA)(9,15) .

Guideline-recommended treatment for people diagnosed with ARF or RHD is multifaceted, including ongoing frequent contact with primary and specialist healthcare providers(11). Treatment includes regular secondary prophylaxis penicillin (BPG) injections, ongoing echocardiographic monitoring, and may also include surgery, medication, dental care and specialist pregnancy care. Jurisdictional RHD Control programs have been established throughout Australia to support health providers to better detect, monitor and treat RHD and ARF. The WA RHD Register (hereafter 'WA register') was established in 2009 and was managed in the Kimberley until 2017 before relocating to Perth(16).

Despite Australia's universal publicly-funded health system and the strategies outlined above, deaths from RHD continue to occur. In Queensland, fractured relationships between health services, barriers to information sharing, and difficulties retaining skilled and culturally competent staff contributed to the RHD-related deaths of three young Aboriginal women in 2019 and 2020(17). In WA, a lack of communication between health services and limited availability of culturally safe services caused missed opportunities for RHD treatment, and contributed to the 2018 RHD death of Mr Yeeda(18). The coronial inquiries into these deaths add to evidence from lived experience research that Australian health systems tend to provide individually-focussed RHD care that does not incorporate the worldviews of Aboriginal patients, many of whom are children and young people, and do not adequately involve their families and communities in decision-making(13).

The narratives around these high-profile deaths and qualitative research regarding system failures are reflected in quantitative studies that report higher RHD mortality rates among Aboriginal people compared to the non-Aboriginal population, with substantial differences between 25–44-year-olds from these groups(4, 5). However, few studies describe RHD mortality in WA specifically, or examine WA's RHD service delivery context. Two WA studies examining data from the late 1990s to early 2000s found high RHD mortality among Aboriginal people, but included Kimberley residents only(19, 20). Other RHD mortality research aggregates mortality in WA with other jurisdictions and focuses on the Northern Territory where RHD prevalence is highest(4,5,21). Between 2012 and 2022, age-standardised RHD-related mortality was 14.9 deaths per 100,000 person-years for Aboriginal people aged <65 in WA, a rate 38 times higher than that in non-Aboriginal people [Supplement A].

To date, quantitative studies focussed on RHD-related mortality have not integrated qualitative data, narrowing contextual understanding of the statistics reported. Therefore the aim of the present study was to integrate quantitative WA Register information regarding RHD-related deaths between 2012

and 2021 with qualitative interview data from RHD stakeholders, to identify system-level opportunities for prevention of RHD-related mortality in the WA health care setting. The specific objectives were to (i) describe clinical and demographic characteristics of RHD patients aged <65 years from the WA Register, stratified by vital status and (ii) examine perspectives of practitioners working with RHD patients and their families regarding systemic factors contributing to or preventing RHD-related mortality within the WA healthcare system.

Methods

Author position statement

VDC is a non-Aboriginal person, who undertook this study during her Master of Philosophy in Applied Epidemiology in collaboration with one Aboriginal and five non-Aboriginal co-authors with substantial experience in Aboriginal health. The study was motivated by concerns about the contribution of health system issues to RHD outcomes for Aboriginal people in WA, emphasised by community and family members during team members' involvement with RHD deaths in clinical and coronial settings. An Aboriginal health advisory group provided advice on scope, study design and framing, and reviewed the final draft of this manuscript.

Objective 1 (quantitative methods)

Data source and participant selection

De-identified person-level records were sourced from the WA Register from 01/01/2012 to 31/12/2021 (extracted March 2022) for cross-sectional analyses. The WA Register includes routinely collected variables associated with ARF and RHD diagnosis, treatment and notification. Date and cause of death information is also recorded within the WA Register upon notification from healthcare providers or after monthly review of hospital records.

Registrants with a RHD diagnosis on or before 31 December 2021 were included in the analysis, with stratification by vital status. Persons with a date of death recorded, who were aged <65 years at the time of their death during the 2012–2021 study period were allocated to the "deceased group"; persons aged <65 years on 31/12/2021 without a recorded death were allocated to the "prevalent group". Participation was restricted to <65 year-olds to focus on premature mortality, maintain consistency with the earlier analysis of death registry data, and to allow comparison with similar Australian research(4).

Variables

Demographic characteristics included year of birth, sex (male, female), ethnicity (Aboriginal, Aboriginal and Torres Strait Islander, Torres Strait Islander, Māori, Pasifika, Asian, African, Middle Eastern, other Australians), and region of primary health provider (metropolitan, Kimberley, Pilbara, Midwest, Wheatbelt, Goldfields, South West, Great Southern). For analysis, values of ethnicity were allocated as

either Aboriginal (including Torres Strait Islanders) or non-Aboriginal, and regions outside the Kimberley and Pilbara were condensed into a single 'other regional' category due to low numbers.

Clinical details included dates of recorded ARF episodes and RHD diagnoses; dates of BPG doses administered; dates and medications for secondary prophylaxis prescriptions; dates and categories of recorded surgeries (repair, replacement, valvuloplasty); dates of most recent echocardiogram and most recent specialist review, and RHD severity recorded at most recent echo (ARF only, mild, moderate, severe). 'Time since' variables were derived as the difference between treatment/service and study exit (death date or 31/12/21 as appropriate). Cause of death category (RHD-related, non-RHD, unknown) was derived from the free-text cause of death variable recorded in the WA register and reviewed by a medical professional.

BPG adherence was estimated pragmatically for the 12 months before exit from the study for each person, by dividing the number of BPG doses received by the number of doses expected(11). Expected doses were estimated based on fact and frequency of BPG prescription in the 12 months before study exit. Persons without a prescription for BPG prophylaxis were excluded from this calculation.

Statistical analysis

Frequencies and proportions were calculated for demographic and clinical covariates within the deceased and prevalent groups, to assess patterns of distribution. Summary statistics (median and range) were calculated for continuous variables.

No formal statistical comparisons were made between the deceased and prevalent groups due to the descriptive aims of the quantitative analyses.

Analyses were conducted in SAS v9.4.

Objective 2 (qualitative methods)

Study Design

The qualitative analysis of semi-structured interviews sought to identify systemic issues contributing to RHD mortality in WA, rather than focussing on the behaviour or decisions of individuals. Cognisant of the sensitivity of mortality discussions with families, the study focussed on stakeholders involved with RHD patients through their work in health or other government systems.

Participant selection

Stakeholders were identified using purposive and snowball sampling and invited to participate via direct email. Purposive sampling sought to identify stakeholders with a range of experience working with WA RHD patients and their families.

Data collection

An interview guide was developed in consultation with an Aboriginal health advisory group [Supplement B]. Interviews were conducted via Microsoft Teams between December 2022 and May 2023 by VDC. Interviewees were asked open-ended questions about their experience with RHD patients, and their perspectives on the health system's role in RHD patient journeys and factors contributing to mortality. Further questioning was responsive to topics raised by interviewees. Interviews were recorded, transcribed, and later checked by participants prior to analysis. The research team met throughout data collection to debrief and discuss interview techniques and emerging themes.

Data analysis

Thematic coding of transcripts was conducted in NVivo by VDC and initiated from midway through data collection. Themes were generated inductively from interview data. In consultation with co-authors, a thematic framework was developed and was updated iteratively to incorporate additional data.

Ethics Approval

Ethics approval for this study was granted by both the WA Country Health Service Human Research Ethics Committee (RGS5578) and the WA Aboriginal Health Ethics Committee (HREC717) in August 2022.

Results

Quantitative Analysis

Of 820 registrants included in the analysis, 60 (7.3%) had a recorded death between 2012 and 2021 (deceased group) and 760 were alive on 31 December 2021 (prevalent group) (Table 1).

Table 1. Characteristics of RHD patients aged <65, WA register, 2012–2021

Characteristic	Deceased group (%)	Prevalent group (%)
TOTAL	N=60	N=760
Age at study exit		
Median	45.5	31.0
Age Group		
0–14	0 (0%)	79 (10%)
15–24	<5	185 (24%)
25–34	9 (15%)	164 (22%)
35–44	13 (22%)	153 (20%)
45–54	22 (37%)	115 (15%)
55–64	12 (20%)	64 (8%)
Ethnicity		
Aboriginal and/or Torres-Strait Islander	59 (98%)	700 (92%)
Sex		
Female	32 (53%)	510 (67%)

Characteristic	Deceased group (%)	Prevalent group (%)
Region		
Kimberley	40 (67%)	420 (55%)
Pilbara	9 (15%)	89 (11%)
Other regional	5 (8%)	134 (18%)
Metropolitan	6 (10%)	110 (14%)
Diagnoses		
Median age at RHD diagnosis	31.5	20
Persons with recorded ARF diagnosis	24 (40%)	498 (66%)
Median age at first ARF diagnosis	13	12
BPG prophylaxis in 12 months before study exit		
Persons with prescription	14 (23%)	498 (66%)
Median BPG adherence %	31	46
BPG adherence 80% or higher	<5	90 (18%)
Previous Surgery for RHD		
Persons with history of surgery	28 (47%)	151 (20%)
Count of procedures	47	245
Valve replacement	36 (77%)	153 (62%)
Valve repair	7 (15%)	65 (27%)
Valvuloplasty	<5	27 (11%)
Echocardiography		
Persons with any echo recorded	60 (100%)	760 (100%)
Time since most recent echo		
Median in days	556	480
<6 months	11 (18%)	169 (22%)
6 months – <1 year	9 (15%)	143 (19%)
1 year – <2 years	18 (30%)	171 (23%)
>2 years	22 (37%)	277 (37%)
RHD severity at most recent echo		
ARF only	<5	90 (12%)
Mild	8 (14%)	247 (33%)
Moderate	7 (12%)	191 (25%)
Severe	43 (73%)	229 (30%)
Missing	<5	3 (<1%)
Specialist review		
Persons with specialist review recorded	54 (90%)	715 (94%)
Time since most recent specialist review		
Median in days	602.5	588
<6 months	11 (20%)	146 (20%)
6 months – <1 year	10 (19%)	110 (15%)
1 year – <2 years	15 (28%)	147 (21%)
>2 years	18 (33%)	312 (44%)
TOTAL	60 (100%)	760 (100%)

Characteristics of Prevalent Group

Among the prevalent group the median age at study exit was 31 years, two-thirds were female and 92% were Aboriginal. Two-thirds (66%) had their primary health care provider in the Kimberley or Pilbara, whereas 32% were in metropolitan or other regions.

Median age at RHD diagnosis among the prevalent group was 20 years, with 66% also having a recorded ARF diagnosis. One-fifth had a recorded surgery, with proportionally more repair or valvuloplasty procedures (38%) than in the deceased group. Among the 30% of the prevalent group with severe RHD, 31% had an echocardiogram (median time since echo 480 days) and 25% had seen a specialist in the 6 months before study exit.

Characteristics of Deceased Group

Among the deceased group, the median age at death was 45.5 (ranging from 15 to 64 years), with four deaths in under 25-year-olds [Table 1]. Most were Aboriginal (98%) and half were female. Most (82%) had their primary healthcare provider in the Kimberley or Pilbara. The median age at RHD diagnosis was 31.5 years and only 40% had a recorded ARF diagnosis. Almost half of the group (n=28, 47%) had received surgery — a total of 47 RHD surgical procedures were performed with over three quarters of these being valve replacements.

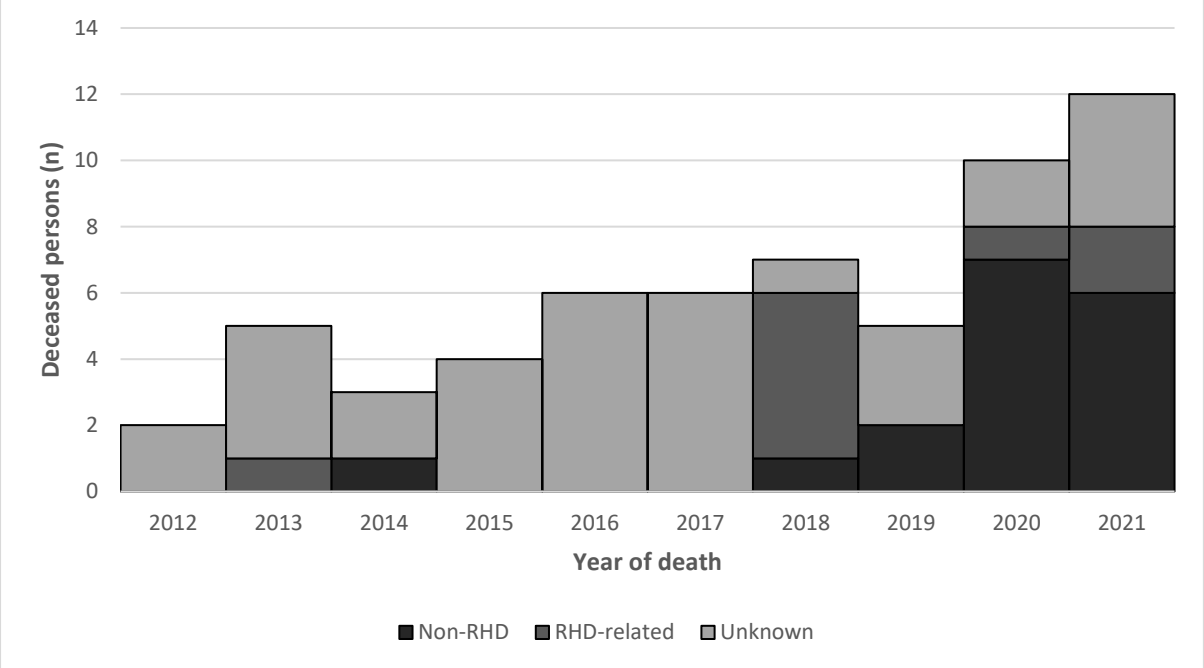

Figure 1. Mortality among RHD patients <65, WA register, 2012–2021, by year and cause of death

The number of deaths increased across the ten-year period, from two deaths in 2012 to 12 deaths in 2021 (Figure 1). Overall, 57% of deaths had no known cause recorded in the register, while 15% were

RHD-related and 28% were not directly related to RHD. Recorded cause of death increased over the study period.

Severe RHD at most recent echocardiogram was recorded for 73% of the deceased group and median time since most recent echocardiogram was 556 days. Only 23% of those with severe RHD had an echocardiogram within six months before study exit, the guideline for patients in this category(11). One quarter with severe RHD had seen a specialist in the six months before their death.

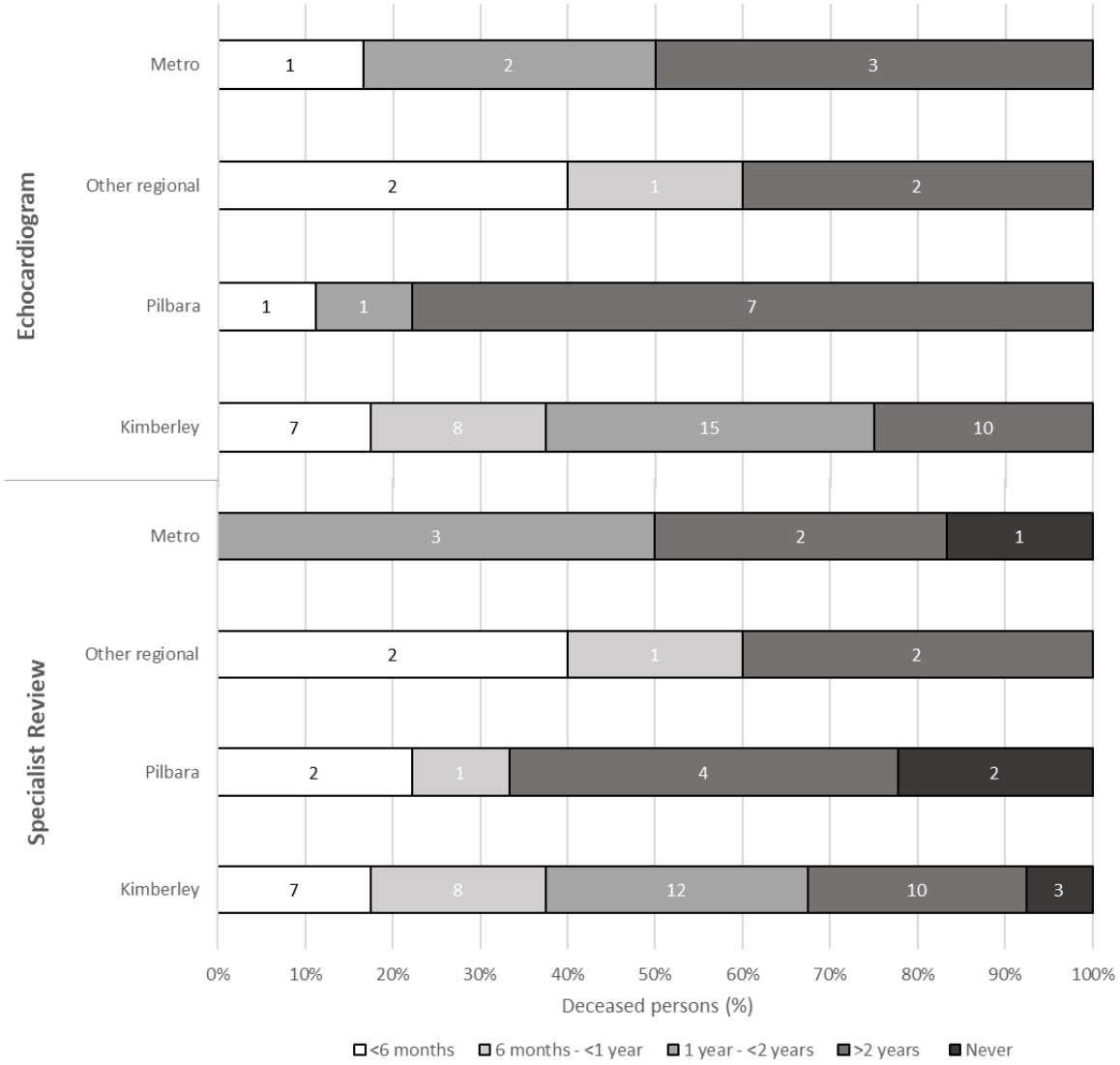

Figure 2. Time since health contacts among deceased RHD patients <65 on the WA Register, 2012–2021, by region

Noting small counts, Figure 2 suggests regional differences in the time since health contacts among the deceased group. For echocardiograms and specialist review, RHD patients in 'other regional' areas had the shortest time since most recent contact, with 60% seen within one year. Conversely, RHD

patients in the Pilbara had the longest time since health contacts, with 7 of 9 people having more than two years since their most recent echocardiogram and 6 having more than two years since their most recent specialist review, or none recorded at all. Among Kimberley cases who died, 75% and 68% received echocardiogram or specialist review within the two years prior, respectively.

Qualitative Analysis

Of 24 stakeholders approached to participate, nine consented to an interview. Details of interviewees are outlined in Table 2. Seven interviewees were based in WA, and two were based in other jurisdictions but had experience working with WA RHD patients.

Table 2. Characteristics of interview participants, 2022–2023

Characteristic	Participants (n)
Total	9
Women	6
Men	3
Aboriginal	3
Non-Aboriginal	6
Experience*	
Primary care	6
Specialist care	2
Care coordination	1
Patient advocacy	2
Research	3

*Participants with experience across multiple sectors are included in more than one category.

The thematic framework generated from interview data focuses on delivery of appropriate care to RHD patients (Figure 3). Interviewees explained that missing secondary prophylaxis, echocardiography, or specialist review could result in unmonitored disease progression, and that access to surgical intervention and holistic follow-up care was vital for patients with severe RHD. Interviewees stressed the importance of rapid intervention for RHD patients who are acutely unwell. The barriers to care and drivers of appropriate care are described in detail below. Aboriginal status is identified alongside interviewee quotes below, but no further detail is provided to maintain confidentiality.

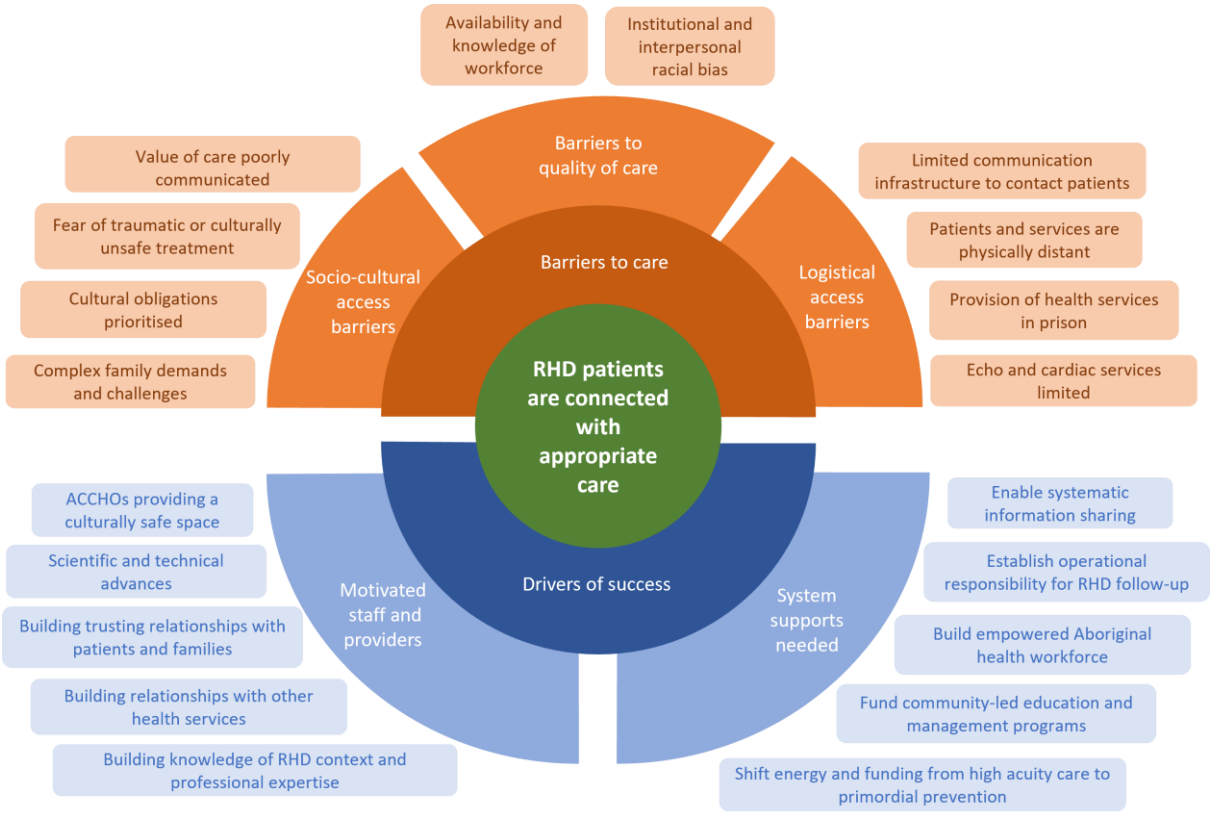

Figure 3. Thematic framework of RHD stakeholders' perspectives on factors contributing to and preventing RHD mortality in WA

Logistical access barriers

Interviewees described how health services in WA face practical constraints reaching RHD patients.

Physical distance was frequently cited as an access barrier, as RHD patients residing in rural and remote areas face long, expensive, and daunting journeys to travel to health services, often complicated by transport availability and weather. This difficulty was highlighted by one Aboriginal interviewee who spoke about investing significant resources to get a patient to the airport, only for them to be turned away because of incorrect footwear. However, another interviewee emphasised that physical proximity alone could not facilitate access, and that *"some of the most disengaged clients we have live two minutes from this hospital"[non-Aboriginal]*.

Interviewees spoke about the importance of mobile cardiology clinics, which provide semi-regular specialist services and echocardiography to rural areas across WA. These services improve access for remote patients who would otherwise need to travel to Broome or Perth to see a cardiologist. However, interviewees also discussed the constraints of visiting services, including their limited frequency and locations. One interviewee noted that visiting clinicians tended to *"sit in the consulting room and expect people to come"[non-Aboriginal]*, which was not sufficient to ensure access. Several

interviewees noted that the establishment of permanent cardiology services across rural WA would be preferable but perceived that this was unfeasible.

Other logistical barriers mentioned included the difficulty of contacting patients who may not have a fixed address, phone number or internet access to organise appointments; and the challenge of providing comprehensive care to RHD patients in prison due to the lack of integration between health and justice medical systems.

Socio-cultural access barriers

Interviewees outlined a range of socio-cultural barriers that RHD patients face when accessing health services, even if logistical challenges can be overcome. Aboriginal RHD patients in particular face complex barriers that make it difficult to access health services.

Several interviewees remarked that Aboriginal knowledge systems do not align with a biomedical framework. Where health providers do not have the cultural understanding or time to explain the need for ongoing RHD treatment in a meaningful way for Aboriginal patients, the value of RHD care may not be fully understood and seeking out care is not prioritised. This is exacerbated when patients are not experiencing RHD symptoms, or *"if you're a young, otherwise fit person who doesn't think of yourself as someone with a chronic illness"[non-Aboriginal]*. Interviewees noted that this barrier was especially prevalent among adolescents.

The importance of meeting cultural obligations, and managing other complex family demands, were also discussed as barriers to RHD care for Aboriginal patients/families/carers. Interviewees noted that RHD appointments were *"taking people away from their own life"[non-Aboriginal]*, and that sorry business (funeral/bereavement obligations) and caring responsibilities often take precedence. Interviewees noted that Aboriginal RHD patients *"live in varying degrees of complex life and dysfunction"[Aboriginal]*, and may be experiencing family violence, poverty, difficulty with school engagement, and other non-RHD health conditions simultaneously, making healthcare access challenging.

Interviewees spoke about how fear of a poor or culturally unsafe health care experience was a barrier to care. The pain associated with BPG injections can make patients reluctant to return, especially young children and their families. Surgical procedures in unfamiliar hospitals can be particularly daunting, especially where patients *"believe that hospitals are a place to go to die, due to generational trauma"[non-Aboriginal]*. However, routine appointments can also be traumatic if providers are not respectful, kind and empathetic. One interviewee commented that *"some nurses feel that…they're a bit better than an Aboriginal person and they growl at them, and talk to them like a child…and that makes fear"[Aboriginal]*.

Barriers to quality of care

Even when RHD patients overcome barriers to access a service, the care provided may be inappropriate. All nine interviewees mentioned transient workforce impacts, with new or shorter-term staff frequently struggling to recognise and understand RHD, which is rarely seen in metropolitan settings. This results in missed opportunities for diagnosis and ongoing management, because *"they just might not be aware of how detrimental [RHD] can be to somebody if they're left unmonitored"[Aboriginal]*. Several interviewees also spoke about how racial bias could affect care, including Aboriginal patients being stereotyped as drug-seeking or alcohol-affected when they attend hospital; treatment being refused even after repeat visits; or health providers *"giving up on our mob without understanding the reasons behind why they may be not showing up to an appointment"[Aboriginal]*.

Motivated staff and providers

While barriers to receiving care are significant, interviewees spoke about how motivated staff *"with a massive care factor"[Aboriginal]* are working actively to overcome challenges and connect RHD patients with appropriate treatment. Building trusting relationships with RHD patients and their families was perceived as vital by interviewees, who described this as involving patients in shared decision making about treatments; providing outreach *"embedded in the community as opposed to in a health setting"[non-Aboriginal]*; and being *"emotionally motivated"[non-Aboriginal]* to improve patient outcomes. The strength of Aboriginal community-controlled services in providing culturally safe care and maintaining strong relationships with RHD patients was also highlighted.

Building strong relationships with other health services was also discussed as an important factor facilitating access to care, with interviewees describing how these relationships allowed for vital cooperation between primary and community health, hospitals, visiting clinics and specialists.

Health practitioners described taking steps to improve their knowledge and professional expertise in RHD to improve care delivery. Interviewees with experience in primary care spoke about training in specialised techniques for BPG injections; learning about their communities to inform their approach to care; and discussed the importance of current initiatives to implement non-expert echocardiography screening services(22). Scientific advances such as a Strep A vaccine in development, virtual reality headsets to distract patients from the pain of an injection, and new technologies to improve BPG administration were raised as *"game changers"[non-Aboriginal]* with the potential to improve patient outcomes.

System supports needed

While the motivation, commitment and continued energy of health staff was perceived to reduce barriers, interviewees emphasised that systemic changes are needed to ensure the reliable and sustainable provision of high-quality care.

Interviewees observed that the health system is adept at providing high-acuity care to seriously unwell RHD patients, including heart surgeries and emergency transport. However, they perceived that insufficient funding and attention was directed to earlier intervention as a result; *"there is a huge focus on worst case scenario as opposed to that primordial prevention in our health system"[non-Aboriginal]*. Interviewees consistently explained that poor housing infrastructure drives RHD progression, and expressed frustration that this was not being adequately addressed; *"Our government should be ashamed of themselves, thinking it's ok for people to live like that"[Aboriginal]*. Surgical treatments were seen as futile in this context: *"it seems stupid that you're repairing their valves and then putting them back in that environment that causes acute rheumatic fever"[Aboriginal]*. Increased funding for environmental health programs was suggested by multiple interviewees as a priority for reducing poor RHD outcomes.

Several interviewees emphasised that greater empowerment of the Aboriginal health workforce in WA would improve RHD outcomes. This included increasing the scope and responsibilities of Aboriginal Liaison Officers and Aboriginal Health Workers, who *"often feel like they're just transport officers"[non-Aboriginal]* despite wanting to have a greater role in decision making and care provision. One interviewee stressed that *"unless they're empowered…unless people listen to them, their role is just decoration"[non-Aboriginal]*.

Enabling more systematic information sharing, and establishing operational responsibility for follow-up, were also suggested as vital for strengthening the health system's ability to track and treat RHD patients. Primary health staff spoke about the fragility of current systems, which largely rely on the initiative of individual staff members. They felt personally responsible for patient follow up and established their own methods to do this, because *"there's no real recall system…no-one is seeking [patients] out"[non-Aboriginal]*. Information from the WA Register was perceived as useful, but difficult and time-intensive to access. Automated reminders, improvements to regional RHD coordination, and *"a nurse that is just allocated to RHD alone"[Aboriginal]* in larger health services were all suggested to improve patient follow-up.

Interviewees also noted that funding for RHD education and management programs that are community-led, and *"embedded with community and cultural meaning"[Aboriginal]* was essential to improve RHD outcomes and connect patients with care.

Discussion

Evidence generated by this study indicates that limited access to best-practice healthcare is likely contributing to RHD-related mortality in WA. RHD mortality estimates among Aboriginal people [Supplement A] are similar to those reported nationally and in the Kimberley, with high premature mortality observed compared to the non-Aboriginal population, even among young people(4,5,19,20,23). Analysis of the WA register for 2012–2021 revealed 60 deaths among under 65-year-olds, 59 of whom were Aboriginal. Each of these deaths represents a person who died prematurely with a preventable disease, with profound impacts for their families and communities. Interviewees expressed that healthcare access barriers permeate the RHD landscape in WA, making it challenging for RHD patients to receive best-practice care. The story of Mr Yeeda, who died from RHD at the age of just 19, places these mortality statistics and healthcare delivery experiences in context and draws attention to the need for systemic change in WA to prevent further mortality(18).

Limited health service contacts among the deceased group were observed in the WA register analysis; this is supported by a qualitative framework centred on the idea that disconnect between RHD patients and appropriate care results in poor outcomes. This is consistent with previously reported associations between experiencing RHD-related complications and lack of recorded ARF in young Australians(23). Rather than contradicting the well-evidenced link between ARF and RHD aetiology, this relationship is indicative of a population for whom opportunities for early intervention, including diagnosis and treatment of Strep A infections, ARF diagnosis, RHD monitoring and secondary prophylaxis, have been limited or missed entirely. Barriers to accessing early intervention and healthcare are heightened for Aboriginal people with RHD, for whom practical challenges are exacerbated by ongoing impacts of colonisation, including fear and mistrust of a biomedical system that often provides care in a manner inconsistent with their values, knowledge systems and priorities(13-15). Australian research has reported, for example, fear of child removal as a strong motivator against seeking care among Aboriginal people(13,24). As a condition that often affects children, and for which families can feel unfairly blamed, access to RHD care may be particularly affected by this fear. In this context, the value of the Aboriginal community-controlled health sector, and RHD programs that are governed by and designed for Aboriginal communities, is clear.

A range of intersecting challenges were identified in the qualitative analysis as contributors to the potential disconnect between patients and appropriate care, including geographical distance from health services, competing demands, and transient healthcare staff. The results demonstrate that barriers to RHD care can be experienced differently by patients based on contextual factors including age, sex and location. Access to RHD care among teenagers has been previously reported as a challenge, as teenagers struggle to prioritise care in the context of adolescence, and may be lost in the

transition between child and adult services(12-14,25). This was reflected in interviewee perspectives that teenagers can be reluctant to seek care, and in the nine deaths observed among people aged under 34 in the quantitative analysis. While women experience higher rates of RHD than men and higher RHD mortality overall(5,20,21), interviewees suggested that women were better engaged with RHD services, which is possibly reflected in the lower proportion of females in the deceased group (53%) than the prevalent group (67%). Australian RHD guidelines advise that remoteness complicates service access and contributes to poorer outcomes(11), consistent with the quantitative results in which 82% of those who died were from the Kimberley and Pilbara regions. Particularly poor health access among the deceased group from the Pilbara mirrored interviewee comments about the restricted availability of echocardiography and specialist services in this region. These findings highlight the need for age, gender, and location-specific strategies to encourage access to RHD care.

Importantly, this study finds that even in the presence of significant barriers, stakeholders perceive that access to RHD care can be facilitated by motivated and passionate healthcare professionals who understand their local communities. These dedicated staff are a precious resource within the WA system, likely contributing to the characteristics of the prevalent group, of whom 56% had accessed a specialist within the previous two years, despite barriers. Interviewees described being proactive in providing care to RHD patients, taking initiative to deliver culturally relevant and age-appropriate health messages, and feeling personally responsible for ensuring that patients accessed the care they needed. Systemic changes are needed in WA to support and retain these committed staff, and to ensure that success in reducing RHD mortality does not rely only on individual motivation alone.

Health providers who are Aboriginal play a vital role in overcoming barriers to care, by building therapeutic relationships based on cultural understanding and specific community knowledge(24,26). Additionally, while trusting relationships between non-Aboriginal health providers, patients and their families take considerable time and effort to develop, these are key facilitators of access to care(27). Both Aboriginal and non-Aboriginal interviewees emphasised the centrality of mutual respect and strong relationships to engaging with RHD patients, mirroring findings from earlier research with RHD practitioners(15). Healthcare providers' acknowledgement of the cultural strengths of their communities, holistic approach to health and incorporation of this into healthcare provision is a key protective factor mitigating the impact of RHD in Aboriginal communities(14). Resourcing, ongoing training and empowerment of the Aboriginal health workforce should therefore be prioritised to ensure sustainable access to culturally safe care for RHD patients in WA, as outlined in existing recommendations(12,15,28). For non-Aboriginal healthcare providers, meaningful and context-specific cultural safety training that goes beyond cultural awareness to prompt critical self-reflection is

needed, and has been effective in shifting health professionals' attitudes and behaviours in the Northern Territory(29).

Exposure to poor RHD outcomes takes a toll on health providers, with feelings of hopelessness, frustration and burnout resulting from systemic failures(9). In this study, interviewees across primary and specialist care expressed emotional fatigue, especially regarding the failure of health and other government systems to improve housing and environmental conditions. Increased investment in these upstream causes has well-understood implications for the primordial prevention of RHD and other infectious and chronic health conditions(12). These results demonstrate that this investment is also important to preserve the morale and motivation of healthcare providers who care for RHD patients.

Practical changes to support healthcare staff in WA would include improved interoperability between the WA register and health provider records systems; implementation of processes for systematic rather than reactive information sharing between providers; and allocation of operational responsibility for ongoing RHD patient follow-up within health services. Similar recommendations were made in the Australian RHD Guidelines and the RHD Endgame Strategy(11,12). These changes may alleviate the pressure that individual providers feel to keep track of patient information, especially in the context of a transient workforce and population.

Strengths and Limitations

This is the first mixed methods study to examine RHD-related mortality in Australia. This approach facilitated a holistic understanding by situating the characteristics of the deceased group from the WA register within the context of health service delivery in WA. This research foregrounds the perspectives and experiences of WA RHD stakeholders and providers, whose voices would have been lost if the study had relied on statistics alone to build knowledge. It is also the first study to examine WA RHD mortality in WA in detail, providing important insights for WA policymakers and public health professionals.

Information on the WA register is recorded manually by register staff and is dependent on clinician notification, which is known to be incomplete(30). Data sourced from the register is therefore likely to underestimate both RHD cases and deaths. Australian RHD registers are more likely to detect cases among younger, Aboriginal and northern Australian residents, who are likely overrepresented in the study population(30). The WA Register was managed from the Kimberley region between 2009 and 2017, which has probably led to higher case ascertainment than for southern regions.

The interview sample size was limited by the small number of RHD stakeholders in WA. While saturation of themes was achieved by the final interview, it is possible that this analysis has missed alternative stakeholder perspectives on RHD mortality and care in WA.

Conclusion

This study combines quantitative and qualitative insights to suggest opportunities for preventing RHD-related mortality in WA. Committed WA healthcare providers endeavour to overcome perceived barriers and connect RHD patients with appropriate care. Trusting relationships between patients, families and providers were identified as essential for this. The stability and motivation of this workforce requires support to ensure sustainable access to best-practice RHD care in WA. Necessary support includes resourcing and empowerment of the Aboriginal health workforce, cultural safety training for non-Aboriginal staff, a shift in funding priorities towards primordial prevention, and practical changes to improve data sharing. These findings support recommendations raised in existing research and reports, including the RHD Endgame Strategy and the Australian RHD Guidelines(11,12,28). Evidence generated by the present study highlights the need for national-level recommendations to be implemented to reduce RHD mortality in WA.

Acknowledgements

Many thanks to the Aboriginal Advisory Group members, Melanie Robinson, Russell Simpson and Lynette Dimer, who provided invaluable advice on the study design and framing of results throughout this project. Thanks to Jessica de Dassel for assistance with the WA Register dataset and Lauren Moran for assistance with the ABS dataset. Thanks also to the interview participants for their open and honest contributions, and for taking time away from other priorities to participate in this study.

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Supplement A: RHD-specific mortality rates in Western Australia, 2012–2021

Background

Research conducted by Australian colleagues demonstrates high RHD mortality rates among Aboriginal compared to non-Aboriginal people across five Australian jurisdictions(4). This analysis used similar methodology to focus on RHD mortality rates in Western Australia.

Methods

Age-specific and age-standardised RHD mortality rates were calculated for Western Australia across a ten-year period from 2012 to 2021, and compared across Aboriginal status, sex and time variables. State-wide RHD mortality rates have not been previously reported in WA.

ICD-coded cause of death data was provided by the Australian Bureau of Statistics (ABS) in April 2023. Deaths in people aged 64 or younger, where RHD was coded as the underlying cause or as an associated cause (ICD codes I05, I06, I07, I08, I09 and their subcodes) were included. Population denominators were sourced from publicly available ABS Estimated Resident Populations across the ten years. Age standardised mortality rates were calculated via direct age standardisation across three age strata using the WHO World Standard Population 2000–2025. 95% confidence intervals were generated for each rate and rate ratio.

In the cause of death data provided, the ABS randomly assigns cells with small values (other than zero count cells), in order to protect individual confidentiality. Therefore, some totals presented below have minor discrepancies across tables.

Results

Mortality rate ratios (MRRs) from the calculations are presented in Table 1–3 below. Age-standardised mortality was 38 times higher among Aboriginal people compared to non-Aboriginal people across the ten years [Table 1]. Age-standardised mortality was significantly higher among Aboriginal females than Aboriginal males, but there was no significant difference by sex for non-Aboriginal people [Table 2]. There was no significant difference in age-standardised mortality between the two five-year periods for either Aboriginal or non-Aboriginal people [Table 3].

Table 1. Age-specific and age-standardised rheumatic heart disease deaths and mortality rate ratios in Western Australia 2012–2021, per 100,000 person-years, by Aboriginal status

	Aboriginal			**Non-Aboriginal**			**Rate Ratio**	
Age	n	Rate	95% CI	n	Rate	95% CI	MRR	95% CI
0–24	3	0.57	0.00–1.21	0	0.00	-	-	-
25–44	17	6.08	3.19–8.97	7	0.10	0.02–0.17	63.63	26.39–153.45
45–64	43	25.49	17.87–33.10	44	0.71	0.50–0.92	35.85	23.55–54.58
Age-standardised rate								
0–64	63	14.87	10.93–18.80	51	0.39	0.28–0.49	38.38	26.53–55.52

Table 2. Age-specific and age-standardised rheumatic heart disease deaths and mortality rate ratios in Western Australia 2012–2021, per 100,000 person-years, by Aboriginal status and sex

Sex	Female			Male			Rate Ratio	
Age	n	Rate	95% CI	n	Rate	95% CI	MRR	95% CI
Aboriginal								
0–24	1	0.39	0.00–1.14	2	0.74	0.00–1.77	0.52	0.05–5.72
25–44	10	7.31	2.78–11.84	7	4.91	1.27–8.54	1.49	0.57–3.91
45–64	31	34.82	22.56–47.07	12	15.06	6.54–23.58	2.31	1.19–4.50
Non-Aboriginal								
0–24	0	0.00	-	0	0.00	-	-	-
25–44	4	0.11	0.00–0.22	1	0.03	0.00–0.08	4.10	0.46–36.69
45–64	18	0.58	0.31–0.85	26	0.84	0.52–1.16	0.69	0.38–1.26
Age-standardised rate Aboriginal								
0–64	42	19.91	13.60–26.22	21	9.29	4.86–13.72	2.14	1.27–3.62
Age-standardised rate Non-Aboriginal								
0–64	22	0.33	0.19–0.47	27	0.43	0.27–0.59	0.76	0.43–1.34

Table 3. Age-specific and age-standardised rheumatic heart disease deaths and mortality rate ratio in Western Australia 2012–2021, per 100,000 person-years, by Aboriginal status and time period

Year	2012 - 2016			2017-2021			Rate Ratio	
Age	n	Rate	95% CI	n	Rate	95% CI	MRR	95% CI
Aboriginal								
0–24	2	0.77	0.00–1.85	2	0.74	0.00–1.76	1.04	0.15–7.44
25–44	1	0.75	0.00–2.23	13	8.86	4.04–13.67	0.09	0.01–0.65
45–64	19	24.34	13.40–35.29	24	26.47	15.88–37.06	0.92	0.50–1.68
Non-Aboriginal								
0–24	0	0.00	-	0	0.00	-	-	-
25–44	6	0.17	0.03–0.30	3	0.08	0.00–0.17	2.05	0.51–8.18
45–64	19	0.64	0.35–0.92	25	0.78	0.47–1.09	0.82	0.45–1.48
Age-standardised rate Aboriginal								
0–64	22	12.55	7.05–18.05	39	16.31	10.77–21.85	1.30	0.77–2.19
Age-standardised rate Non-Aboriginal								
0–64	25	0.37	0.22–0.52	28	0.42	0.26–0.57	1.18	0.65–1.92

Interpretation

The results from this analysis are consistent with existing Australian research demonstrating a significant disparity in RHD-related mortality between Aboriginal and non-Aboriginal people(4,5). While the age-standardised mortality rate among Aboriginal people in this analysis (14.87) was lower than that reported in the Northern Territory for a similar time period (21.70), the size of the disparity between Aboriginal and non-Aboriginal people was similar (RR = 36.78 and 38.38 respectively)(4). This quantitative finding is consistent with high mortality among Aboriginal people reported in the analysis of the WA RHD Register, and with the qualitative analysis suggesting significant healthcare barriers for Aboriginal people with RHD.

The finding of a higher RHD mortality rate among Aboriginal females compared to Aboriginal males is consistent with evidence that RHD is more common in women than men, and with known risks of RHD complications during pregnancy(11). It also agrees with the findings of the WA RHD Register

analysis, which found that 53 percent of all-cause deaths during the study period were among women.

The lack of significant change in mortality rates between the two five-year time periods may be indicative of some random variation given the small sample size. Without a third time period it is difficult to interpret this as a trend, although the increase in absolute deaths is consistent with all-cause deaths recorded in the RHD register over the same period. Further analysis is needed in WA to determine the trajectory of RHD deaths over time.

Supplement B: Interview Guide

Note: The interviews will follow a semi-structured approach. While the below questions outline the proposed general structure of an interview, these may change and/or be omitted depending on the responses of an individual interviewee. Interviewees will not be discouraged from discussing topics, issues or subject matter outside of the below questions, and probing questions may be asked about these discussions, as outlined below.

Can you tell me about your experience/work with RHD?
Prompts if necessary:

- How long have you been working in this area?
- What different roles have you had?
- What work do you do as part of your current role?
- How do you engage with people with RHD?
- How does your experience relate to WA specifically? Are there differences in your experience/work in WA compared to other jurisdictions?

Rheumatic heart disease is an umbrella term that captures a long journey that a person may go through, from a Strep A infection up to heart surgery in some cases, and can span many years. This journey can involve many different encounters with the health system and other associated institutions. In your experience, what parts of the health system do patients come into contact with and how does the system itself impact on their journey with RHD?
Prompts if necessary:

- Who provides care to RHD patients?
- Are there multiple parts of the health system involved? Which other systems are involved with RHD patients?
- Do different parts of the health system work well together? How is the communication?
- What have you heard or observed from patients and communities about the way that the health system impacts on them?

How have you seen the health system work effectively and/or contribute to positive patient outcomes?
Prompts if necessary:

- Can you think of any programs or services that have made positive differences for patients?
- In your experience, which parts of the health system have worked well together?

Where might the health system be going wrong?

- In your experience, what kind of negative impacts do people with RHD experience as a result of interacting with the health system?
- When have you seen this happen and what factors were at play?

The research area for this project is RHD mortality in particular. How might systemic factors be contributing to RHD-related mortality in WA?

- *Build on answer to last question, to focus on mortality if relevant/appropriate

As part of this research we've conducted some quantitative analyses using ABS data and information from the WA RHD Register. Those analyses suggest that _____ . Is that consistent with your experience? How would you explain that relationship?

- *Prompts will depend on preliminary quantitative findings

What health system improvements do you think should be prioritised to help to avoid RHD-related mortality in the future?

- What changes would you like to see in the parts of the health system you work in/with?
- Have you seen system changes work well elsewhere in Australia or overseas that you would like to see in WA?
- What changes/improvements do you think would have the biggest impact?
- What are the potential roadblocks to implementing these changes?

General prompts to encourage further discussion:

- Can you expand on that?
- When you said _____, what did you mean?
- Can you give me an example?
- Tell me more about [x issue].
- Why do you think [x issue] is the case?

<u>After Interview Concludes</u>

- The recording will be stopped when the interview comes to a natural conclusion.
- The interviewee will be thanked for their time and invited to get in touch with the research team if they think of other issues or themes they would like to add to the perspectives they have provided.
- The interviewee will be reminded to seek support if they have experienced any emotional distress as a result of the interview.

Appendix 2: Conference Presentation Slides

Government of Western Australia
WA Country Health Service

Australian National University

Rheumatic heart disease-related mortality in Western Australia

Presented by
Virginia DeCourcy, MAE Scholar, WACHS/ANU
Dr Daniel Hunt, General Practitioner, Derbarl Yerrigan Health Service

Co-authors:
Ingrid Stacey, UWA School of Population and Global Health
Dr Emma Haynes, UWA School of Population and Global Health
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Dr Marisa Gilles, WACHS Population Health
A/Prof Judith Katzenellenbogen, UWA School of Population and Global Health

1

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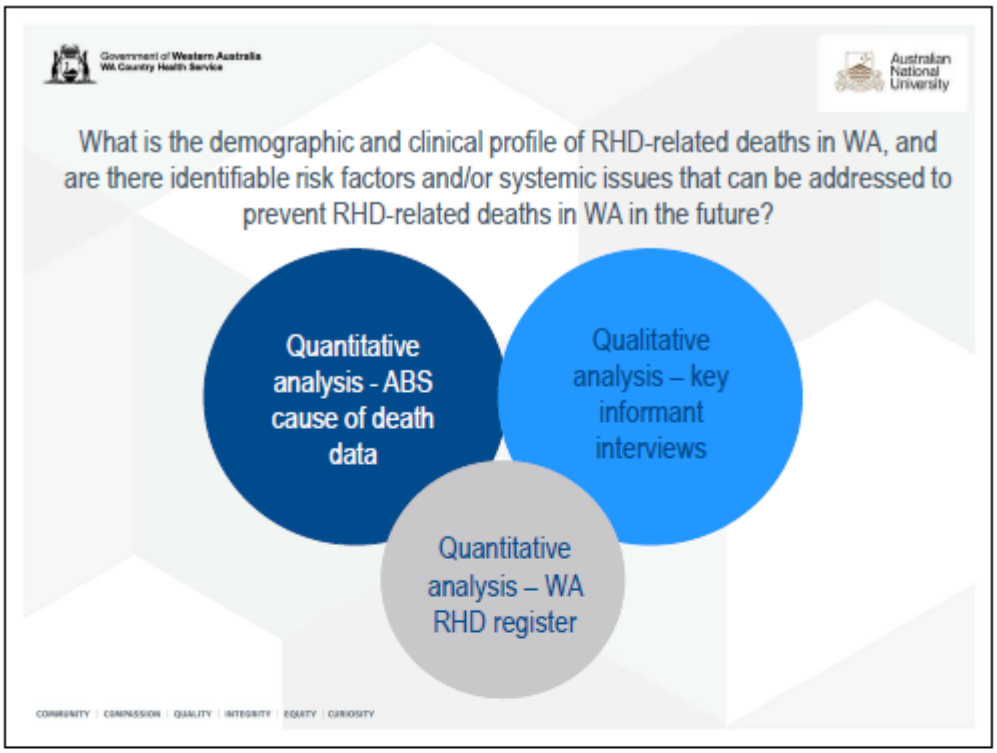
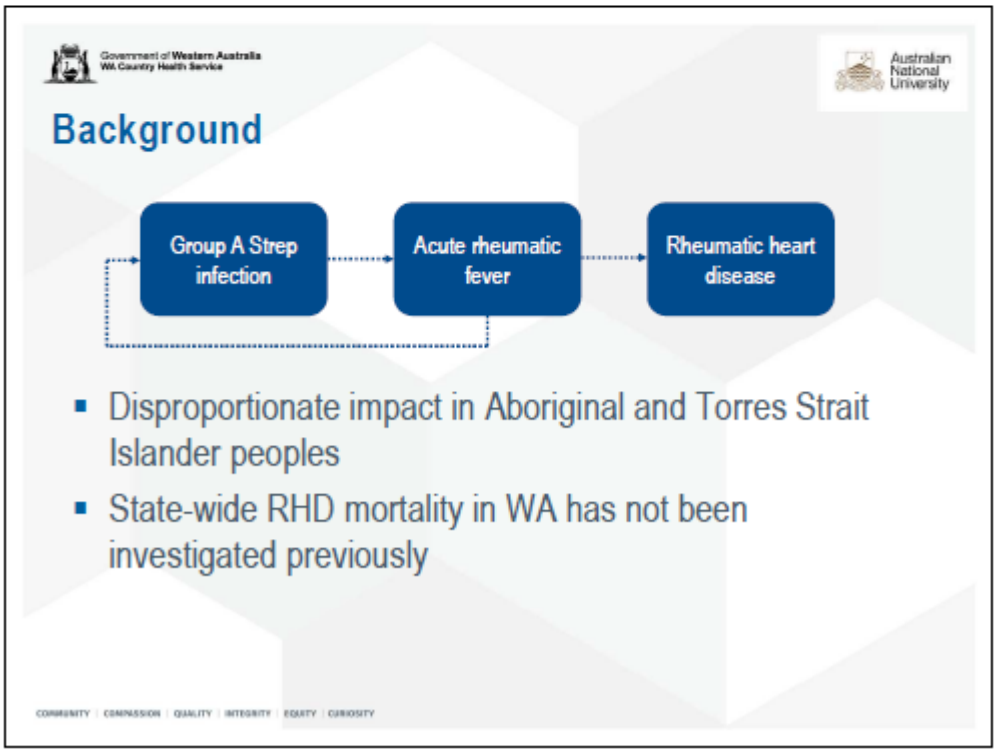
2


Government of Western Australia
WA Country Health Service
Australian National University
What is the demographic and clinical profile of RHD-related deaths in WA, and are there identifiable risk factors and/or systemic issues that can be addressed to prevent RHD-related deaths in WA in the future?
Quantitative analysis - ABS cause of death data
Qualitative analysis – key informant interviews
Quantitative analysis – WA RHD register
COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

3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WA Country Health Service
Australian National University
Background
Group A Strep infection
Acute rheumatic fever
Rheumatic heart disease
Disproportionate impact in Aboriginal and Torres Strait Islander peoples
State-wide RHD mortality in WA has not been investigated previously
COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

4


Government of Western Australia
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Australian National University
Mortality rates: methodology
Time period: 2012-2021
Calculated age-specific and age-standardised mortality rates using ICD-coded cause of death data
Restricted to people <65 years
Underlying and associated cause
Denominator: person-years using ABS ERPs
Compared rates across Aboriginal status, sex, time, and jurisdiction variables
Limitations: small counts
COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

5


Government of Western Australia
WA Country Health Service
Australian National University
Mortality rates by Aboriginal status
RHD mortality in WA from 2012-2021 was 38 times higher in Aboriginal people than Non-aboriginal people
Age-standardised rate
Rate ratio
Aboriginal
Non-aboriginal
14.87 (10.93-18.80)
0.39 (0.28-0.49)
38.38 (26.53 – 55.52)
COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

6

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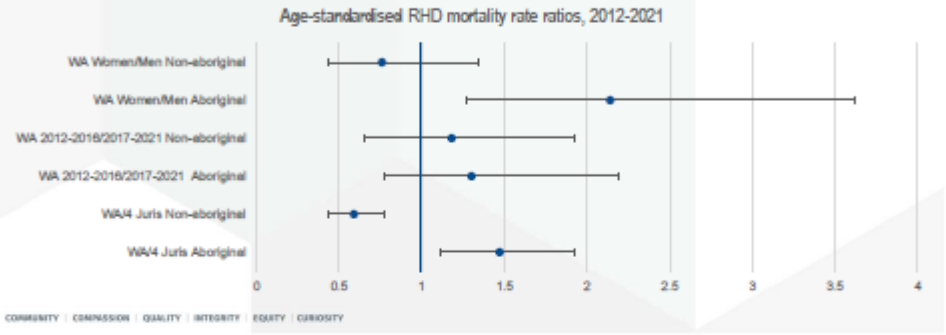
Mortality rate ratios by sex, time, jurisdiction

Higher RHD mortality rates among Aboriginal women compared to Aboriginal men

No difference in RHD mortality rates across five-year time periods

Higher RHD mortality rates in WA compared to NT/SA/QLD/NSW for Aboriginal people, but lower rates in WA for non-Aboriginal people



COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

7

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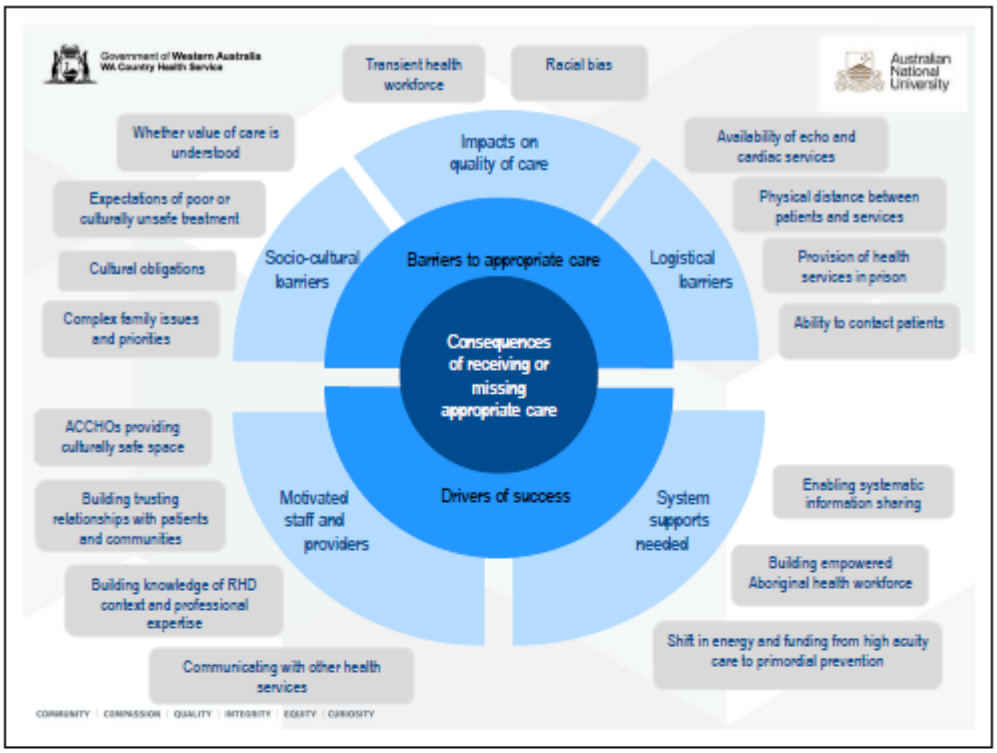
Key informant interviews: methodology

- Aim: collect stakeholder views on systemic factors contributing to, or avoiding, RHD mortality in WA
- Purposive sampling of health and non-health stakeholders
- 8 semi-structured interviews conducted
- Iterative thematic analysis
- Themes coded in Nvivo

COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

8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Transient health workforce
Racial bias
Whether value of care is understood
Impacts on quality of care
Availability of echo and cardiac services
Expectations of poor or culturally unsafe treatment
Physical distance between patients and services
Cultural obligations
Socio-cultural barriers
Barriers to appropriate care
Logistical barriers
Provision of health services in prison
Complex family issues and priorities
Ability to contact patients
Consequences of receiving or missing appropriate care
ACCHOs providing culturally safe space
Building trusting relationships with patients and communities
Motivated staff and providers
Drivers of success
System supports needed
Enabling systematic information sharing
Building empowered Aboriginal health workforce
Building knowledge of RHD context and professional expertise
Shift in energy and funding from high acuity care to primordial prevention
Communicating with other health services
COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

9


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Building trusting relationships
Motivated staff and providers
Drivers of success
Consequences of receiving appropriate care
"We've got a really proactive team here that are young and engaging and really care about the health of these people. I mean, how can you not you when you've got these beautiful young Aboriginal children in front of you that are receiving awful injections for something that could have been prevented. It's very hard to not become quite emotionally motivated, I think to be a part of that change and to help these families."
"Teleconferencing can create a disconnect between patient and practitioner, meaning the trust the patient has with their doctor is compromised. However, if there's a warm and caring person at the other end helping, such as an advocate for the patient, you might be able to use that process, but they have to be a sympathetic, culturally safe, understanding person who can actually elicit the information that's necessary to protect and save that person's life."
"So we have it written up on the board, all of our rheumatic patients are written up on a board, when they're due, when their monthly injections are due. And we physically go out to the community, and find them, and say you've got to come up to the clinic today, your medicine is due today, your injection is due today or it was due yesterday, or it's due tomorrow."
COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

10

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Concluding remarks

COMMUNITY | COMPASSION | QUALITY | INTEGRITY | EQUITY | CURIOSITY

11

Chapter 6: Teaching Field Epidemiology

Contents

Background

This chapter describes the activities I undertook to fulfil the teaching epidemiology competencies for the Master of Philosophy in Applied Epidemiology (MAE). This included preparing and delivering a Lesson From the Field (LFF) to peers within my MAE cohort; and preparing and delivering an epidemiology training lesson for first-year scholars.

Lesson from the field

Overview

I prepared my LFF in January 2023 and delivered it on 3 February via Zoom. After consulting with my supervisors, I decided to focus my LFF on qualitative research methods. I realised that my experience in this area was relatively strong compared to my peers, following discussions about their projects and our introductory session on qualitative methods in Course Block 2. As many MAE students will conduct interviews for their surveillance evaluation chapter, I decided to structure the LFF around planning and conducting a qualitative interview because I thought this would be useful for others in my group.

Qualitative research has tended to be undervalued in the field of epidemiological inquiry, which focusses primarily on quantitative methods to generate evidence. Common criticisms of qualitative methods in mainstream epidemiology include that they are subjective, non-rigorous and unscientific(1). However, there is growing awareness of the value of using qualitative methods in epidemiology, including their importance in answering 'how' and 'why' questions; building understanding of motivations for behaviour and the social consequences of disease; and as a valid evidence source for causal inference(1-3). Qualitative interviewing in particular is useful for collecting data on the perspectives and motivations of participants, especially regarding issues that are personal or sensitive in nature(1,4). Qualitative interviews are particularly important for epidemiological research regarding Aboriginal and Torres Strait Islander peoples, because they allow participants to characterise their experience in their own words rather than requiring evidence generated to fit into predetermined quantitative concepts or categories(4,5). Methods to ensure rigour in qualitative research include prolonged engagement with subjects to build trust; triangulation of results with other data and across multiple researchers; peer debriefing to gauge the effect of interviewer biases and assumptions on the results; negative case analysis to interrogate contradictory data; and reflexivity to ensure that the positions and values of the researchers are understood and clearly stated in the results(6,7).

For the pre-session activity [Appendix 1], I asked my peers to consider a hypothetical scenario, which I created based on my project on rheumatic heart disease (RHD). I then stepped them through the main elements of semi-structured interviews, which included: composing an appropriate research

question; choosing an interview approach; identifying potential interviewees; creating an interview guide; incorporating techniques to ensure rigour; and preparing a participant information sheet and consent form. At each point they were asked to apply these steps to the scenario and provided with links to relevant resources they could refer to.

Because we had all completed the previous introductory session, I assumed a high-level understanding of what qualitative research means, but generally pitched the activity at a beginner level to ensure that all group members could participate and learn.

Three of the six people in my LFF group completed the activity before the LFF session and sent me their answers. Overall, the activity was completed well and those three people grasped the concepts appropriately. Because I wasn't sure of the confidence of the remaining three members, I decided to spend the LFF session itself taking the group through each of the questions in the activity and discussing model answers. I particularly focused on the section about designing an interview guide, as those who had completed the activity did not do as well on this question (for example, proposing questions that were too targeted/directive, or prompting yes/no answers). In going through the questions, I also spoke about my experiences and shared tips I had learnt in different settings about the practicalities of conducting qualitative interviews. All six people in my group engaged in the session and proposed insightful answers to questions.

Lessons Learnt

Although I had experience using qualitative interview techniques, I learnt a lot about qualitative interviewing from preparing and delivering the session. I reviewed a range of sources while preparing the worksheet, including the United States Centre for Disease Control Field Epidemiology Manual's chapter *Collecting and Analyzing Qualitative Data* and Lincoln and Guba's 1985 criteria for rigour in qualitative research(4,6). These documents helped me to build on my existing knowledge, and to describe processes and techniques that I have used before without knowing their formal names (for example 'key informant interviews' and 'member checking').

Another lesson learnt was the importance of having real-world examples to discuss in a theoretical lesson. Firstly, the application of the scenario worked well and was a good way to focus the conversation throughout the lesson. Secondly, having my own experiences and mistakes to draw from in discussions prompted a lot of the conversation, and my peers suggested that they found this aspect of the lesson useful and interesting.

Finally, delivering the LFF was a good lesson in adaptability and the challenges of online learning. Delivering a class via Zoom was difficult, as comments and conversation do not flow as easily as in a

face-to-face setting. It was also tricky to cater the session to the group while only having responses from half of them, and meant I needed to pivot throughout the presentation to address questions and discussion topics as they arose. If I delivered this session again, I could remove some of the requirements in the pre-session activity to decrease the time investment required and increase the completion rate. Overall, I enjoyed teaching my peers about this topic, despite the challenges, and found it a worthwhile part of the MAE program.

Teaching to first-year scholars

Overview

I delivered a tutorial on age standardisation to the cohort of approximately 25 first-year MAE scholars on 21 February 2023, along with fellow MAE second years Zoe Baldwin and Maddy Marsland. The session was delivered in-person at ANU over 1.5 hours.

Zoe, Maddy and I were provided with materials from the age standardisation session that our own cohort had completed in February 2022, including suggested pre-readings, Powerpoint slides, and an Excel activity for conducting age standardisation calculations. We met to discuss the relevance of the existing material, and agreed on some updates. These included adding knowledge-check questions throughout the session via an online poll, updating wording and examples, including clearer instructions for the activities, and adding an additional exercise using an Indigenous Standard Population.

I was responsible for delivering the section on indirect standardisation, including a theoretical description and taking the students through the practical Excel activity. I also took responsibility for designing and testing the additional exercise.

During the tutorial, we had very good engagement from the first-year scholars, who had variable existing knowledge of age standardisation. Students freely posed questions and answers during the theoretical sections. During the practical exercises, students worked on Excel on their own computers, with Maddy, Zoe and I providing assistance as needed. We asked for volunteers to demonstrate for the class how they had done each exercise, and then provided feedback on this. Although we didn't have time to go through the additional exercise, I gave students a brief summary of how using a different standard population could change the results. Maddy and I were also able to discuss our experiences using age standardisation in our field projects.

The results of our evaluation [Appendix B] indicated that the first-year scholars found the session useful and engaging, regardless of their existing knowledge of age standardisation.

Lessons Learnt

Similarly to my experience with the LFF, preparing to teach the age standardisation session meant that I had to solidify my own knowledge of age standardisation concepts, particularly related to indirect standardisation. I was especially interested by the pre-reading on using an Indigenous Standard Population and how this might transform the messaging and results of a calculation (8). This competency made me consider the strengths and weaknesses of my approach to age standardisation in my RHD project.

As per the results of the evaluation [Appendix B], one of the first-year scholars reported that the session did not help them to understand age standardisation, and another said that they would need additional support to conduct an age standardisation calculation again. As I had assisted a few people in the session who were struggling to use Excel, I was not surprised to see this result. This experience highlighted to me the complexity of pitching a session to an audience with differing technical skills. While we aimed to make the session engaging and interesting for the whole class, including those already familiar with Excel, we were cognisant that someone who had never used Excel would likely find it difficult. If I was to conduct a similar session again, I would try to ameliorate this by providing some introductory resources on Excel and suggesting that students who were not familiar with Excel consult these prior to the session.

I was grateful to have the opportunity to conduct the session face-to-face and meet the first-year scholars in person. I found the physical classroom more comfortable for teaching than the online environment, and it was especially useful monitoring students' progress on the exercises. Overall I found that teaching this session boosted my confidence in communicating epidemiological concepts and added to my knowledge of age standardisation.

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Appendix 1: Lesson From the Field handout and model answers

Lesson from the field: Planning and conducting a qualitative interview for epidemiological research

Background

Although it has been (and continues to be) somewhat undervalued in the scientific community, qualitative research can provide important value for the health sector and for epidemiology specifically. It is vital for answering 'how' or 'why' questions, understanding local contexts and behaviours, and designing programs and policies that are acceptable in a real-world setting. Semi-structured interviews are a common form of qualitative research method and are a useful tool for a field epidemiologist. The CDC Field Epidemiology Manual's chapter on Collecting and Analysing Qualitative Data provides a useful background on interview approaches, methods and analysis.

Rheumatic heart disease is an entirely preventable disease that contributes significantly to mortality and morbidity in Australia, especially among Aboriginal and Torres Strait Islander peoples and communities. RHD is characterised by valvular heart damage that develops following one or more episodes of Acute Rheumatic Fever (ARF), which is itself an immune reaction to a Group A Streptococcal (GAS) infection.

Learning Objectives

After this LFF session, you will be able to:

- Understand how qualitative approaches can add value to epidemiological research
- Describe the basic steps of planning a qualitative interview
- Choose an appropriate interview approach for a research question
- Develop a question guide for a semi-structured interview
- Outline different techniques used to ensure rigour in qualitative research

Scenario

You are working in a social epidemiology research unit, investigating health outcomes among people in a densely populated urban area. You have been assigned as the lead investigator for a research project examining health-seeking behaviour among people with Rheumatic Heart Disease (RHD). You conduct a quantitative analysis using administrative data, and find that Aboriginal and Torres Strait Islander people with RHD are less likely to have attended scheduled specialist appointments than non-Indigenous people with RHD. Your research team is interested in understanding this relationship more deeply and, after reading some great articles on the value of qualitative research, you decide to conduct some qualitative interviews as part of your research project. You're familiar with the NHMRC Guideline for ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities, and you have Aboriginal colleagues on your research team advising you on the research methods, data collection and analysis. You start pulling together material that you'll need for your ethics application.

Activity

Why do you think qualitative research might be useful for this research area? Brainstorm some possible research questions and choose one to focus on for this activity.

- *Qualitative research is useful for answering 'how' or 'why' questions*
- *Qualitative research can shed light on complex issues that are difficult or impossible to measure using quantitative metrics, and enable nuanced results*
- *Qualitative research helps to explore research questions and areas for which researchers do not have an existing hypothesis*

Possible research question:

- *Are Aboriginal people with RHD in this area facing barriers to accessing health care? How might these barriers be affecting their care-seeking behaviour?*

In your ethics application, you'll need to describe your qualitative methodology. You have a read of the 'Commonly Used Qualitative Methods in Field Investigations' section of the CDC Guideline to learn about different approaches for interviews. What are some advantages and disadvantages of each approach for your research question?

	Advantages	Disadvantages
In-depth interview	• *First-hand accounts from patients about their experience* • *Allows for personal and sensitive topics to be discussed*	• *Time consuming* • *Requires high level of ethical approval involving complex process*
Key informant interview	• *Participants have high-level understanding of broad issues that may be relevant across community*	• *Time consuming* • *Excludes first-hand accounts and experiences*
Community focus group	• *Time efficient* • *Group dynamics may bring up additional data and topics*	• *Quieter people may not feel comfortable to speak, especially about personal or sensitive issues*
Key informant focus group	• *As above*	• *May be difficult to organise as stakeholders likely to have busy schedules*

Because you have limited time to conduct this research, your research colleagues advise that you conduct about ten one-on-one interviews with key informants. This will reduce the potential ethical considerations involved with conducting interviews, and will allow you to get a broad perspective on the issue.

Your research team also advises that you use a purposive sampling technique, considering your limited time and small sample size. As per the CDC Guideline, purposive sampling means that interviewees "are selected because they are exceptional rather than simply representative. Their value lies not in their generalizability but in their ability to generate insight into the key questions driving the study."

Make a "wish list" of five key informants that you would like to interview. What kinds of people might be able to provide insight on your research topic?

1. *Specialist treating RHD patients*
2. *Local Aboriginal Health Worker or Practitioner treating RHD patients*
3. *Aboriginal community leader or advocate*
4. *Government staff member from RHD register or control program*
5. *Staff member from Aboriginal community-controlled health service*

For your ethics application, you also need to provide a copy of the question guide for your interviews. Because you've read this handy resource on interview guides, you know they should:

a) Be focussed around approximately ten, open-ended questions (to avoid short, especially one-word answers);
b) Progress from introductory, broad questions to more specialised questions about the research area; and
c) Include room for flexibility, like follow-up questions, skipping questions, changing order, or probing an answer if appropriate.

Have a think about the first few questions you will include in your interview guide. What kind of questions can you start with to make your interviewee feel comfortable and talkative?

1. Please describe your experience working with RHD patients. How long have you been working in/involved in this area for?

2. What kind of health services do people with RHD come into contact with and why?

3. In your experience, how does having RHD impact a patient's life more broadly?

After the first part of the interview, you'll move on to questions more directly related to the research area. Some examples are included below. In interview guides, it's a good idea to include some ideas for prompts in case the answer to the first question is short or does not provide much detail. Brainstorm some ways that you could reframe or break down these questions when this happens.

4. In your opinion, what kinds of things do you think influence whether people with Rheumatic Heart Disease attend a medical appointment, and why?

- Prompt 1: *How might stories from family and friends affect whether someone attends a medical appointment?*
- Prompt 2: *What have people with RHD told you about barriers to accessing health care?*
- Prompt 3: *How might their relationship with health care providers impact someone's decision to attend a medical appointment?*

5. This research is specifically looking at health-seeking behaviour among Aboriginal and Torres Strait Islander people with RHD. What have you heard from people in this group about accessing health services?

- Prompt 1: *Why do you think the experience of Aboriginal and Torres Strait Islander people with RHD accessing health services is different to that of non-Indigenous people?*
- Prompt 2: *How might the health services themselves be affecting whether Aboriginal and Torres Strait Islander people with RHD attend medical appointments?*
- Prompt 3: *Why might attending a medical appointment not be a high priority for Aboriginal and Torres Strait Islander people with RHD?*

Your ethics application should also explain how you will ensure your research process is rigorous. You and your research team have decided that you will pursue a thematic analysis of the interview transcripts. Using Lincoln and Guba's 1985 criteria for rigour in qualitative research, choose one technique from the list below and describe in a few sentences how you will use it in your study.

- Negative case analysis
- Triangulation
- Member-checking
- Reflexivity

Negative case analysis: I will use this in my study by ensuring that any data that disagrees with a theme or finding is examined in consultation with the rest of the research team, in order to understand how and whether this fits with our findings.

Triangulation: I will use this in my study by comparing my results with the results of previous research on this topic, as well as the results from my quantitative analysis.

Member-checking: I will use this in my study by providing participants with a copy of their transcript after the interview and giving them an opportunity to add or change it.

Reflexivity: I will use this in my study by regularly examining the impact of my own background and experience on how the interviews are conducted and data analysed. I will keep notes of my own experience of each interview as well as discussing this with research team members regularly.

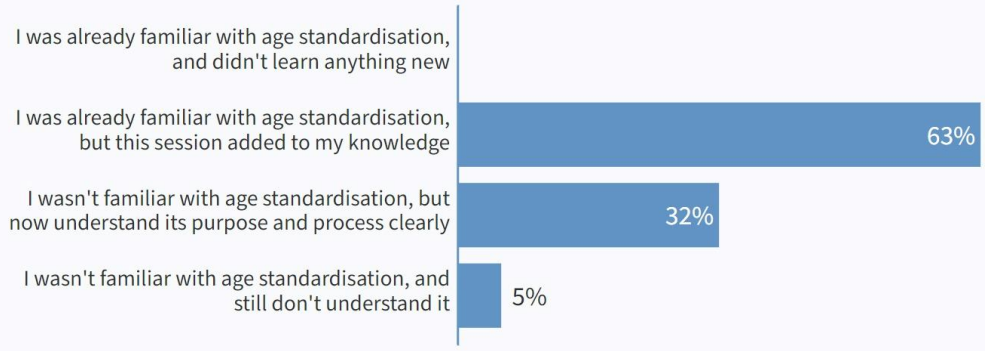
Finally, you should prepare a participant information sheet and consent form to send to interviewees before the study. Have a look at this template from the NHMRC. What section do you think is the most important for potential participants in your study to understand, and why?

The most important section for participants to understand is that participation is voluntary, and that there will be no negative repercussions if they choose not to participate. This is especially relevant for research with Aboriginal and Torres Strait Islander communities.

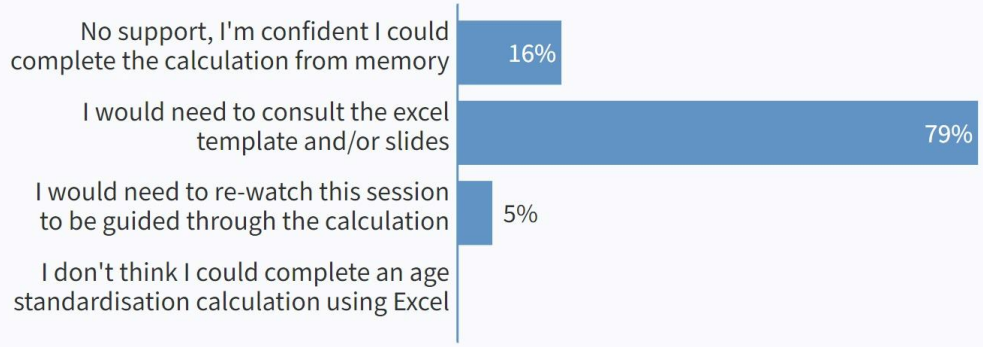
Congratulations! After months of toiling over paperwork, you are informed that your ethics application has been approved. In our LFF session on 3rd February we'll go over the content above as well as some practicalities for conducting an interview.

Appendix 2: Evaluation Results, Age Standardisation Tutorial

How would you describe your knowledge of age standardisation following this session?



After this session, what support would you need to do an age standardisation calculation in Excel?



How enjoyable was this session for you?