IMPROVING THE HEALTH AND WELLBEING OF ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN IN AUSTRALIA

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NHMRC CENTRE OF RESEARCH EXCELLENCE

IMPROVING HEALTH SERVICES FOR ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN

ORIGINALITY STATEMENT

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

Signed: 

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ABSTRACT

I completed my Masters of Applied Epidemiology during 2017-18 with the NHMRC funded Centre for Research Excellence in Improving Health Services for Aboriginal and Torres Strait Islander Children (CRE ISAC) located at the University of Western Australia. My projects focussed mostly on social epidemiology, with the exception of my outbreak.

Chapter two provides a case-control study of a point source outbreak of *Salmonella* Typhimurium, which occurred at a university residential college in April 2018. Epidemiological and environmental investigation identified the most likely source of the outbreak to be raw eggs used in coleslaw. Public health action was the provision of information on the safe handling of eggs to prevent further outbreaks.

Chapter three, public health data analysis, was a population-based birth cohort study using linked datasets with information on a cohort of Aboriginal and Torres Strait Islander children, and their mothers and siblings. The 2009 and 2012 Australian Early Development Census was used to assess developmental vulnerability across five domains of development in Aboriginal children born in Western Australia. Latent class analysis was used identify and describe profiles of risk for developmental vulnerability. Six distinct classes were identified.

My surveillance project, provided in chapter four, was the evaluation of the Western Australian population based data linkage Intellectual Disability Exploring Answers (IDEA) surveillance system. I evaluated the usefulness, simplicity, flexibility, data quality, acceptability, representativeness, timeliness, and stability of the IDEA system. This was completed by process observation, semi-structured interviews and data

analysis. The IDEA system has successfully been used to understand prevalence rates and inform resource allocation. Advocacy organisations could play an important role in the sustainability of the system. Additional variables or enhanced surveillance for functional capacity could strengthen the system and provide information for people living with intellectual disability and their families.

Chapter five is my epidemiology project which was a cross-sectional study of 1554 clinical child health audits and associated systems assessments from 74 primary care services from 2012-2014. Composite process of care indicators (PoCIs) were developed for social and emotional wellbeing, child neurodevelopment and anaemia. Crude and adjusted logistic regression models were fitted clustering for health services. 32.0% (449) of records had a social and emotional wellbeing PoCI, 56.6% (791) had an anaemia PoCI and 49.3% (430) had a child neurodevelopment PoCI. The study found that the need for young Indigenous children aged 24-59 months to receive quality care for important social and health indicators should be a priority. Processes of care and organisational systems within primary care services are important for the optimal management of anaemia in Indigenous children.

The final chapter concludes with my lessons from the field. This provided me with an opportunity to deliver a count regression teaching opportunity to my peers.

ACKNOWLEDGEMENT

I would like to thank my supervisors Associate Professor Dan McAullay (field), Professor Karen Edmond (field), and Dr Alice Richardson (academic). Dan provided me with ongoing support and advice at all stages of the thesis. This included making sure that my regular work did not overwhelm me so that I could complete my MAE on time. To Karen, who without her encouragement to go back and study epidemiology I might not have gone down this path. Finally, thanks to Martyn Kirk's foresight on pairing me with Alice and her fabulous biostatistician skills. I feel like I have learnt a substantial amount about biostatistics and epidemiology, far more than I anticipated. Also thanks Alice for your statistical advice on projects outside of my MAE.

To all of my collaborators who I have named throughout the thesis thank you for the support, guidance and your expertise. I would like to personally acknowledge my colleague and friend Dr Kimberley McAuley who has provided me with both friendship and epidemiology advice in all of the projects outlined in this thesis.

To the MAE 2017 cohort, I have had a fabulous time meeting you all. Having a group of friends to throw ideas around and help me when I needed it was an extra bonus of the MAE. I have laughed my way with you all, drank lovely wine and eaten my bodyweight in dumplings. I look forward to our continued friendship in the coming years.

I would like to thank the National Centre for Epidemiology and Population Health (NCEPH) for this great program and opportunity to take part in it. I have learnt a tremendous amount from the guest lecturers, course content, and presentations that have occurred over the two years.

Thank you to my Mum, Dad and Jamie for their support over the two years. Thankfully, this wasn’t as crazy as my PhD and you didn’t need to financially support me this time! Lastly, I would like to thank my husband, Barry, for his unwavering support and all the laughs along the way.

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ABBREVIATIONS

ABCD	Audit and Best Practice for Chronic Disease
aOR	Adjusted odds ratio
ANU	Australian National University
CI	95% confidence interval
CRE ISAC	Centre for Research Excellence in Improving Health Services for Aboriginal and Torres Strait Islander Children
CQI	Continuous quality improvement
DSC	Disability Services Commission
EHO	Environmental Health Officer
EN	Educational need
FTE	Full time equivalent
GEE	Generalised estimating equation
ID	Intellectual disability
IDEA	Intellectual Disability Exploring Answers
IQ	Intelligence quotient
LCA	Latent class analysis
LFF	Lessons from the field
MAE	Master of Applied Epidemiology
MLVA	Multiple-locus variable number tandem repeat analysis
NHMRC	National Health and Medical Research Council
OR	Odds ratio
PoCI	Quality of care indicators
SAT	Systems Assessment Tool
SEWB	Social and emotional wellbeing
TKI	Telethon Kids Institute
UWA	University of Western Australia

CHAPTER 1: OVERVIEW OF MASTERS OF APPLIED EPIDEMIOLOGY EXPERIENCE

1.1 Introduction

My field placement was with the NHMRC funded Centre for Research Excellence in Improving Health Services for Aboriginal and Torres Strait Islander Children (CRE ISAC) located at the University of Western Australia. I have been employed as a researcher on the CRE ISAC since October 2014 working on a number of evidence synthesis, epidemiology and health services projects. Since completing my PhD in Human Movement Studies in 2010 I have been working in health services research and epidemiology, however, have been largely supported by many experienced epidemiologists. During my employment at the CRE ISAC the opportunity arose to apply for the MAE program, which would provide me with the knowledge and experience to become an independent epidemiologist.

1.2 CRE ISAC

In 2014, the CRE ISAC, was awarded to Professor Karen Edmond (previous Director), A/Professor Dan McAullay (current Director), Professor David Atkinson, Professor Rhonda Marriott, Professor Ross Bailie, A/Professor Alan Ruben, A/Professor Mark Wenitong, Professor Victor Nossar, and Professor Betty Kirkwood. The CRE ISAC was funded for five years (2014-2018) with the overall aim to improve health and developmental outcomes in Aboriginal and Torres Strait Islander children in Australia through improvements in health services. The objectives of the CRE ISAC were to:

- Generate new knowledge that leads to improved health and developmental outcomes in Aboriginal and Torres Strait Islander children
- Ensure effective transfer of research outcomes into health policy and practice

- Develop the health and medical research workforce by providing opportunities to advance the training of new researchers
- Facilitate collaboration across ISAC and national and international networks
- Work across primary, secondary and tertiary level health services but have a specific focus on improving pathways within primary community care.

The CRE ISAC is a collaborative centre that brings together national and international researchers from Aboriginal, Torres Strait Islander, non-government and mainstream organisations. The Chief and Associate investigators within ISAC are uniquely placed in leadership positions in international and national academic, and service delivery institutions. The centre includes health services researchers, epidemiologists, child health researchers, undergraduate and post graduate students, university lecturers, Aboriginal Community Controlled Health Services staff, government service providers and policy makers. The CRE ISAC's area of expertise is in improving health services for disadvantaged communities. Specific research strengths include health service evaluation, quality improvement and epidemiology for disadvantaged children. The CRE ISAC is administered from Perth and has partners in Western Australia (Perth, Kimberley), Northern Territory (Darwin, Nhulunbuy) and Far North Queensland (Cairns, Townsville and Cape York).

1.3 Summary of experience and public health impact

As I was a full-time employee with the CRE ISAC my field placement included delivering the MAE core competences and maintaining my responsibilities within ISAC. As part of my MAE two projects were part of my core ISAC work, the epidemiology project and public health data analysis. Other responsibilities included the team leader of the evidence synthesis stream, working on a number of epidemiology and health service research projects, building capacity through co-supervising higher degree research students and paediatric registrars, and providing administrative support.

1.3.1 Evidence synthesis

The CRE ISAC aims to support capacity building for individuals and teams to complete systematic reviews. It aims to reduce duplication at the initial review stage of developing preventive and clinical practice guidelines, and make important contributions to the evidence base for improving the health outcomes of Aboriginal and Torres Strait Islander children and their families. We are often approached by researchers, health service providers and policy makers to help provide expertise in four main areas of evidence synthesis. These areas are:

- How to determine the effectiveness of interventions
- How to determine the gaps in the evidence on a topic
- How to improve preventive and clinical practice guidelines
- What other types of synthesis are available.

As a result I developed a document providing practical guidance and reference to methods that will enable individuals and teams to complete these four main areas of evidence synthesis (1).

In addition to this, I am working on and supporting a number of evidence synthesis publications including Cochrane and non-Cochrane systematic reviews and scoping reviews on care coordination (2), family centred care (3, 4), cultural security, infant male circumcision (5) and child development (6).

1.3.2 Epidemiology and health services projects

I have completed and supported a number of epidemiology projects since working at the CRE ISAC and during my MAE. These projects have focussed on Aboriginal and Torres Strait Islander infants and their use of health services (7, 8), health service continuous quality improvement on quality of care for Aboriginal and Torres Strait Islander infants (9, 10) and infant male circumcision (11-13).

1.4 Summary of core competencies

Table 1.1 provides a summary of the core competencies delivered by chapter as required by the MAE.

Table 1.1 Summary of core competencies

	Chapter 2	Chapter 3	Chapter 4	Chapter 5	Chapter 6
Field projects					
Investigate an acute public health problem	✓				
Analyse a public health dataset		✓			
Evaluate or establish a surveillance or other health information system			✓		
Design and conduct an epidemiological study				✓	
Additional requirements					
Complete a literature review		✓			
Report to a non-scientific audience			✓		
Publish a peer review journal article				✓	
Complete an oral presentation		✓	✓		
Teaching					
Lessons from the field					✓

1.5 Aboriginal and Torres Strait Islander people

A brief note on the definition of Aboriginal and/or Torres Strait Islander people used in this thesis. Within the Western Australian context, I have referred to Aboriginal and Torres Strait Islander and then used the preferred term Aboriginal as they are the original inhabitants of Western Australia. Within the national and international context, I have first recognised Aboriginal and Torres Strait Islander peoples and then used the term Indigenous. I would like to recognise and acknowledge the diversity amongst Aboriginal and Torres Strait Islander people and their communities. The results provided in this thesis should be interpreted with caution for any one community or group.

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CHAPTER 2: AN OUTBREAK OF *SALMONELLA* TYPHIMURIUM GASTROENTERITIS LINKED TO A RAW EGG DISH AT A UNIVERSITY RESIDENTIAL COLLEGE IN WESTERN AUSTRALIA

2.1 Prologue

2.1.1 My role

The experience of working with OzFoodNet WA was exactly what I wanted for my first outbreak; a contained food outbreak with a known population. During the outbreak my tasks included:

- interviewing and collect data on one case using the OzFoodNet Salmonella Hypothesis Generating Questionnaire
- liaising with the Dean of Residence at the university residential college where the outbreak occurred for food menus over the outbreak time period
- developing the first draft of the SurveyMonkey food survey. Working with Barry at OzFoodNet I received feedback and suggestions for the questionnaire that I then incorporated into the drafts until the final version was completed
- downloading and cleaning the data to completed the analysis for the outbreak
- completing internal OzFoodNet documents including the timeline of all activities and correspondence associated with the outbreak, a line list of known cases from the hypothesis generating part of the outbreak, and the internal Department of Health outbreak summary report
- providing email updates to the Scientific Officer in the Environmental Health Directorate of the epidemiology of the outbreak and requested information for the environmental investigation
- contacting the residential college to request if they would like a letter of the results for their records, which I completed the first draft of and worked with staff at OzFoodNet and the Scientific Officer until it was finalised.

2.1.2 Lessons learned

During the outbreak I was able to consolidate the theory of working on an outbreak to actually completing an outbreak. I learnt how to determine what information needs to go into the food questionnaire. When there are multiple days with numerous amounts of different foods that could be added to the survey, knowing what foods to remove and keep was interesting. To determine this you needed to know about the cause of the outbreak (if possible), use the hypothesis generating questionnaire to develop a hypothesis and have a lot of experience in developing these surveys. I discovered how OzFoodNet works with local government who employ environmental health officers to go into food establishments. In WA, the Scientific Officer liaises between the local governments and OzFoodNet, which helps communication between the two areas. Lastly, the outbreak resulted in a number of interesting occurrences such as the environmental health officers being refused entry onto the premises, and the college having concerns that the survey itself and the survey wording would unnecessarily tarnish the reputation of the college. These situations were dealt with by the senior Environmental Health Officer reminding the college of the Power of Entry for officers and by working with the college on the survey until all parties were satisfied.

2.1.3 Public health implications

Salmonella outbreaks in WA have increased over the last five years and are at an all time high. The Western Australian government has put in place strategies to reduce the number of cases that are notified in foodborne outbreaks. For this outbreak, Environmental Health Officers explained the inherent risks of using raw eggs without a relevant ‘kill step’, and recommended that all products containing raw egg be disposed of within 24 hours of manufacture. This included any product that has been dressed with the raw egg mayonnaise or aioli. They were also provided with the WA Health Notice, ‘Safe Handling of Eggs and Products Containing Eggs’.

2.1.4 Acknowledgements

Through my placement there was no capacity to complete an outbreak. As a result I enlisted the help of a previous MAE scholar, Darren Westphal, who introduced me to the OzFoodNet team in WA. I would like to acknowledge Barry Combs and Niki Foster from OzFoodNet WA. Barry was my main contact at OzFoodNet who provided me with his time, feedback on all of my work and advice on what to do. I learnt a lot about how to complete an outbreak investigation from Barry. Niki also provided time, support and feedback on the outbreak. In particular, she provided important feedback on my outbreak chapter. I would also like to acknowledge Dr Alice Richardson (primary supervisor ANU) and Associate Professor Dan McAullay (placement supervisor UWA) on providing feedback and comments for the outbreak chapter.

2.1.5 MAE core requirements

This chapter fulfils the requirement to investigate an acute public health problem.

2.2 Abstract

2.2.1 Background

In Western Australia, Salmonella notifications have been increasing with *Salmonella* Typhimurium contributing the highest proportion of *Salmonella* notifications. On 10 and 11 May 2018 two *S*.Typhimurium cases were contacted as part of a cluster investigation. As both cases resided at the same university residential college, an outbreak investigation was initiated.

2.2.2 Objectives

The objectives of this investigation were to determine the cause of illness and implement appropriate public health action to prevent future illness.

2.2.3 Method

This was a case-control study of 80 participants who had resided in the college between the 23 and 26 April 2018. Environmental and laboratory investigations were

also completed. Univariate logistic regression was used to determine an association between illness and food exposures. Odds ratios and 95% confidence intervals were derived.

2.2.4 Results

There were 80 people who completed the survey, 13 (16.3%) cases and 67 (83.7%) controls. Our analysis found cases (8/10; 80%) were 16 times more likely to have eaten coleslaw on 25 April than controls (8/40; 20%) (OR 16.0, 95% CI 2.37-170.07, p value <0.001). Jam pudding was also statistically associated with being ill. Cases (4/10; 40%) were five times more likely to have become ill after eating the jam pudding on the 24 April than controls (6/52; 12%) (OR 5.11, 95% CI 0.79-29.26; p 0.046). The environmental investigation found raw eggs were used in dishes on the premises including the coleslaw on 25 April.

2.2.5 Discussion

In light of the evidence from the case-control study and that raw eggs were used in the mayonnaise, it is likely that the coleslaw eaten on 25 April was the source of the illness. Public health action including explaining the risks associated with using raw egg dishes. The college was provided with a food safety notice discussing how to prepare raw eggs dishes in the future.

2.3 Introduction

Non-typhoidal *Salmonella* infections are self-limiting illnesses that are characterised by gastrointestinal symptoms such as diarrhoea, vomiting, nausea, headaches and abdominal cramps. In 2010, non-typhoidal *Salmonella* infections were estimated to have attributed to 78.4 million foodbourne illnesses globally.(1) Within Australia, the most common cause of non-typhoidal *Salmonella* infections are foodbourne-related.(2) Animals are a major reservoir for non-typhoidal *Salmonella* infections with consumption of eggs, pork, beef, poultry meat and dairy products commonly associated with these infections.(3-5)

Within Australian states and territories all laboratory confirmed *Salmonella* cases are notifiable to health departments.(6) Between 2000-2013, there was a significant increase in the number of *Salmonella* notifications in Australia.(7) During this period the serovar *Salmonella* Typhimurium contributed the highest proportion of *Salmonella* notifications, constituting nearly 44% of these notifications.(7) In 2011, *S*.Typhimurium was the most common *Salmonella* serovar implicated in foodbourne illness in Australia and continues to be the dominant cause of *Salmonella* foodbourne outbreaks in the country.(8)

In Western Australia (WA), *S*.Typhimurium has become the most commonly reported serovar.(9) Prevalence rates of *S*.Typhimurium in the last five years have significantly increased with a 2.9 fold higher rate in 2017 (n=1440) compared to the five year mean from 2012-2016 (n=491). In response to these increased rates, the Department of Health WA has developed a foodborne illness strategy to reduce the rate of foodborne illness through surveillance and monitoring, stakeholder engagement and awareness, policy and networking, and research, science and epidemiology.(10) The reduction of Salmonellosis by 30% is the first foodborne target.(11) Consumer awareness, stakeholder engagement, managing, surveying and monitoring food safety both in primary industry and food service industries, strengthening partnerships, implementing state and national level strategies, and collaborative research have been identified as mechanisms in which to support these reduction efforts.(11)

The Department of Health WA investigates clusters and possible outbreaks of notifiable enteric diseases including salmonellosis. On 10 May 2018 a notified *S*.Typhimurium case was contacted as part of a cluster investigation. The individual reported living at a university residential college and mentioned that a number of other students had

become ill with gastro-like symptoms at the same time. A survey distributed by the college found approximately 20-25 students out of 180 respondents had reported getting sick during the week of 23 April 2018 to 27 April 2018. On 11 May 2018, a second *S*.Typhimurium case was identified by the Department of Health as a resident at the same university residential college during the week of interest. As a result, an outbreak investigation was initiated. The objectives of this investigation were to determine the cause of illness and implement appropriate public health action to prevent future illness.

2.4 Methods

2.4.1 Epidemiological investigation

After making enquires with the residential college it was established that a staff member was also ill. The two notified cases and the college staff member were interviewed using the National OzFoodNet Salmonella Hypothesis Generation questionnaire (12), which included taking a detailed history of food eaten prior to illness from 23 April to 26 April 2018. The staff member reported eating one meal at the college during this period, which was coleslaw, chicken schnitzel and undressed green salad for lunch on 25 April 2018. Based on this information we hypothesised that the illness was associated with a dish or dishes served at lunch on this date.

A menu of food eaten was provided by the college and structured online survey was developed to identify symptoms, onset date and determine which foods were eaten at the college between Monday 23 April to Thursday 26 April. The survey was distributed by the college by email to approximately 12 staff and 220 students, irrespective of illness, on 21 May 2018 and the college sent another reminder on 24 May. The survey was open for a week after it was sent out.

Based on a response rate of <60%, the data were analysed as a case control study as opposed to a cohort study. A case was defined as any person who resided or worked at the college and had diarrhoea with an onset of symptoms between 23 April and 30 April. A control was defined as any person who resided or worked at the college and reported having no diarrhoea between 23 April and 30 April. Individuals were excluded from the study if i) they did not attend the college between 23 April and 26 April (n=3), ii) were ill but the date of onset was outside of the case definition (n=2), or iii) stated they were ill but did not provide an onset date and/or list of symptoms (n=4).

Data were collated in Microsoft Excel (2016) and analysed using STATA 14.2. Odds ratios and 95% confidence intervals were derived and a Fisher's exact test was used to determine whether an association between illness and food exposure was statistically significant (2-sided p value <0.05). Food exposures were unable to be stratified to adjust for potential confounding as the number of respondents was too small.

2.4.2 Environmental investigation

There were three visits to the university residential college by the local government as the appropriate enforcement agency in accordance with the *Food Act 2008* (Act). The first was a routine inspection on 7 May 2018. The other two were completed on 25 May 2018 and 21 June 2018 in response to the suspected outbreak and the epidemiological investigation. This included an on-site investigation of the food business and questioning of relevant staff relating to the usage of raw eggs. No food or environmental samples were collected for testing due to the length of time that had passed from the date of the outbreak to when the environmental investigation was completed.

2.4.3 Laboratory investigation

Stool culture, *Salmonella* serotyping, and *S.* Typhimurium multiple-locus variable number tandem repeat analysis (MLVA) were conducted by PathWest Laboratory Medicine, Nedlands.(13)

2.4.4 Ethics

Epidemiological investigations of foodborne outbreaks in WA are carried out under the Public Health Act, 2016. In addition as a MAE student was conducting the investigation, ethics approval was provided by Australian National University Human Research Ethics Committee under protocol 2017/909.

2.5 Results

2.5.1 Descriptive epidemiology

We received a response rate of 34.5% (80/232) from staff and students at the residential college. Of the 80 people who completed the survey there were 13 (16.3%) cases and 67 (83.7%) controls. There were eight (62%) male and five (38%) female cases. The median age of cases was 20 years (range: 18-43 years). The median incubation period was two days (range: 0-2 days). The median duration of diarrhoea for cases was four days (range: 1-14 days). Seven (54%) cases sought medical attention and two (15%) cases were hospitalised (Table 2.1). Symptoms of cases are provided in Table 2.1. The epidemic curve indicated a point source outbreak with most cases (54%) reporting their date on onset of illness as 27 April 2018 (Figure 2.1). Of the 13 cases identified in the investigation, one case had eaten only one meal during 23-26 April 2018 period. This was on Wednesday 25 April and included chicken schnitzel, coleslaw and undressed green salad.

Table 2.1 Demographic characteristics and symptoms of cases at the college, April 2018

	Cases (n=13)	Controls (n=67)
Sex		
Male	8 (61.5%)	41 (61.2%)
Female	5 (38.5%)	26 (38.5%)
College attendees		
Staff	1 (7.7%)	8 (11.9%)
Student	12 (92.3%)	59 (88.1%)
Symptoms		
Diarrhoea	13 (100%)	
Bloody diarrhoea	1 (7.7%)	
Vomiting	3 (23.1%)	
Fever	11 (84.6%)	
Nausea	8 (61.5%)	
Abdominal pain	10 (76.9%)	
Headache	12 (92.3%)	
Join or muscle pain	10 (76.9%)	
Other	1 (7.7%)	
Sought medical attention		
Sought medical attention	7 (53.8%)	
Hospitalised	2 (15.3%)	

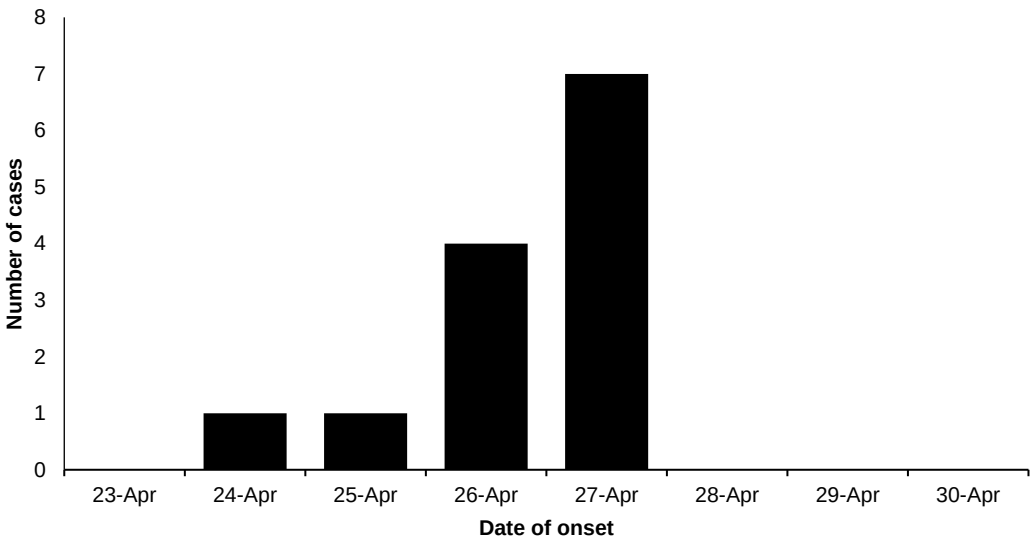

Figure 2.1 Epidemiological curve of onset date of illness for cases (n=13) linked to the college, April 2018

2.5.2 Analytical epidemiology

There were 60 dishes served over the four days of interest (Table 2.2). The five most frequently eaten foods on any given day were undressed green salad (21 April: 81%; 25 April: 74%), chips (21 April: 73%; 25 April: 74%), and teriyaki chicken (26 April: 77%) (Table 2.2). Our univariate analysis found cases (80%) were 16 times more likely to have eaten coleslaw on 25 April than controls (20%) (OR 16.0, 95% CI 2.37-170.07, p value <0.001) (Table 2.2). Jam pudding was also statistically associated with being

ill. Cases (40%) were five times more likely to have become ill after eating the jam pudding on the 24 April than controls (12%) (OR 5.11, 95% CI 0.79-29.26; p 0.046) (Table 2.2). Although not significant, the total proportion of cases who ate mash potato on 21 April was very high. Cases (90%) who ate the mash potato on 24 April were six times more likely to become ill than controls (57%) (OR 6.15, 95% CI 0.70-286.41; p 0.131) (Table 2.2).

2.5.3 Environmental investigation

On 11 May 2018, OzFoodNet reported the outbreak to the Environmental Health Directorate who subsequently forwarded the information onto the appropriate local government. The initial routine inspection conducted by the local government on 7 May 2018 found that foods were being displayed without adequate protection or temperature control. The second investigation that was completed based on the identification of the outbreak by Department of Health, occurred on 25 May 2018. Local government environment health officers (EHOs) were initially denied entry by the college, however entered upon explanation by the senior EHO of the Power of Entry for officers. During this visit, kitchen staff and the kitchen manager were interviewed separately. The information that was provided to the EHOs differed between interviewees. One EHO was advised that raw eggs were not used in any products and the other EHO was advised by the staff member who made the mayonnaise that raw eggs were used in the mayonnaise for potato salad and coleslaw. Additionally, the Dean of the college reported that raw eggs were not being used in the manufacture of mayonnaise.

Table 2.2 Univariate analysis between the association of gastroenteritis and food exposures by day consumed, April 2018

Food consumed	Total exposed (n=80)			Cases exposed (n=13)			Controls exposed (n=67)			OR	95% CI	p value
	Exposed	Total*	%	Exposed	Total*	%	Exposed	Total*	%			
Monday 23 April												
Fried eggs	14	54	25.9%	4	9	44.4%	10	45	22.2%	2.80	0.45-16.65	0.216
Cereal	27	64	42.2%	5	11	45.5%	22	53	41.5%	1.17	0.25-5.28	1.000
Steak lunch	36	61	59.0%	5	11	45.5%	31	50	62.0%	0.51	0.11-2.35	0.333
Stuffed mushroom	11	58	19.0%	2	9	22.2%	9	49	18.4%	1.27	0.11-8.35	1.000
Hot chips	43	59	72.9%	9	11	81.8%	34	48	70.8%	1.85	0.32-19.58	0.710
Hainanese chicken	28	55	50.9%	4	10	40.0%	24	45	53.3%	0.58	0.11-2.88	0.503
Rice	40	57	70.2%	8	10	80.0%	32	47	68.1%	1.88	0.31-20.04	0.706
Tofu and vegetables	14	60	23.3%	1	9	11.1%	13	51	24.5%	0.37	0.01-3.24	0.671
Undressed green salad	46	57	80.7%	10	11	90.9%	36	46	78.2%	2.78	0.31-132.41	0.672
St Georges day cake	33	63	52.4%	7	11	63.6%	26	52	50.0%	1.75	0.39-9.09	0.515
Potato salad non mayo	17	59	28.8%	2	9	22.2%	15	50	30.0%	0.67	0.06-411	1.000
Cous cous salad	12	55	21.8%	3	10	30.0%	9	45	20.0%	1.71	0.24-9.52	0.673
Sprouts	18	55	32.7%	1	9	11.1%	17	46	37.0%	0.21	0.00-1.87	0.244
Rocket pear and parmesan salad	22	56	39.3%	2	9	22.2%	20	47	42.6%	0.39	0.36-2.36	0.458
Tuesday 24 April												
Poached eggs	14	52	26.9%	2	7	28.6%	12	45	26.7%	1.10	0.09-7.91	1.000
Bacon	14	60	23.3%	2	10	20.0%	12	50	24.0%	0.79	0.07-4.81	1.000
Cereal	25	64	39.1%	5	10	50.0%	20	54	37.0%	1.70	0.34-8.34	0.494
Tacos beef	42	60	70.0%	7	10	70.0%	35	50	70.0%	1.00	0.19-6.80	1.000
Sour cream	24	55	43.6%	5	9	55.6%	19	46	41.3%	1.78	0.33-10.10	0.482
Roasted vegetables	37	57	64.9%	7	10	70.0%	30	47	63.8%	1.32	0.26-8.92	1.000
Chickpea vegetarian dish	18	49	36.7%	2	7	28.6%	16	42	38.1%	0.65	0.56-4.61	1.000
Lamb hotpot	19	49	38.8%	5	9	55.6%	14	40	35.0%	2.32	0.42-12.50	0.282
Mashed potato	34	55	61.8%	8	9	88.9%	26	46	56.5%	6.15	0.70-286.41	0.131
Ginger split pea dhal	11	50	22.0%	1	9	11.1%	10	41	24.4%	0.39	0.001-3.61	0.662
Jam pudding	10	62	16.1%	4	10	40.0%	6	52	11.5%	5.11	0.79-29.26	**0.046**
Custard	12	61	19.7%	3	10	30.0%	9	51	17.7%	2.0	0.28-11.01	0.397
Undressed green salad	38	55	69.1%	7	9	77.8%	31	46	67.4%	1.69	0.27-18.48	0.705
Potato salad no mayonnaise	4	51	7.8%	1	7	14.3%	3	44	6.8%	2.28	0.04-33.86	0.457
Cous cous salad	7	52	13.5%	0	7	0.0%	7	45	15.6%	0.00	0.00-3.34	0.574
Sprouts	11	55	20.0%	1	7	14.3%	10	48	20.8%	0.63	0.01-6.30	1.000
Rocket pear and parmesan salad	11	54	20.4%	0	8	0.0%	11	46	23.9%	0.00	0.00-1.66	0.184

Wednesday 25 April												
Scrambled eggs	14	55	25.5%	2	12	16.8%	12	43	27.9%	0.52	0.05-3.03	0.709
Hot cakes	18	52	34.6%	4	10	40.0%	14	42	33.3%	1.33	0.24-6.70	0.723
Cereal	14	56	25.0%	3	12	25.0%	11	44	25.0%	1.00	015-5.05	1.000
Chicken schnitzel	38	56	67.9%	9	12	75.0%	29	44	65.9%	1.55	0.32-10.16	0.732
Hot chips	39	53	73.6%	9	10	90.0%	30	43	69.8%	3.90	0.44-183.85	0.258
Coleslaw	16	50	32.0%	8	10	80.0%	8	40	20.0%	16.0	2.37-170.07	**<0.001**
Vegetarian stuffed potatoes	8	49	16.3%	1	10	10.0%	7	39	17.8%	0.51	0.01-4.96	1.000
Moroccan Lamb Shanks	25	64	39.1%	4	12	33.3%	21	52	52.5%	0.45	0.09-2.06	0.329
Vegetarian chickpea curry	23	53	43.4%	4	12	33.3%	19	41	46.3%	0.58	0.11-2.62	0.519
Anzac biscuits	31	55	56.4%	6	12	50.0%	25	43	58.2%	0.72	0.17-3.20	0.745
Undressed green salad	37	50	74.0%	8	12	66.7%	29	38	76.3%	0.62	013-5.53	0.707
Potato salad no mayonnaise	6	46	13.0%	2	10	20.0%	4	36	11.1%	2.00	0.15-16.9	0.598
Cous cous salad	6	47	12.8%	1	10	10.0%	5	37	13.5%	0.71	0.01-7.72	1.000
Sprouts	9	48	18.8%	1	10	10.0%	8	38	21.1%	0.42	0.01-3.96	0.661
Rocket pear and parmesan salad	6	47	12.8%	0	10	0.0%	6	37	16.2%	0.00	0.00-2.20	0.317
Thursday 26 April												
Fried eggs	13	54	24.1%	4	11	36.4%	9	43	20.9%	2.16	0.37-10.85	0.429
Sautéed mushrooms	10	59	16.9%	1	11	9.1%	9	48	18.8%	0.43	0.01-3.89	0.670
Cereal	21	60	35.0%	5	11	45.5%	16	49	32.7%	1.72	0.35-7.89	0.493
Macaroni and cheese	31	54	57.4%	8	11	72.7%	23	43	53.5%	2.32	0.47-15.18	0.319
Teriyaki chicken	43	56	76.8%	8	11	72.7%	35	45	77.8%	0.76	0.14-5.31	0.705
Teriyaki tofu	15	56	26.8%	1	10	10.0%	14	46	30.4%	0.25	0.01-2.20	0.259
Vegetarian pasta	13	49	26.5%	4	9	44.4%	9	40	22.5%	2.76	0.44-15.80	0.220
Farro salad	9	41	22.0%	1	9	11.1%	8	32	25.0%	0.38	0.01-3.71	0.654
Undressed green salad	39	55	70.9%	9	11	81.8%	30	44	68.2%	2.10	0.36-22.23	0.478
Apple slice	16	56	28.6%	2	11	18.2%	14	45	31.1%	0.49	0.05-2.89	0.483
Potato salad non-mayonnaise	5	52	9.6%	1	9	11.1%	4	43	9.3%	1.22	0.02-12.68	1.000
Cous cous salad	5	53	9.4%	0	9	0.0%	5	44	11.4%	0.00	0.00-3.73	0.574
Sprouts	7	53	13.2%	1	9	11.1%	6	44	13.6%	0.79	0.02-8.16	1.000
Rocket pear and parmesan salad	4	58	6.9%	0	9	0.0%	4	49	10.0%	0.00	0.00-4.34	1.000

*Denominator varies due to missing responses in survey; bold indicates food exposures that are significantly associated with cases becoming ill.

As a consequence of the conflicting statements by staff concerning the use of raw eggs and the previous non-compliance with the Australia New Zealand Food Standards Code relating to the storage of food, officers conducted a follow up inspection on 21 June 2018. During this inspection, it was confirmed that mayonnaise and aioli were manufactured on site at least fortnightly, and that raw eggs were used. Further, management advised that such products were normally kept under refrigeration for two days before being discarded. Based on this information, EHOs explained the inherent risks of using raw eggs without a relevant 'kill step', and recommended that all products containing raw egg be disposed of within 24 hours of manufacture. This included any product that has been dressed with the raw egg mayonnaise or aioli. They were also provided with a WA Health Notice, 'Safe Handling of Eggs and Products Containing Eggs'.(14) The name of the egg brand used at the time of the outbreak was identified and confirmed based on the unique stamp identifier. No further traceback investigation was completed.

2.5.4 Laboratory investigation

Only two cases provided stool samples for testing and both were positive for *S.* Typhimurium MLVA type 03-17-09-12-523.

2.6 Discussion

We completed a case-control study to identify the source of an *S*.Typhimurium outbreak at a university residential college and to implement appropriate public health action. The analytical study showed that the jam pudding served on Tuesday (24 April 2018) and coleslaw served on Wednesday (25 April 2018) were associated with sources of illness. In light of the additional evidence from the environmental investigation that raw eggs were used in the mayonnaise and that one case had eaten only one meal consisting of chicken schnitzel, coleslaw and undressed green salad, it is likely that the coleslaw eaten on 25 April was the source of the illness. The college

was provided with a food safety notice explaining the risks and appropriate preparation of raw egg dishes.

Of the S. Typhimurium outbreaks investigated in Australia between 2001-2011 that identified an implicated food dish, 90% were egg-associated.(4) During 2017 in WA, 83% (35/42) of outbreaks were related to S.Typhimurium with 74% (23/31) of these outbreaks directly related to eggs as the source of the outbreak.(9) The most common MLVA type in these outbreaks was the same as this investigation, MLVA 03-17-09-12-523. This MLVA pattern was first notified in WA in September 2016. During 2017, 610 cases had this MLVA with 500 community cases and 110 cases associated with 16 point source outbreaks. Although only eight of the point source outbreaks were egg-related, one WA egg producer was common to half of the outbreaks that occurred in this time period.(9) Current proposed approaches to reduce the number of salmonellosis cases in WA include working with the primary egg producers and the food service industry to support them in managing food safety risks.(11)

The initial EHO investigation also noted that inadequate protection or temperature control was found for salads. Incorrect temperature control can result in the proliferation of salmonella in raw egg dishes, which is likely to have contributed to the outbreak.(15, 16) This may also explain the severity of the outbreak with seven cases seeking medical attention and two admitted to hospital. Food standards regarding using raw eggs for recipes such as mayonnaise state that they should be prepared just before consumption and that they be refrigerated immediately at 5°C or below so bacteria cannot grow.(17) In this outbreak the residential college was provided with information on the safe handling of eggs to prevent further outbreaks.

The jam pudding eaten on 24 April was also identified as being significantly associated with cases becoming ill. There was also one case who became ill on 24 April which is prior to when the coleslaw was served on 25 April. It is possible the jam pudding was undercooked, and may have been the cause of the outbreak. However, only 40% of cases ate the jam pudding compared to 80% of cases consuming the coleslaw. This also does not take into account that one case only ate at the university college on 25 April. It is more likely that the coleslaw was the source of the outbreak rather than the jam pudding, and that the case on 24 April was due to other reasons.

The public health response in WA to the *Salmonella* increase has been limited when compared to the recent public health action taken by the US in a multistate outbreak of *Salmonella* Braenderup in June 2018. A ten state outbreak resulted in 45 cases with 11 hospitalisations. Based on the trace-back of the egg manufacturer it was identified that the eggs were linked to one farm. As a result the egg manufacturer voluntarily recalled and destroyed over 206.7 million eggs.(18) This was serious voluntary action taken by the egg manufacturer based on 45 cases and 11 hospitalisations. This example highlights both the differences in action that can be taken by government and private industry, in addition to differences in public health action that can occur internationally.

There are several limitations to this study. As the outbreak was not identified by the Department of Health until 13 days after the initial notification and the survey was not disseminated until 25 days after cases were ill, recall bias would have occurred. Delayed reporting on a suspected outbreak can occur at a number of stages: delay from onset of disease to notification to state/territory governments; laboratory confirmation and notification to state/territory governments; reporting between notification to state/territory government to other government departments; and reporting of notification from state/territory government departments to national

governments.(19) In this outbreak, the delay was largely the result of the college having concerns that the survey itself and the survey wording would unnecessarily tarnish the reputation of the college. After some negotiation and word changes, the college agreed to send out the survey. In addition the college had suspected that an outbreak may have occurred as they distributed an in-house survey in response to the numbers of students who were sick. Education and public awareness on the importance of reporting outbreaks and reducing the stigma associated with outbreaks by the food industry to one of quality improvement and prevention is important in improving the timeliness of outbreak reporting. To support individual recall of the foods eaten, prompts such as the event occurring in the week of ANZAC Day was used to help people remember what foods were eaten on what day. There is likely to have been bias towards those individuals who were sick being more likely to recall the foods that they ate. There was a 14 day lag time between when OzFoodNet advised the local government via Environmental Health Directorate of the suspected outbreak and when EHOs went out to the college. The follow-up environmental investigation was also delayed as additional measures needed to be put into place due to being denied entry by the college on the previous visit. As a result, only specific queries about eggs were asked and no sampling of foods was undertaken. Only 35% of people responded to the survey and this only appeared to include half of the cases identified by the initial in-house survey completed by the college. Therefore, we were not able to stratify our analysis to account for confounding. However, other evidence provided made a compelling case for coleslaw being the source of the outbreak. Lastly, although the jam pudding was significant, the confidence interval of the odds ratio crossed one. This is the result of how confidence intervals were calculated by STATA when using Fisher's exact 2-sided p values.(20) Despite this overlap in confidence intervals the p value is still correct and remains significant at $p<0.05$.(20)

2.7 Conclusion

There has been a significant increase in the notifications of *S*.Typhumurium in WA. The Western Australian government has put in place a number of strategies to reduce the number of cases that are notified in foodborne outbreaks. It remains to be seen whether these will have an impact. The increase in salmonellosis outbreaks poses serious health and economic burden. As a result, engagement and collaboration between government departments, food sector and industry, and public awareness are needed if there is to be a reduction in the number of cases seen.

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CHAPTER 3: MODELLING FACTORS FOR ABORIGINAL AND TORRES STRAIT ISLANDER CHILD NEURODEVELOPMENTAL OUTCOMES: A LATENT CLASS ANALYSIS

3.1 Prologue

3.1.1 My role

For the public health data analysis project I:

- Conceived the data analysis project and developed the data analysis plan that guided the analysis of the data
- made the appropriate changes to the data analysis plan based on feedback from co-authors
- explored and learnt how to complete a latent class analysis
- liaised with specialists to discuss various aspects of the latent class analysis to ensure all conditions were being met for the analysis
- used the master file for the cohort data recode variables and explore data
- completed the data analysis and interpreted the data
- drafted the first copy of the manuscript
- liaised with co-authors for feedback and comments, which led to changes I made to the manuscript.

3.1.2 Lessons learned

The lesson I learnt in this chapter was how to complete a latent class analysis. On the outset I knew the type of analysis I wanted to complete. I wanted to investigate how to integrate different variables into one model to see if they influenced early child development. With guidance from my supervisor, Alice, who suggested a factor analysis and investigating the literature I found a latent class analysis to be the best type of model that meet my expectations for this study. As a result, I spent a substantial amount of time reading and learning about latent class analysis to make sure that I

correctly applied the model. I met with Daniel Christenson from Telethon Kids Institute, who has previously run this model, to discuss different aspects of the model such as local independence and assigning classes to each individual child. Overall, I really enjoyed the challenge of being able to apply a latent class analysis to the data, which has resulted in important implications for Aboriginal children in Western Australia.

3.1.3 Public health implications

This is the first study to identify important configurations of risk that were associated with early developmental vulnerabilities in Aboriginal children. Using data from children, their mothers, siblings and community this study identified six groups from our LCA; Healthy family, Young mother, High needs young mother, Premature infant, High needs family, and Large Family. We identified that many Aboriginal children in WA are entering school with at least one developmental vulnerability. Child protection issues, maternal mental health, young mothers and premature birth were important factors contributing to the latent classes. Providing support, services and empowering families is important for improving early child development of young Aboriginal children.

3.1.4 Acknowledgements

I would like to acknowledge the support of Drs Alice Richardson (primary supervisor ANU) and Carrington Sheppard (Telethon Kids Institute) in the statistical analysis of the paper. This is the first latent class analysis I have completed and appreciate the time and discussions they have provided. Co-author Dr Kimberley McAuley completed the data linkage for the analysis. Co-authors Professors Karen Edmond (placement supervisor UNICEF), Rhonda Marriott (Murdoch University), Associate Professor Dan McAullay (placement supervisor UWA) and Drs Alice Richardson, Carrington Shepherd and Kimberley McAuley supported me in the interpretation and reviewing drafts for feedback.

I would like to thank the Aboriginal elders and community members for their time and contributions in this project. The Noongar people are from the south-west of Western Australia and are the traditional owners of these lands. I would also like to thank Mr Daniel Christenson (Telethon Kids Institute) who provided me with some guidance for the latent class analysis.

3.1.5 MAE core requirements

This chapter fulfils the public health data analysis component and literature review (see below for method) of the MAE. The chapter has been presented at the Australian Epidemiology Association 2018 in Fremantle, Australia. The abstract titled, 'Factors influencing developmental vulnerability in Aboriginal and Torres Strait Islander children', was awarded the 2018 Australian Epidemiology Association Student Award. The abstract and presentation slides are provided in Appendix A.

3.1.6 Literature review search

To inform the introduction of this paper a search was completed on PubMed using search terminology: child* AND develop* AND "latent class analysis". Articles were included in the review if they were on children < 18 years old, the outcome of the analysis was child neurodevelopment and a latent class had been completed. Based on the search 118 articles were found of which 18 articles were full text reviewed for relevance to the topic. Four articles were relevant to this study. In addition, I checked the reference lists of the four articles and no additional studies were found to be relevant.

3.2 Abstract

3.2.1 Background

The Australian Early Developmental Census (AEDC) provides a measure of early child neurodevelopment. Understanding which combination of risks and protective factors influence Aboriginal child neurodevelopment is important to inform policy and practice.

3.2.2 Objectives

Our primary objective was to use latent class analysis (LCA) to model AEDC profiles and identify the highest risk profiles. Our secondary objective was to determine the impact of these high risk profiles on the likelihood of a child becoming developmentally vulnerable.

3.2.3 Methods

This was a prospective population-based birth cohort study (n=2715) using linked datasets with information on Aboriginal cohort children, and their mothers and siblings in Western Australia. Specific neurodevelopmental indicators in the 2009 and 2012 AEDC were used to assess developmental vulnerability. Latent class analysis methods were used to determine risk profiles and their association with developmental vulnerability.

3.2.4 Results

49.3% of Aboriginal children were vulnerable on at least one developmental domain and 37.5% were vulnerable on two or more domains. Latent class analysis found six unique profiles. High needs family, High needs young mother and Premature infant comprised 49% of the cohort and were considered to have high risk configurations. These groups were more than twice as likely to have children who had at least one or two developmental vulnerabilities compared to the Low Risk Family group.

3.2.5 Conclusion

Many Aboriginal children in Western Australia enter school with at least one developmental vulnerability. We have highlighted a range of unique profiles that can be used to empower Aboriginal families for change and develop targeted programs for improving the early development of young Aboriginal children.

3.3 Introduction

The first five years of childhood is widely established as a critical time for growth, neurodevelopment and learning.(1) Child neurodevelopment involves several interlinked domains of sensorimotor, cognitive-language, and social-emotional function, with neurodevelopmental delay defined as a child not reaching his/her age appropriate milestone for any of these domains. Early childhood neurodevelopment is influenced by sociocultural factors, poverty, psychosocial and biological risk factors, and central nervous system development and function.(2) Poor early child neurodevelopment can have long term impacts into adulthood including, but not limited to, schooling outcomes, which can later influence earning capacity.(3)

Despite an increased awareness that the first five years of a child's life are critical for influencing health and well-being in adulthood, a significant proportion of children with, or at risk of, neurodevelopmental delay are not identified and do not receiving the care they need.(4-7) Many vulnerable children are not identified as having a delay until they reach their first year of school, which seriously impacts on their educational outcomes as well as their social and emotional well-being.(4) This is particularly evident for children with a mild delay who have the capacity to thrive if they receive support from early intervention services. In Australia, Aboriginal and Torres Strait Islander (Aboriginal) children are a vulnerable group whose families have typically experienced historical and ongoing adverse events that have had cumulative impacts on their health and wellbeing.(8) As a result, Aboriginal children under 5 years of age can have poor health and social experiences which influence their developmental capacity upon entering school and later in life.(9)

Numerous studies have investigated the risk and protective factors associated with child neurodevelopmental outcomes,(10-12) although few have focused on Australian

Aboriginal children.(13-15) Evidence suggests that early child neurodevelopment is not shaped by a singularly important risk or protective factor or an accumulation of events, but rather multiple aspects of a child's life that are integrated.(16, 17) These findings have been supported by analytic methods that incorporate known risk variables (sex, socio-economic status and ethnicity) in group analyses to highlight individual pathways, rather than using a more individualistic approach.(18) Latent class analysis (LCA) is one such example and is a person-centred approach that identifies patterns in individuals that may be experiencing similar combinations of risk and/or protective factors.(19) Through completing a LCA, profiles can be ascertained that provide interpretable groups, which can subsequently be used to identify those at risk of a particular outcome, ultimately resulting in tailored interventions.

To date, LCA has been used to describe the combination of risk factors and their association to early child neurodevelopment in only a handful of studies.(20-23) Of these, one was completed in Australia using the Longitudinal Study of Australian Children and investigated risk factors associated with language in children aged 4-8 years old.(21) Two studies included children in the United States (US) with one investigating the influence of the class profiles on cognitive function (20) and the other on executive function and language.(23) Lastly, LCA was used to determine risk profiles of United Kingdom children aged 7-8 years old and the association between these profiles and cognitive outcomes.(22) Only two US studies looked at differences within ethnic groups, namely Hispanic, African-American and White children.(20, 23) This is an important distinction as many minority and Indigenous groups have different histories and circumstances that resulted in poor health and social outcomes. Therefore, LCA is likely to be very helpful in understanding which combination of risks or protective factors are likely to have the greatest impact on child development in these groups. For Aboriginal families in Australia this could lead to a better recognition of the combination of factors that influence early Aboriginal child neurodevelopment.

Within Western Australia there is a large de-identified prospective longitudinal population-based data system of total population administrative health data sets.(24) Data are available for Aboriginal birth cohorts, their mothers and siblings and include variables on maternal and child health outcomes, hospital utilisation, socio-economic status, child protection, disability and early child neurodevelopment. These family linked datasets provide a unique opportunity to investigate the relationship between factors that may influence early child development.

Focusing on early child neurodevelopment of Aboriginal children aged 5 years in Western Australia, our study was designed to determine patterns of risk factors that best identifies groups of health, social and community factors. Our primary objective was to use LCA to model Australian Early Development Census (AEDC) profiles and identify the highest risk profiles. Our secondary objective was to determine the impact of these high risk profiles on the likelihood of a child becoming developmentally vulnerable.

3.4 Methods

3.4.1 Study setting and databases

This population-based cohort study included all Aboriginal children born in Western Australia between 2003-2004 and 2006-2007 who participated in the 2009 or 2012 AEDC at age 5 years. This study used population-based data that were systematically linked by the Western Australian Department of Health data linkage staff using probabilistic matching, then de-identified. Databases included the Midwifes Notification System, Birth Register, AEDC, Hospital Morbidity Data Collection, Emergency Department Data Collection, Mental Health Information System, Death Registrations, Department for Child Protection and Family Support, and the Western Australia Registry of Developmental Anomalies (WARDA). Only a unique identifier on the

individual's clinical information was provided to the researchers, and any identifying information was removed.

The Midwives' Notification System includes clinical (infant weight, gestational age, Apgar score, multiple birth, gravidity) and socio-demographic (baby's gender, mother's age, Indigenous status, socio-economic status, geographical remoteness) data on all Western Australian live births and stillbirths of more than 20 weeks' gestation or birth weight greater than 400g which are reported by trained midwives within 48 hours of delivery. The AEDC provides population-based data on all Australian children who are entering their first year of school and is a measure of a child's neurodevelopment.(25) The Hospital Morbidity Data System and Emergency Department Data Collection include data on all completed hospital admissions (public and private) and emergency department presentations (mostly public) to all public hospitals in WA. Death Registrations are linked monthly and include date and cause of death. The Mental Health Information System provides data on mental health related inpatient (public and private) and outpatient (public only) contacts. The Department for Child Protection and Family Support database provides data on notifications, substantiations, and out-of-home care. Lastly, the WARDA is a statutory notification database on developmental anomalies and provides data on all birth defects.

The Index of Relative Socio-Economic Disadvantage (IRSD), provided by the Australian Bureau of Statistics, uses data on individuals (within small areas) from the Australian national Census to rank the relative level of disadvantage of areas. The measure used in this study is based on 2006 Census and has been categorised into quintiles—from most deprived (1) to least deprived (5).(26) The Accessibility/Remoteness Index of Australia (ARIA) was developed by the Department of Health and Aged Care and is maintained by the Australian Institute of Health and

Welfare.(27) This index classifies geographic location on the basis of isolation and distance from service centres and health care facilities. ARIA data are split into five categories that denote relative geographical remoteness—with categories ranging from least remote (1) (major cities) to most remote (5) (remote area communities).

3.4.2 Inclusion and exclusion criteria

Children were classified as Aboriginal using the *Getting our story right* indictor.(28) This indicator uses a number of datasets to produce a single indicator of Aboriginal status for each individual. It is considered an optimal approach to identifying Aboriginal persons in administrative datasets. Mother-sibling-child links were identified by the Western Australian Data Linkage Branch, using the Midwives' Notification System and Birth Register. This enabled linkage between maternal health characteristics and our study cohort. Children in the cohort were included if they were born in Western Australia and completed the AEDC at age 5.

Children were excluded from the cohort if they had missing AEDC domain scores (n=323), an intellectual disability, autism or cerebral palsy (n=62), or were identified as having special needs by teachers within the AEDC (n=150). In cases of multiple birth or where a sibling was recorded in the 2012 AEDC, one child from each twin, triplet or sibling set was randomly selected (excluded n=324). Siblings were excluded from the analysis if they had no date of birth recorded (n=221) or were >18 years of age when AEDC cohort child was born (n=218).

3.4.3 Definitions

The AEDC is a developmental census that is conducted every three years in Australia, with data collected by teachers with an instrument designed to measure five developmental domains (physical, social competence, emotional maturity, language and cognition and communication) at age 5 years. Developmental vulnerability is defined as the bottom 10% of the national AEDC population distribution. In this study

we examined the proportion of children who were developmentally vulnerable in at least one domain or two or more domains in the 2009 or 2012 AEDC.(25) (29) Contact with child protection services was considered to have occurred if a child had at least one contact in the form of a notification or substantiation, or if the child, had been removed at least once from their family prior to 5 years of age. A mental health contact occurred when a mother had any contact with mental health services (an outpatient service or hospital admission) in the period from one year prior to their cohort child's birth and up to 5 years of age.(30) Child hospital admissions included admissions to a WA hospital ward for care between discharge from the birth admission to 5 years of age; for mothers, it included the year prior to her child's birth to when their child was 5 years old. Between hospital transfers were included as one admission. The frequency of emergency department presentations was defined as the count of presentations to any emergency department regardless of whether the mother or child was admitted to hospital. Due to small numbers, inner and outer regional areas were grouped together (ARIA 2-3) as were the highest two IRSD quintiles (IRSD 4-5).

3.4.4 Imputation of missing data

Missing data for IRSD (n=356) and ARIA (n=367) from the 2006 Census was substituted with data from the Census year closest to the birth of the child, where available. If these data were still missing, we then went to the next Census year and so on until we had considered all four Census years. This method has previously been used by Fairthorne et al.(31)

3.4.5 Statistical analysis

Descriptive statistics were calculated as counts and percentages for all categorical variables. Crude and adjusted logistic regression models were used to examine the effect of child, maternal, community measures and hospital utilisation factors on having at least one or two developmental vulnerabilities. Odds ratios (ORs) and 95% confidence intervals (95% CI) were calculated. Multivariable logistic regression models were constructed *a priori* to adjust for the effect of important explanatory variables:

child factors (gender of child, birth weight), maternal characteristics (maternal age, gravidity) and socioeconomic status (IRSD).

The LCA was guided by the previous work from Lanza et al.(17, 19) Sixteen variables were included in the analysis with all child, maternal, community measures and hospital utilisation factors dichotomised (Table 3.1). Child protection, number of siblings, maternal age, gravidity, geographic location, socio-economic status, child and mother number of hospitalisations variables were dichotomised based on the point at which a significant relation (p value <0.05) was achieved in the adjusted logistic regression analysis of the probability that children have at least one development vulnerability. Dichotomising child and mother emergency presentations were based on a conservative approach of a child and mother having at least one emergency presentation. We investigated leaving the variables with multiple categories as outlined in Table 3.2, however, this did not provide any additional information to any class.

Table 3.1 Coding for LCA

Number	Variable	No risk (coded 0)	Risk (coded 1)
1	Child sex	Female	Male
2	Prematurity	Not premature	<37 weeks gestational age
3	Birth weight	≥2500g weight	<2500g weight
4	APGAR 5 score	Healthy ≥7	Unhealthy <7
5	Contact with Child Protection	Not removed	Had contact or was removed
6	Siblings	0-2 Siblings	≥3 siblings
7	Disabled siblings	No disabled siblings	Disabled siblings
8	Maternal Age	≥20 years old	<20 years old
9	Gravidity	<3 pregnancies	≥3 pregnancies
10	Mental health contact	No mental health contact	At least one mental health contact
11	Geographic location (ARIA)	Major cities to remote	Very remote
12	Socio-economic status	2-5 ISRD	1 ISRD
13	Child hospitalisation	<2 hospitalisations	≥2 hospitalisations
14	Child emergency presentation	<2 emergency presentations	≥2 emergency presentations
15	Mother hospitalisation	<4 hospitalisations	≥4 hospitalisations
16	Mother emergency utilisation	<2 emergency presentations	≥2 emergency presentations

Variables were dichotomised to ensure best fit and interpretability of the model. To determine the best fit and parsimony of the LCA model we used information from the Akaike information criterion (AIC) and the Bayesian information criterion (BIC). For each of these two criteria the lowest values are considered to indicate the best fitting

model. In establishing the classes, we also considered whether: each class of the models was qualitatively and quantitatively distinguishable from one another; and that groups could be named based on discernible characteristics within the model. Classes were given descriptive names based on the highest probability of the variable response for that class. Interpretation of the model involved recognising that each child's status within each class is not known, and that is it the probability of membership for that variable in each class that is provided. The probability of class membership sums to 1 across the classes, and reflects the relative proportion of individuals within each class.

Using estimated maximum posterior probability, we assigned a probability of each child being in each class and accepted the highest probability of them being in a particular class.(19) We then used this to determine how each class profile related to a child's developmental vulnerability. Unadjusted logistic regression analysis was completed to determine whether developmental vulnerability was associated with the predicted class membership. We did not adjust for covariates as all variables are used to determine each class for the LCA. Data analysis was completed using STATA 15.1.

3.4.6 Community participation

As part of knowledge sharing and ensuring the data are relevant to communities that they represent, our findings were presented to three Noongar elders and three Aboriginal community members. Our two Aboriginal authors (RM and DM) also had substantial input into the interpretation of the data. This group decided on the descriptive names for the six classes identified from the LCA and discussed whether the groups were representative of the community. It is important to note that within Western Australia there is diversity amongst Aboriginal peoples and that data should be interpreted with caution for any one community or group.

3.4.7 Ethics

This study has ethical approval from the Western Australian Department of Health Human Research Ethics Committee (2014/21), the Western Australian Aboriginal Health Ethics Committee (WAAHEC) (416), the Australian National University Ethics Committee (2018/013), the Murdoch University Human Research Ethics Committee (2014/025), and the University of Western Australia Human Research Ethics Committee (RA/4/20/4920).

3.5 Results

In Western Australia in 2009 and 2012, 2715 Aboriginal children aged 5 years completed the AEDC. In total, 49.3% (1338/2715) had at least one developmental vulnerability, while 37.5% (825/2202) had at least two developmental vulnerabilities (Table 3.2 and Appendix 3.1). Of those children with at least one developmental vulnerability, 16.1% (215) were born prematurely (<37 weeks) compared with 11.6% (160) who had no developmental vulnerabilities. Close to half (46.2%; 618) of Aboriginal children with at least one developmental vulnerability had a mother with a mental health contact compared with 34.7% (478) of children who had no developmental vulnerabilities (Table 3.2).

Children who had at least one contact with child protection services (58.3%) were 1.6 times more likely to be developmentally vulnerable on one or more domains compared to those with no contacts (46.8%) (aOR 1.60, 95% CI 1.28-1.99) (Table 3.3). Children whose mother had experienced a mental health contact (between 1 year prior to, and up to 5 years post birth) (56.4%) were more likely to have at least one developmental vulnerability compared to children who whose mother had experienced no mental health contacts (44.5%) (aOR 1.51, 95% CI 1.28-1.78) (Table 3.3). Those children who were in the most disadvantaged socio-economic group (53.1%) were 1.6 times more likely to have a developmental vulnerability compared to those in the least

disadvantaged group (40.2%) (aOR 1.61, 95% CI 1.19-2.16). For children who had at least one developmental vulnerability and at least one hospital admission, there was increasing risk associated with an increasing number of admissions (Table 3.3). Children with two or more developmental vulnerabilities had a similar risk profile as children who had at least one developmental vulnerability (Appendix 3.1 and Appendix 3.2).

Table 3.2 Socio demographic characteristics of Aboriginal children with at least one developmental vulnerability, 2009 and 2012 AEDC

Characteristics	All children n = 2715	Developmentally vulnerable on 1+ domains n = 1338 (49.3%)	No development vulnerabilities n = 1377 (50.7%)	OR 95% CI	P value
Child					
AEDC year					
2009	1277 (47.0%)	653 (48.8%)	624 (45.3%)	1.15 (0.99-1.34)	0.069
2012	1438 (53.0%)	685 (51.2%)	753 (54.7%)	0.87 (0.75-1.01)	0.069
Child sex					
Male	1348 (49.7%)	785 (58.7%)	563 (40.9%)	2.1 (1.76-2.39)	<0.001
Female	1367 (50.4%)	553 (41.3%)	814 (59.1%)	0.49 (0.42-0.57)	<0.001
Prematurity					
<37wk	375 (13.8%)	215 (16.1%)	160 (11.6%)	1.46 (1.17-1.82)	0.001
≥ 37wk	2337 (86.1%)	1121 (83.8%)	1216 (88.3%)	0.69 (0.55-0.85)	0.001
Data missing	NP	NP	NP		
Birth weight					
Low birth weight (<2500g)	323 (11.9%)	184 (13.8%)	139 (10.1%)	1.42 (1.12-1.80)	0.003
Normal birth weight (≥2500g)	2392 (88.1%)	1154 (86.3%)	1238 (89.9%)	0.70 (0.056-0.89)	0.003
APGAR 5 score					
< 7 (abnormal)	51 (1.9%)	25 (1.9%)	26 (1.9%)	0.99 (0.57-1.71)	0.966
≥7 (healthy)	2654 (97.8%)	≥90%	1345 (97.7%)	1.01 (0.58-1.76)	0.966
Data missing	NP	NP	NP		
Contact with Child Protection					
Not removed	2055 (75.7%)	961 (71.8%)	1094 (79.5%)	0.66 (0.55-0.79)	<0.001
At least one contact (excl. removals)	470 (17.3%)	274 (20.5%)	196 (14.2%)	1.55 (1.27-1.90)	<0.001
Removed	190 (7.0%)	103 (7.7%)	87 (6.3%)	1.24 (0.92-1.66)	0.159
Siblings					
0	304 (11.2%)	132 (9.9%)	172 (12.5%)	0.77 (0.60-0.98)	0.030
1	619 (22.8%)	271 (20.3%)	348 (25.3%)	0.75 (0.63-0.90)	0.002
2	600 (22.1%)	298 (22.3%)	302 (21.9%)	1.02 (0.85-0.1.22)	0.831
≥3	1192 (43.9%)	637 (47.6%)	555 (40.3%)	1.35 (1.16-1.57)	<0.001
Disabled siblings					
Disabilities	261 (9.6%)	140 (10.5%)	121 (8.8%)	1.24 (0.94-1.57)	0.139
No disabilities	2454 (90.4%)	1198 (89.5%)	1256 (91.2%)	0.82 (0.64-1.06)	0.139
Mother					
Maternal Age					
<20 yrs	624 (23.0%)	334 (25.0%)	290 (21.1%)	1.25 (1.04-1.49)	0.016
20-24 yrs	906 (33.4%)	434 (32.4%)	472 (34.3%)	0.92 (0.78-1.08)	0.309
25-29 yrs	609 (22.4%)	293 (21.9%)	316 (23.0%)	0.94 (0.79-1.13)	0.512
30-34 yrs	389 (14.3%)	181 (13.5%)	208 (15.1%)	0.88 (0.71-1.09)	0.241

35+ yrs	187 (6.9%)	96 (7.2%)	91 (6.6%)	1.09 (0.81-1.47)	0.560
Gravidity					
0	683 (25.2%)	326 (24.4%)	357 (25.9%)	0.92 (0.77-1.09)	0.349
1	581 (21.4%)	265 (19.8%)	316 (23.0%)	0.83 (0.69-1.00)	0.046
2	451 (16.6%)	222 (16.6%)	229 (16.6%)	1.00 (0.82-1.22)	0.986
≥3	997 (36.7%)	523 (39.1%)	474 (34.4%)	1.22 (1.05-1.43)	0.011
Data missing	NP	NP	NP		
Mental health contact					
At least 1 contact	1096 (40.4%)	618 (46.2%)	478 (34.7%)	1.61 (1.38-1.88)	<0.001
No contact	1619 (59.6%)	720 (53.8%)	899 (65.3%)	0.62 (0.53-0.72)	<0.001
Community					
Geographic location (ARIA)					
Major city	973 (35.8%	455 (34.0%)	518 (37.6%)	0.85 (0.73-1.00)	0.050
Regional	626 (23.1%)	298 (22.3%)	328 (23.8%)	0.92 (0.77-1.10)	0.338
Remote	399 (14.7%)	190 (14.2%)	209 (15.8%)	0.94 (0.76-1.16)	0.569
Very remote	571 (21.0%)	314 (23.5%)	257 (18.7%)	1.37 (1.13-1.65)	0.001
Data missing	146 (5.4%)	81 (6.1%)	65 (4.7%)		
Socio-economic status					
Most disadvantaged 1	1530 (56.4%)	813 (60.8%)	717 (52.1%)	1.43 (1.22-1.66)	<0.001
2	544 (20.0%)	240 (17.9%)	304 (22.1%)	0.77 (0.64-0.93)	0.007
3	276 (10.2%)	116 (8.7%)	160 (11.6%)	0.72 (0.56-0.93)	0.011
Least disadvantaged 4-5	219 (8.1%)	88 (6.6%)	131 (9.5%)	0.68 (0.51-0.90)	0.007
Data missing	146 (5.4%)	81 (6.1%)	65 (4.7%)		
Hospital utilisation					
Child hospitalisation					
0	665 (24.5%)	263 (20.0%)	402 (29.2%)	0.59 (0.50-0.71)	<0.001
1	770 (28.4%)	345 (25.8%)	425 (30.9%)	0.78 (0.66-0.92)	0.003
2	503 (18.5%)	261 (19.5%)	242 (17.6%)	1.14 (0.94-.38)	0.195
3	292 (10.1%)	167 (12.5%)	125 (9.1%)	1.43 (1.12-1.83)	0.004
4	169 (6.2%)	104 (7.8%)	65 (4.7%)	1.70 (1.24-2.34)	0.001
≥5	316 (11.4%)	198 (14.8%)	118 (8.6%)	1.85 (1.46-2.36)	<0.001
Child emergency presentation					
0	82 (3.0%)	37 (2.8%)	45 (3.3%)	0.84 (0.54-1.31)	0.445
1	193 (7.1%)	95 (7.1%)	98 (7.1%)	1.00 (0.74-1.34)	0.986
2	177 (6.5%)	72 (5.4%)	105 (7.6%)	0.69 (0.51-0.94)	0.018
3	196 (7.2%)	77 (5.8%)	119 (8.6%)	0.65 (0.48-0.87)	0.004
4	189 (7.0%)	91 (6.8%)	98 (7.1%)	0.95 (0.71-1.28)	0.747
≥5	1878 (69.2%)	966 (72.2%)	912 (66.2%)	1.32 (1.12-1.56)	0.001
Mother hospitalisation					
0	NP	NP	NP	NP	NP
1	275 (10.1%)	115 (8.6%)	160 (11.6%)	0.72 (0.56-0.92)	0.009
2	447 (16.5%)	184 (13.8%)	263 (19.1%)	0.68 (0.55-0.83)	<0.001
3	502 (18.5%)	216 (16.1%)	286 (20.8%)	0.74 (0.60-0.89)	0.002
4	395 (14.6%)	207 (15.5%)	188 (13.7%)	1.16 (0.93-1.43)	0.179
≥5	1095 (40.3%)	616 (46.0%)	479 (34.8%)	1.60 (1.37-1.87)	<0.001
Mother emergency utilisation					
0	176 (6.5%)	78 (5.8%)	98 (7.1%)	0.81 (0.59-1.10)	0.174
1	228 (8.4%)	90 (6.7%)	138 (10.0%)	0.65 (0.49-0.85)	0.002
2	212 (7.8%)	86 (6.4%)	126 (9.2%)	0.68 (0.52-0.91)	0.009
3	193 (7.1%)	89 (6.7%)	104 (7.6%)	0.87 (0.65-1.17)	0.361
4	196 (7.2%)	93 (7.0%)	103 (7.5%)	0.92 (0.69-1.24)	0.594
≥5	1710 (63.0%)	902 (67.4%)	808 (56.7%)	1.46 (1.25-1.70)	<0.001

≥90%, not publishable due to high numbers and confidentiality restrictions; NP, not publishable due to small numbers and confidentiality restrictions

Table 3.3 Associations between socio-demographic characteristics and Aboriginal children with at least one developmental vulnerability, 2009 and 2012 AEDC

Characteristics	Total number of infants n=2715	Number with at least 1 developmentally vulnerable n = 1338	OR (95% CI)	p value	aOR (95% CI)*	p value
Child						
AEDC year						
2009	1277 (47.0%)	653 (51.1%)	1.00		1.00	
2012	1438 (53.0%)	685 (47.6%)	0.87 (0.75-1.01)	0.069	0.90 (0.77-1.06)	0.204
Child sex						
Male	1348 (49.7%)	785 (58.2%)	2.05 (1.76-2.39)	<0.001	2.21 (1.86-2.57)	<0.001
Female	1367 (50.4%)	553 (40.5%)	1.00		1.00	
Prematurity						
<37wk	375 (13.8%)	215 (57.3%)	1.46 (1.17-1.82)	0.001	1.53 (1.21-1.93)	<0.001
≥ 37wk	2337 (86.1%)	1121 (48.0%)	1.00		1.00	
Birth weight						
Low birth weight (<2500g)	323 (11.9%)	184 (57.0%)	1.422 (1.12-1.80)	0.003	1.28 (0.93-1.74)	0.126
Normal birth weight (≥2500g)	2392 (88.1%)	1154 (48.2%)	1.00		1.00	
APGAR 5 score						
< 7 (abnormal)	51 (1.9%)	25 (49.0%)	0.99 (0.57-1.72)	0.966	0.98 (0.55-1.74)	0.942
≥7 (healthy)	2654 (97.8%)	1309 (49.3%)	1.00		1.00	
Contact with Child Protection						
Not removed	2055 (75.7%)	961 (46.8%)	1.00		1.00	
At least one contact (excl. removals)	470 (17.3%)	274 (58.3%)	1.59 (1.3-1.95)	<0.001	1.60 (1.28-1.99)	<0.001
Removed	190 (7.0%)	103 (54.2%)	1.35 (1.00-1.82)	0.050	1.19 (0.86-1.64	0.290
Siblings						
0	304 (11.2%)	132 (43.4%)	0.99 (0.75-1.30)	0.918	0.97 (0.72-1.31)	0.835
1	619 (22.8%)	271 (43.8%)	1.00		1.00	
2	600 (22.1%)	298 (49.7%)	1.27 (1.01-1.59)	0.040	1.27 (0.99-1.63)	0.062
≥3	1192 (43.9%)	637 (53.4%)	1.47 (1.21-1.79)	<0.001	1.52 (1.18-1.98)	0.001
Disabled siblings						
Disabilities	261 (9.6%)	140 (53.6%)	1..21 (0.94-1.57)	0.139	1.06 (0.81-1.39)	0.677
No disabilities	2454 (90.4%)	1198 (48.8%)	1.00		1.00	

Mother						
Maternal Age						
<20 yrs	624 (23.0%)	334 (53.5%)	1.24 (0.99-1.55)	0.057	1.78 (1.33-2.38)	<0.001
20-24 yrs	906 (33.4%)	434 (47.9%)	0.99 (0.81-1.22)	0.936	1.17 (0.93-1.48)	0.182
25-29 yrs	609 (22.4%)	293 (48.1%)	1.00		1.00	
30-34 yrs	389 (14.3%)	181 (46.5%)	0.94 (0.73-1.21)	0625	0.86 (0.66-1.13)	0.285
35+ yrs	187 (6.9%)	96 (51.3)	1.14 (0.82-1.58)	0.440	1.08 (0.76-1.54)	0.657
Gravidity						
0	683 (25.2%)	326 (47.7%)	0.94 (0.74-1.20)	0.622	0.71 (0.54-0.94)	0.016
1	581 (21.4%)	265 (45.6%)	0.87 (0.68-1.11)	0.249	0.76 (0.58-1.00)	0.047
2	451 (16.6%)	222 (49.2%)	1.00		1.00	
≥3	997 (36.7%)	523 (52.5%)	1.14 (0.91-1.42)	0.254	1.27 (0.99-1.63)	0.060
Mental health contact						
At least 1 contact	1096 (40.4%)	618 (56.4%)	1.61 (1.38-1.88)	<0.001	1.51 (1.28-1.78)	<0.001
No contact	1619 (59.6%)	720 (44.5%)	1.00		1.00	
Community						
Geographic location (ARIA)						
Major city	973 (35.8%)	455 (46.8%)	1.00		1.00	
Regional	626 (23.1%)	298 (47.6%)	1.03 (0.85-1.26)	0.742	0.93 (0.75-1.15)	0.487
Remote	399 (14.7%)	190 (47.6%)	1.03 (0.82-1.31)	0773	1.05 (0.93-1.34)	0.677
Very remote	571 (21.0%)	314 (55.0%)	1.39 (1.13-1.71)	0.002	1.32 (1.06-1.64)	0.012
Socio-economic status						
Most disadvantaged 1	1530 (56.4%)	813 (53.1%)	1.9 (1.27-2.25)	<0.001	1.61 (1.19-2.16)	0.002
2	544 (20.0%)	240 (44.1%)	1.18 (0.85-1.62)	0.321	1.12 (0.81-1.56)	0.487
3	276 (10.2%)	116 (42.0%)	1.08 (075-1.55)	0.679	1.08 (0.74-1.56)	0.694
Least disadvantaged 4-5	219 (8.1%)	88 (40.2%)	1.00		1.00	
Hospital utilisation						
Child hospitalisation						
0	665 (24.5%)	263 (39.5%)	1.00		1.00	
1	770 (28.4%)	345 (44.8%)	1.24 (1.01-1.53)	0.045	1.20 (0.96-1.50)	0.108
2	503 (18.5%)	261 (51.9%)	1.65 (1.30-2.08)	<0.001	1.52 (1.18-1.95)	0.001
3	292 (10.1%)	167 (57.2%)	2.04 (1.54-2.70)	<0.001	1.92 (1.43-2.59)	<0.001
4	169 (6.2%)	104 (61.5%)	2.45 (1.73-2.46)	<0.001	2.11 (1.46-3.07)	<0.001
≥5	316 (11.4%)	198 (62.7%)	2.56 (1.95-3.38)	<0.001	2.24 (1.65-3.03)	<0.001

Child emergency presentation						
0	82 (3.0%)	37 (45.1%)	1.00		1.00	
1	193 (7.1%)	95 (49.2%)	1.18 (0.70-1.98)	0.534	1.14 (0.65-1.98)	0.645
2	177 (6.5%)	72 (40.7%)	0.83 (0.49-1.41)	0.501	0.79 (0.45-1.40)	0.423
3	196 (7.2%)	77 (39.3%)	0.79 (0.47-1.32)	0.367	0.76 (0.44-1.33)	0.339
4	189 (7.0%)	91 (48.1%)	1.13 (0.67-1.90)	0.647	1.20 (0.69-2.10)	0.515
≥5	1878 (69.2%)	966 (51.4%)	1.29 (0.83-2.01)	0.264	1.19 (0.73-1.92)	0.482
Mother hospitalisation						
1	275 (10.1%)	115 (41.8%)	1.00		1.00	
2	447 (16.5%)	184 (41.2%)	0.97 (0.72-1.32)	0.862	0.89 (0.64-1.23)	0.468
3	502 (18.5%)	216 (43.0%)	1.05 (078-1.42)	0.744	1.00 (0.73-1.37)	0.998
4	395 (14.6%)	207 (52.4%)	1.53 (1.12-2.09)	0.007	1.40 (1.01-1.95)	0.046
≥5	1095 (40.3%)	616 (56.3%)	1.79 (1.37-2.34)	<0.001	1.66 (1.25-2.22)	<0.001
Mother emergency utilisation						
0	176 (6.5%)	78 (44.3%)	1.00		1.00	
1	228 (8.4%)	90 (39.5%)	0.82 (0.55-1.22)	0.328	0.89 (0.58-1.35)	0.580
2	212 (7.8%)	86 (40.6%)	0.86 (0.57-1.29)	0.456	0.84 (0.55-1.30)	0436
3	193 (7.1%)	89 (46.1%)	1.08 (0.72-1.62)	0.729	1.12 (0.72-1.73)	0.615
4	196 (7.2%)	93 (47.4%)	1.13 (0.75-1.71)	0.545	1.22 (0.79-1.89)	0.374
≥5	1710 (63.0%)	902 (52.7%)	1.40 (1.02-1.02)	0.133	1.36 (0.97-1.90)	0.072

*adjusted for sex, mother's age, SES, gravidity, prematurity

We fitted models that had one to six latent classes. Although the six latent class model had the smallest AIC and BIC, there was little difference in the five and six class model for BIC (Table 3.4). After assessing both models for 1) distinguishable variables between classes, and 2) that groups could be named based on discernible characteristics; it was determined the six class model was the most appropriate.

Table 3.4 Measures of model fit for latent class analysis

Number classes	Measures of fit			
	LR G sq.	DF	AIC	BIC
1	7600.810	16	44819.017	44913.521
2	6154.232	33	43406.438	43601.354
3	4898.424	49	42182.630	42472.051
4	4505.957	65	41822.163	42206.089
5	4022.034	83	41374.240	41864.483
6	3901.970	98	41284.176	41863.018

The probability of belonging to a class ranged from 9% to 21% (Table 3.5). The first identified class was the ‘Healthy family’ with a 19% probability of being included in this class. These families had children who had healthy birth outcomes and mothers who had the lowest probability of having any risk factors. ‘High needs family’ contained 21% of the sample. This group had the overall highest number of child, mother and community risks making it a complicated and high risk group. Children had a high probability of having contact with child protection services (47.2%), living in remote areas (69.7%), having more than three siblings (88.1%), having a mother who had contact with mental health services (69.9%) and more than three maternal hospital admissions (84.5%).

‘Premature infant’ were the smallest class and comprised 9% of the sample. This group had a high probability of being premature (97.4%) and, having a low birth weight (91.1%). Contact with child protection services (33.8%), children having two or more hospital admissions (84.9%). Maternal mental health contacts (51.2%) were also prominent features of this class.

Table 3.5 Conditional probabilities and distributions of risk for a six class latent analysis

Variables	Healthy Family	High needs family	Premature Infant	High needs young Mother	Young mother	Large Family
C: Male	0.532	0.505	0.418	0.451	0.556	0.456
C: <37 weeks gestational age	0.042	0.113	**0.974**	0.054	0.046	0.027
C: <2500g weight	0.000	0.059	**0.911**	0.115	0.047	0.023
C: Unhealthy AGPAR score <7	0.010	0.008	0.063	0.038	0.005	0.023
C: Had contact with CP or was removed from family	0.061	**0.472**	**0.338**	**0.453**	0.152	0.103
C: ≥3 siblings	0.000	**0.881**	0.408	0.115	0.243	**0.764**
C: Had disabled siblings	0.020	0.183	0.129	0.031	0.067	0.126
M: <20 years old	0.267	0.011	0.223	**0.578**	**0.475**	0.007
M: ≥3 pregnancies	0.006	0.819	0.340	0.000	0.016	0.779
M: At least one mental health contact	0.129	**0.699**	**0.519**	**1.000**	0.166	0.201
C: Lived in very remote area	0.464	**0.697**	0.584	**0.709**	**0.615**	0.541
C: Most socio-disadvantaged quintile	0.188	0.257	0.241	**0.395**	0.173	0.165
C: ≥2 hospitalisations	0.294	0.617	**0.849**	0.612	0.445	0.270
C: ≥2 emergency presentations	0.831	0.963	0.931	0.915	0.976	0.799
M: ≥4 hospitalisations	0.126	**0.845**	0.700	0.785	0.717	0.283
M: ≥2 emergency presentations	0.619	0.990	0.896	0.974	1.000	0.697
	Class membership					
Probabilities	0.19	0.21	0.09	0.11	0.19	0.20
Standard error	0.02	0.02	0.01	0.02	0.02	0.02

C:=child related variable; CP=child protection; M:=mother related variable

The ‘High needs young mother’ class were 11% of the sample and had 100% probability of having a maternal mental health contact. In addition, the majority of the children in this class were born to young mothers (57.8%) and lived in a remote area (70.9%), with relatively high levels of socioeconomic disadvantage (39.5% in the highest quintile). Almost half the children had contact with child protection services (45.3%). In comparison, the ‘Young mother’ class (19% of the sample) were characterised by a relatively small proportion of maternal mental health contacts (16.6%), 47.5% young mothers and 61.5% living in a remote area. The last class were named ‘Larger family’ and contributed to 20% of the sample. Overall these families are typified as having three or more siblings (76.4%), however, they had few other outstanding features.

After assigning each child to their predicted class membership, the proportion of children with at least one development vulnerability ranged from 34.3% (196) in the Healthy family group to 57.9% (199) among the High needs young mothers group (Table 3.6). Logistic regression model results highlighted that, when compared with the Healthy family class, children in all other classes were at an elevated odds of having at least one developmental vulnerability (Table 3.6). Odds ratios were between 2.0 and 2.6 for High needs family, Premature infant, High needs young mother and Young mother classes, and of a smaller magnitude for the Large Family class (OR=1.61; 95% CI: 1.26-2.05). This pattern of results (and effect sizes) were similar when modelling the odds of having two or more developmental vulnerabilities (Table 3.6).

3.6 Discussion

Our population-based cohort study found 49% of Aboriginal children were vulnerable on at least one developmental domain and 38% were vulnerable on at least two or more developmental domains. This is the first study to identify important configurations of risk that were associated with early developmental vulnerabilities in Aboriginal children. Based on our LCA using data from children, their mothers, siblings and community we identified six groups: Healthy family; High needs family; Premature infant; High needs young mother; Young mother; and Large family. High needs family, High needs young mother and Premature infant comprised 49% of the cohort and were considered to have high risk configurations. These groups were more than twice as likely to have children who had at least one or two developmental vulnerabilities compared to the Healthy family group (Table 3.6).

Table 3.6 Association between class membership and developmental vulnerability in Aboriginal children, 2009 and 2012 AEDC

	Total (n=2715)	No. with at least 1 developmental vulnerability n = 1338	OR 95% CI	P value	Total children (n=2202)	No. with at least 2 developmental vulnerabilities n = 825	OR 95% CI	P value
Healthy family	571	196 (34.3%)	1.00		487	112 (23.0%)	1.00	
High needs family	583	334 (57.3%)	2.57 (2.02-3.26)	<0.001	467	218 (46.7%)	2.93 (2.22-3.87)	<0.001
Premature infants	240	138 (57.5%)	2.59 (1.90-3.52)	<0.001	186	84 (45.2%)	2.76 (1.93-3.94)	<0.001
High needs young mother	344	199 (57.9%)	2.63 (1.99-3.46)	<0.001	282	137 (48.6%)	3.16 (2.31-4.33)	<0.001
Young mother	443	227 (51.2%)	2.01 (1.56-2.59)	<0.001	351	135 (38.5%)	2.09 (1.55-2.83)	<0.001
Large families	534	244 (45.7%)	1.61 (1.26-2.05)	<0.001	429	139 (32.4%)	1.60 (1.20-2.15)	0.002

Our initial analysis found a number of important individual risk factors that were associated with a child having at least one or more developmental vulnerabilities. Similar to our study it has previously been reported that prematurity(32), maternal mental health(33), maternal age <20 years at delivery(14), and male children(15) have been associated with developmental vulnerabilities in Aboriginal children. In addition, we found important variables such as contact with child protection agencies, children in the lowest socioeconomic bracket and child and maternal hospitalisations to be risk factors for developmental vulnerability, which are comparable to developmentally vulnerable children internationally.(12, 34) We also found similar risks for children who had at least two or more developmental vulnerabilities. As developmental vulnerabilities increase children are more likely to have trouble with numeracy and literacy as they go through school.(35) As a result ensuring this group has access to early learning opportunities is imperative for their positive transition to and through school.

Nearly half (49%) of children were characterised within three high risk groups: High needs family, High needs young mother and Premature infant. Interpretation of these classes should proceed with caution as although they provide an important source of information, no one child falls ‘neatly’ into any one class and each child has some probability of falling into each class. Each child may also have other important social characteristics that have not been accounted for in this analysis. The High needs family group was the largest group and accounted for 21% of the sample. They had multiple risks relating to the child, mother, siblings and community. Although risks were not the same, similar complex multiple risk groups have been identified in other LCA studies and have been found to be associated with poor child neurodevelopment.(21-23) It is unsurprising that a multiple risk group was identified in our cohort given that the complex number of factors that can influence a child’s development. Improvements in

quality and access to mental health services in remote areas could provide substantial improvements and support to these families.

The Premature infant class comprised only 9% of the sample group. Within this class the probability of being preterm was very high (97.4%). A recent study in WA has shown that Aboriginal preterm infants have a higher incidence of hospital admission and emergency presentations in their first year of life compared with non-Aboriginal preterm infants.(36) This group also has a relatively high probability of hospitalisations (84.9%), child protection (33.8%) and maternal mental health (51.9%) contacts, which have been previously cited as risk factors from preterm birth.(37, 38) These factors can be targeted through improving transition of care from hospital to primary health and early child neurodevelopment care.

Maternal stress features prominently within half of the classes, particularly the High needs young mother class. Within this class young mothers tend to have few children, are in very remote areas, and are in the lowest socioeconomic bracket. They also have a reasonable amount of contact with child protection. This group has the highest odds of having a child that has at least two developmental vulnerabilities. A possible reason is the lack of available services in remote areas, which results in less opportunity to engage in prevention and early treatment of mental health problems. As a result, mental health problems escalate, resulting in a higher level of service provision needed. Once mothers are experiencing mental health problems, caring for their young children becomes difficult, and is once again compounded by the lack of available services to support young families in remote areas. This is likely to result in the involvement of child protection. However, this is in direct contrast to the Young mother's group who also live in remote areas but have far less probability of having poor maternal mental health (16.6%) and having contact with child protection (15.2%).

Further work to discern the differences between these two groups of young mothers is fundamental for delivering targeted programs of care.

3.6.1 Community participation

We reported our findings back to an Aboriginal community group who discussed and agreed on the names of the six classes found in this paper. After discussion about the attributes within each of these classes our community group found that the data were believable for Western Australian families. Improving access to services, particularly for mental health, was an important solution to improving the health and wellbeing of Aboriginal families. Also additional data such as whether mother's had previous contact with the justice or the child protection system would have provided important background, however, these data were unavailable for our study.

3.6.2 Limitations and strengths

While our study uses total population data, it has some limitations. We only used administrative data sources, which do not include important social variables that are often available in survey data. As a result, we have not captured the full spectrum of stressors and protective factors a family may have. However, we have included a number of important variables through high quality data linkage on children, their mothers and siblings. There may have been misclassification error using maximum posterior probability as some children may have similar probabilities of being in two classes. By using the *Getting our story right* indictor on children of a young age we have assumed children identify as being Aboriginal, however, some children who have been included may not identify as being Aboriginal. Lastly, due to the type of analysis that was completed it is difficult to compare across studies whether these classes are valid, however, our Aboriginal community group found the classes to be believable.

There are a number of strengths in this study including the large population based dataset which had minimal missing data. We included a number of important variables

for our cohort and linked our cohort to information on their mothers and siblings to provide a more comprehensive picture of the cohort's family. We also ensured that there was Aboriginal community participation in the interpretation of these results, which provided important contextual information about the results.

3.7 Conclusion

Our results have important implications for policy and program development. Using LCA analysis we have been able to report on combinations of factors that can be targeted to help support Aboriginal children and their families. Addressing important issues such as child protection, supporting maternal mental health and improving access to care for preterm infants are important for improving the early neurodevelopment trajectories of young Aboriginal children.

3.8 Publication disclaimer

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3.10 Appendix 1

Appendix 3.1 Socio demographic characteristics of Aboriginal children with at least two developmental vulnerabilities, 2009 and 2012 AEDC

Characteristics	All children n = 2202	Developmentally vulnerable on 2+ domains n = 825 (37.5%)	No developmental vulnerability n = 1377 (62.5%)	OR 95% CI	P value
Child					
AEDC year					
2009	1023 (46.5%)	399 (48.4%)	624 (45.3%)	1.13 (0.95-1.34)	0.165
2012	1179 (53.5%)	426 (51.6%)	752 (54.7%)	0.88 (0.74-1.05)	0.165
Child sex					
Male	1089 (49.5%)	526 (63.8%)	563 (40.9%)	2.54 (2.12-3.04)	<0.001
Female	1113 (50.5%)	299 (36.2%)	814 (59.1%)	0.39 (0.33-0.47)	<0.001
Prematurity					
<37wk	297 (13.5%)	137 (16.6%)	160 (11.6%)	1.52 (1.18-1.94)	0.001
≥ 37wk	1903 (86.4%)	687 (83.3%)	1216 (88.3%)	0.66 (0.52-0.84)	0.001
Data missing	NP	NP	NP		
Birth weight					
Low birth weight (<2500g)	252 (11.4%)	113 (13.7%)	139 (10.1%)	1.41 (1.08-1.84)	0.010
Normal birth weight (≥2500g)	1905 (88.6%)	712 (86.3%)	1238 (89.9%)	0.71 (0.54-0.92)	0.010
APGAR 5 score					
< 7 (abnormal)	43 (1.9%)	17 (2.1%)	17 (2.1%)	1.09 (0.59-2.02)	0.785
≥7 (healthy)	2152 (97.7%)	≥90%	1345 (97.7%)	0.92 (0.49-1.70)	0.785
Data missing	NP	NP	NP		
Contact with Child Protection					
Not removed	1669 (75.8%)	575 (69.7%)	1094 (79.5%)	0.59 (0.49-0.73)	<0.001
At least one contact (excl. removals)	377 (17.1%)	181 (21.9%)	196 (14.2%)	1.69 (1.35-2.12)	<0.001
Removed	156 (7.1%)	69 (8.4%)	87 (6.3%)	1.35 (0.97-1.88)	0.071
Siblings					
0	253 (11.5%)	81 (9.8%)	172 (12.5%)	0.76 (0.58-1.01)	0.058
1	528 (24.0%)	180 (21.8%)	348 (25.3%)	0.83 (0.67-1.01)	0.066
2	479 (21.7%)	177 (21.5%)	302 (21.9%)	0.97 (0.79-1.20)	0.793
≥3	942 (42.8%)	387 (46.9%)	555 (40.3%)	1.31 (1.10-1.56)	0.002
Disabled siblings					
Disabilities	213 (9.7%)	92 (11.2%)	121 (8.8%)	1.30 (0.98-1.73)	0.070
No disabilities	1989 (90.3%)	733 (88.9%)	1256 (91.2%)	0.77 (0.58-1.02)	0.070
Mother					
Maternal Age					
<20 yrs	511 (23.2%)	221 (26.8%)	290 (21.1%)	1.37 (1.12-1.68)	0.002
20-24 yrs	727 (33.0%)	255 (30.9%)	472 (34.3%)	0.86 (0.71-1.03)	0.104
25-29 yrs	503 (22.8%)	187 (22.7%)	316 (23.0%)	0.98 (0.80-1.21)	0.879
30-34 yrs	309 (14.0%)	101 (12.2%)	208 (15.1%)	0.78 (0.61-1.01)	0.062
35+ yrs	152 (6.9%)	61 (7.4%)	91 (6.6%)	1.13 (0.81-1.58)	0.482
Gravidity					
0	561 (25.5%)	204 (24.7%)	357 (25.9%)	0.94 (0.77-1.15)	0.532
1	479 (21.8%)	163 (19.8%)	316 (23.0%)	0.83 (0.67-1.02)	0.079
2	362 (16.4%)	133 (16.1%)	229 (16.6%)	0.96 (0.76-1.22)	0.759
≥3	798 (36.2%)	324 (39.3%)	474 (34.4%)	1.23 (1.03-1.47)	0.021
Data missing	NP	NP	NP		
Mental health contact					
At least 1 contact	884 (40.2%)	406 (49.2%)	478 (34.7%)	1.82 (1.53-2.17)	<0.001
No contact	1318 (59.8%)	419 (50.8%)	899 (65.3%)	0.55 (0.46-0.65)	<0.001

Community					
Geographic location (ARIA)					
Major city	793 (36.0%)	275 (33.3%)	518 (37.6%)	0.83 (0.69-0.99)	0.043
Regional	510 (23.2%)	182 (22.1%)	328 (23.8%)	0.91 (0.74-1.11)	0.344
Remote	314 (14.3%)	105 (12.7%)	209 (15.2%)	0.83 (0.65-1.07)	0.158
Very remote	465 (21.1%)	208 (25.2%)	257 (18.7%)	1.52 (1.23-1.87)	<0.001
Data missing	120 (5.5%)	55 (6.7%)	65 (4.7%)		
Socio-economic status					
Most disadvantaged 1	1226 (55.7%)	509 (61.7%)	717 (52.1%)	1.48 (1.24-1.77)	<0.001
2	455 (20.7%)	151 (18.3%)	304 (22.1%)	0.79 (0.64-0.98)	0.034
3	223 (10.1%)	63 (7.6%)	160 (11.6%)	0.63 (0.46-0.85)	0.003
Least disadvantaged 4-5	178 (8.1%)	47 (5.7%)	131 (9.5%)	0.59 (0.41-0.83)	0.002
Data missing	120 (5.5%)	55 (6.7%)	65 (4.7%)		
Hospital utilisation					
Child hospitalisation					
0	551 (25.0%)	149 (18.1%)	402 (29.2%)	0.53 (0.43-0.66)	<0.001
1	630 (28.6%)	205 (24.9%)	425 (30.9%)	0.74 (0.61-0.90)	0.003
2	398 (18.1%)	156 (18.9%)	242 (17.6%)	1.09 (0.88-1.37)	0.431
3	237 (10.8%)	112 (13.6%)	125 (9.1%)	1.57 (1.20-2.06)	0.001
4	132 (6.0%)	67 (8.1%)	65 (4.7%)	1.78 (1.25-2.54)	0.001
≥5	254 (11.5%)	136 (16.5%)	118 (8.6%)	2.11 (1.62-2.74)	<0.001
Child emergency presentation					
0	67 (3.0%)	22 (2.7%)	45 (3.3%)	0.81 (0.48-1.36)	0.427
1	159 (7.2%)	61 (7.4%)	98 (7.1%)	1.04 (0.75-1.45)	0.808
2	147 (6.7%)	42 (5.1%)	105 (7.6%)	0.65 (0.45-0.94)	0.022
3	169 (7.7%)	50 (6.1%)	119 (8.6%)	0.68 (0.48-0.96)	0.028
4	158 (7.2%)	60 (7.3%)	98 (7.1%)	1.02 (0.73-1.43)	0.891
≥5	1502 (68.2%)	590 (71.5%)	912 (66.2%)	1.28 (1.03-1.54)	0.010
Mother hospitalisation					
0	NP	NP	NP		
1	225 (10.2%)	65 (7.9%)	160 (11.6%)	0.65 (0.48-0.88)	0.005
2	389 (17.7%)	126 (15.3%)	263 (19.1%)	0.76 (0.61-0.96)	0.023
3	405 (18.4%)	119 (14.4%)	286 (20.8%)	0.64 (0.51-0.81)	<0.001
4	306 (13.9%)	118 (14.3%)	188 (13.7%)	1.06 (0.82-1.35)	0.669
≥5	876 (39.8%)	397 (48.1%)	479 (34.8%)	1.74 (1.46-207)	<0.001
Mother emergency utilisation					
0	146 (6.6%)	48 (5.8%)	98 (7.1%)	0.81 (0.56-1.15)	0.237
1	185 (8.4%)	47 (5.7%)	138 (10.0%)	0.54 (0.38-0.76)	<0.001
2	176 (8.0%)	50 (6.1%)	126 (9.2%)	0.64 (0.45-0.90)	0.010
3	159 (7.2%)	55 (6.7%)	105 (7.6%)	0.87 (0.62-1.23)	0.437
4	159 (7.2%)	56 (6.8%)	103 (7.5%)	0.90 (0.64-1.26)	0.544
≥5	1377 (62.5%)	569 (69.0%)	808 (58.7%)	1.57 (1.30-1.88)	<0.001

≥90%, not publishable due to high numbers and confidentiality restrictions; NP, not publishable due to small numbers and confidentiality restrictions

3.11 Appendix 2

Appendix 3.2 Associations between characteristics and Aboriginal children with at least two developmental vulnerabilities, 2009 and 2012 AEDC

Characteristics	Total number of infants n=2202	Developmentally vulnerable on 2+ domains n = 825	OR (95% CI)	p value	aOR (95% CI)*	p value
Child						
AEDC year						
2009	1023 (46.5%)	399 (39.0%)	0.88 (0.74-1.05)	0.165	0.91 (0.76-1.10)	0.334
2012	1179 (53.5%)	426 (36.1%)	1.00		1.00	
Child sex						
Male	1089 (49.5%)	526 (48.3%)	2.54 (2.13-3.04)	<0.001	2.78 (2.30-3.36)	<0.001
Female	1113 (50.5%)	299 (26.9%)	1.00		1.00	
Prematurity						
<37wk	297 (13.5%)	137 (46.1%)	1.52 (1.18-1.94)	0.001	1.61 (1.23-2.10)	<0.001
≥ 37wk	1903 (86.4%)	687 (36.1%)	1.00		1.00	
Birth weight						
Low birth weight (<2500g)	252 (11.4%)	113 (44.8%)	1.41 (1.08-1.84)	0.010	1.24 (0.86-1.78)	0.242
Normal birth weight (≥2500g)	1905 (88.6%)	712 (37.3%)	1.00		1.00	
APGAR 5 score						
< 7 (abnormal)	43 (1.9%)	17 (39.5%)	1.09 (0.59-2.02)	0.785	1.06 (0.55-2.05)	0.861
≥7 (healthy)	2152 (97.7%)	≥90%	1.00		1.00	
Contact with Child Protection						
Not removed	1669 (75.8%)	575 (34.5%)	1.00		1.00	
At least one contact (excl. removals)	377 (17.1%)	181 (48.0%)	1.76 (1.40-2.20)	<0.001	1.86 (1.452.38)	<0.001
Removed	156 (7.1%)	69 (44.2%)	1.51 (1.08-2.10)	0.015	1.32 (0.92-1.91)	0.133
Siblings						
0	253 (11.5%)	81 (32.0%)	0.91 (0.66-1.25)	0.565	0.82 (0.57-1.17)	0.266
1	528 (24.0%)	180 (34.1%)	1.00		1.00	
2	479 (21.7%)	177 (37.0%)	1.13 (0.88-1.47)	0.343	1.11 (0.83-1.50)	0.469
≥3	942 (42.8%)	387 (41.1%)	1.35 (1.08-1.68)	0.008	1.39 (1.02-1.88)	0.035
Disabled siblings						
Disabilities	213 (9.7%)	92 (43.2%)	1.30 (0.98-1.73)	0.070	1.11 (0.81-1.52)	0.513
No disabilities	1989 (90.3%)	733 (36.9%)	1.00		1.00	

Mother						
Maternal Age						
<20 yrs	511 (23.2%)	221 (43.2%)	1.29 (1.00-1.66)	0.049	1.97 (1.42-2.75)	<0.001
20-24 yrs	727 (33.0%)	255 (35.1%)	0.91 (0.72-1.16)	0.450	1.08 (0.82-1.42)	0.575
25-29 yrs	503 (22.8%)	187 (37.2%)	1.00		1.00	
30-34 yrs	309 (14.0%)	101 (32.7%)	0.82 (0.61-1.11)	0.194	0.75 (0.54-1.03)	0.078
35+ yrs	152 (6.9%)	61 (40.1%)	1.13 (0.78-1.64)	0.511	1.12 (0.75-1.67)	0.589
Gravidity						
0	561 (25.5%)	204 (36.4%)	0.98 (0.75-1.29)	0.908	0.65 (0.47-0.90)	0.010
1	479 (21.8%)	163 (34.0%)	0.89 (0.67-1.18)	0.415	0.73 (0.53-0.99)	0.046
2	362 (16.4%)	133 (36.7%)	1.00		1.00	
≥3	798 (36.2%)	324 (40.6%)	1.18 (0.91-1.52)	0.213	1.27 (0.95-1.70)	0.105
Mental health contact						
At least 1 contact	884 (40.2%)	406 (45.9%)	1.82 (1.53-2.17)	<0.001	1.71 (1.41-2.07)	<0.001
No contact	1318 (59.8%)	419 (31.8%)	1.00		1.00	
Community						
Geographic location (ARIA)						
Major city	793 (36.0%)	275 (34.7%)	1.00		1.00	
Regional	510 (23.2%)	182 (35.7%)	1.05 (0.83-1.32)	0.710	0.94 (0.73-1.20)	0.602
Remote	314 (14.3%)	105 (33.4%)	0.95 (0.72-1.25)	0.696	0.97 (0.72-1.29)	0.811
Very remote	465 (21.1%)	208 (44.7%)	1.52 (1.21-1.93)	<0.001	1.48 (1.15-1.90)	0.002
Socio-economic status						
Most disadvantaged 1	1226 (55.7%)	509 (41.5%)	1.98 (1.39-2.81)	<0.001	1.91 (1.32-2.76)	0.001
2	455 (20.7%)	151 (33.2%)	1.38 (0.94-2.04)	0.099	1.32 (0.88-1.97)	0.178
3	223 (10.1%)	63 (28.3%)	1.10 (0.70-1.71)	0.681	1.09 (0.69-1.72)	0.724
Least disadvantaged 4-5	178 (8.1%)	47 (26.4%)	1.00		1.00	
Hospital utilisation						
Child hospitalisation						
0	551 (25.0%)	149 (27.0%)	1.00		1.00	
1	630 (28.6%)	205 (32.5%)	1.30 (1.01-1.67)	0.040	1.20 (0.91-1.57)	0.194
2	398 (18.1%)	156 (39.2%)	1.74 (1.32-2.29)	<0.001	1.56 (1.16-2.11)	0.003
3	237 (10.8%)	112 (47.3%)	2.42 (1.76-3.32)	<0.001	2.30 (1.63-3.24)	<0.001
4	132 (6.0%)	67 (50.8%)	2.78 (1.88-4.11)	<0.001	2.21 (1.45-3.38)	<0.001
≥5	254 (11.5%)	136 (53.5%)	3.11 (2.28-4.24)	<0.001	2.63 (1.86-3.72)	<0.001

Child emergency presentation						
0	67 (3.0%)	22 (32.8%)	1.00		1.00	
1	159 (7.2%)	61 (38.4%)	1.27 (0.70-2.32)	0.432	1.20 (0.62-2.30)	0.589
2	147 (6.7%)	42 (28.6%)	0.82 (0.44-1.53)	0.528	0.72 (0.36-1.42)	0.345
3	169 (7.7%)	50 (29.6%)	0.86 (0.47-1.58)	0.625	0.82 (0.42-1.58)	0.554
4	158 (7.2%)	60 (38.0%)	1.25 (0.69-2.29)	0.464	1.38 (0.72-2.65)	0.335
≥5	1502 (68.2%)	590 (39.3%)	1.32 (0.79-2.23)	0.291	1.20 (0.68-2.12)	0.530
Mother hospitalisation						
1	225 (10.2%)	65 (28.9%)	1.00		1.00	
2	389 (17.7%)	126 (32.4%)	1.18 (0.82-1.69)	0.367	1.06 (0.72-1.56)	0.769
3	405 (18.4%)	119 (29.4%)	1.02 (0.72-1.47)	0.896	0.98 (0.67-1.44)	0.916
4	306 (13.9%)	118 (38.6%)	1.55 (1.07-2.23)	0.021	1.37 (0.92-2.05)	0.121
≥5	876 (39.8%)	397 (45.3%)	2.04 (1.49-2.80)	<0.001	1.86 (1.32-2.63)	<0.001
Mother emergency utilisation						
0	146 (6.6%)	48 (32.9%)	1.00		1.00	
1	185 (8.4%)	47 (25.4%)	0.70 (0.43-1.12)	0.137	0.77 (0.46-1.29)	0.325
2	176 (8.0%)	50 (28.4%)	0.81 (0.50-1.30)	0.386	0.78 (0.46-1.31)	0.344
3	159 (7.2%)	55 (34.6%)	1.08 (0.67-1.74)	0.752	1.11 (0.67-1.86)	0.687
4	159 (7.2%)	56 (35.2%)	1.11 (0.69-1.78)	0.666	1.16 (0.69-1.94)	0.579
≥5	1377 (62.5%)	569 (41.3%)	1.44 (1.00-2.06)	0.049	1.36 (0.91-2.02)	0.129

*adjusted for sex, mother's age, SES, gravidity, prematurity; ≥90%, not publishable due to high numbers and confidentiality restrictions

CHAPTER 4: EVALUATION OF THE WESTERN AUSTRALIAN POPULATION BASED INTELLECTUAL DISABILITY EXPLORING ANSWERS (IDEA) SURVEILLANCE SYSTEM

4.1 Prologue

4.1.1 My role

For the evaluation of the surveillance system I:

- conceived and designed the evaluation and then completed the first draft of the evaluation protocol
- drafted the first interview schedule for feedback and made the necessary changes based on this feedback
- completed all the interviews, had them transcribed and reviewed them to make sure they were correct
- completed the thematic analysis on the interviews
- analysed the data for comparison between the IDEA and Western Australian Registry of Birth Defects-Cerebral Palsy
- met IDEA management team for observations on how the system worked and helped draft the flow chart for the process of data collection for the IDEA system
- interpreted the data and completed the first draft
- liaised with authors for feedback and comments, which I made to the manuscript.

4.1.2 Lessons learned

A major lesson I learnt in completing the evaluation is that you do need to evaluate all the attributes of a system even if you don't think some of the attributes are important. I evaluated eight of the ten recognised attributes from the 2001 U.S. Centers for Disease Control and Prevention guidelines. I did not evaluate two due to lack of primary data.

However, on reflection I realised I believed that it wouldn't be necessary to evaluate all attributes, in particular the attributes of simplicity and timeliness. This is because I thought the data from these two attributes did not contribute to the overall evaluation as they can't be changed due to the how the system works. I have since been convinced otherwise. Having all of the information on the system attributes is important for policy makers and stakeholder to make decisions even if components of the system can't be changed. It's a good thing I did assess all the attributes!

4.1.3 Public health implications

The IDEA system is the only data collection for intellectual disability currently in Australia and one of the few internationally. It has made significant contributions to the policy and practice through providing crucial data on people living with an intellectual disability. With the introduction of the National Disability Insurance Scheme data collection on intellectual disability will vary. Some data will now be collected through the Australian Government and other data will still remain within the Western Australian State Government. As a result, the collection of Western Australian population based data on intellectual disability is in jeopardy. This evaluation has provided the IDEA management team with an extensive summary of the contributions the IDEA system has had both nationally and internationally and clear recommendations for moving forward. Through this work the IDEA management team can devise a pathway to ensure future data collection and hopefully maintain this important population based data system in Western Australia.

4.1.4 Acknowledgements

I would like to acknowledge my co-authors and supervisors. Ms Jenny Bourke (Telethon Kids Institute), Professor Helen Leonard (Telethon Kids Institute), Dr Alice Richardson (primary supervisor ANU) and Associate Professor Dan McAullay (placement supervisor UWA) supported the conception and design of the evaluation. Ms Jenny Bourke helped perform the interviews through contacting stakeholders and explaining the IDEA system to me in detail for data analysis. Ms Jenny Bourke,

Professor Helen Leonard, Dr Alice Richardson, Associate Professor Dan McAullay and Dr Karen Edmond (placement supervisor UNICEF) all contributed intellectual input through comments and suggestions for improving the manuscript.

In addition, I would like to acknowledge the time of the stakeholders in providing their thoughts on the IDEA system. We are very grateful to DSC and Department of Education for their ongoing support of the IDEA database.

4.1.5 MAE core requirement

This project fulfils the evaluation of a surveillance system component of the MAE. The chapter has been submitted for publication to BMJ Open. This project was also presented at the 2018 International Population Data Linkage Conference in Banff, Canada. A lay summary has also been developed for dissemination to stakeholders who participated in the evaluation and to the wider community. The presentation abstract and slides, and lay summary have been provided in Appendix B at the end of the thesis.

4.2 Abstract

4.2.1 Objectives

Our overall aim was to evaluate the Western Australian 'Intellectual Disability Exploring Answers' (IDEA) surveillance system. The primary objective was to evaluate the attributes of the system. The secondary objective was to provide recommendations to data custodians and stakeholders to strengthen the system.

4.2.2 Method

The IDEA system was evaluated using process observation, interviews and secondary data analysis of system attributes: usefulness, simplicity, data quality, acceptability, representativeness, timeliness, and stability. 2001 U.S. Centers for Disease Control and Prevention guidelines were used.

4.2.3 Results

We found that the IDEA system was useful, simple, flexible, acceptable, representative, timely and stable. We compared individuals from the IDEA system (n=10593) to those with cerebral palsy and ID (n=582) from another surveillance system. Of the 582 with cerebral palsy and ID, 501 (86.1%) were in the IDEA system and 81 (13.9%) were not. In total 0.7% of cases (81/10674) with ID were not identified in the IDEA system. There were little differences in cases that were not identified in the IDEA system between Indigenous status, sex and place of residence.

4.2.4 Conclusions

The strengths of the IDEA system include having a high data quality resource contributing to national and international data on ID, strong government support and a dedicated management team. Output from studies linking to IDEA data have had major contributions to the international literature about ID. However, limited resources have prevented it from realising its full potential in relation to translational activities. The IDEA system is a valuable resource to address the needs of people living with ID.

4.3 Introduction

People living with an intellectual disability (ID) have impaired thought processes, learning, communication, and remembering, which contribute to their overall intelligence including cognition, and language and may affect motor and social abilities. As a result, people with IDs are more likely to suffer from maltreatment as children,(1) have increased co-morbidities,(2) mental health diagnoses(3) and often experience stigmatisation and discrimination resulting in poor access to health services(4) compared to their counterparts who do not have ID. In addition, with advances in health care, many people with ID now have elderly carers or will outlive their carers. Additional government input for care services previously managed by families will be needed in the years to come.(5)

Internationally there are few dedicated public health surveillance systems for ID. Many rely on data from existing state and national surveys, administrative datasets, registries or integrated data systems.(6-8) In Western Australia (WA), the 'Intellectual Disability Exploring Answers' (IDEA) database is a population-based linked data surveillance system which is internationally recognised for its collection of prevalence and incidence data for ID.(9) The IDEA system originated from a dataset of individuals with ID receiving support from the WA government, was established in 1953 and maintained by successive state governments performing this role. In 2002, the IDEA system was moved to the Telethon Kids Institute (TKI, WA) to become a permanent population-based data linkage surveillance system. The original objective of the surveillance system was to provide high-quality, complete and population based information on ID in WA. It was anticipated that this information might be used for the following purposes: monitoring trends and investigating changes in the prevalence of ID, overall and in various subgroups; providing an infrastructure for population-based epidemiological and genetic research into the causes and prevention of ID; providing an infrastructure for research into the health status and service needs of children and adults with ID; allowing the identification of population based subgroups with specific characteristics who might benefit from new scientific advances; evaluating screening programs for prevention of ID; facilitating planning and providing infrastructure for the evaluation of early intervention and therapy programs; and increasing community and professional knowledge about ID.(10)

With the recent introduction of the Australian National Disability Insurance Scheme (NDIS), the future of the IDEA surveillance system has become unclear. It is still not known whether government will continue to undertake assessments for ID, the information needed to categorise cases in the IDEA system.(11) Information on the current strengths and limitations of the IDEA surveillance system could help stakeholders and data custodians better understand how the system can evolve in light

of current policy initiatives. Therefore, an evaluation of the IDEA surveillance system was undertaken to assess the quality, efficiency and usefulness of the system. The primary objective was to systematically and objectively evaluate the attributes of the system. The secondary objective was to provide recommendations to data custodians and stakeholders to strengthen the surveillance system.

4.4 Methods

4.4.1 Design

This evaluation is based on the methods from the 2001 U.S. Centers for Disease Control and Prevention guidelines on evaluation of public health surveillance systems.(12) We assessed the following system attributes: usefulness (how important is the collection of ID; does it respond to prevention, early detection and evaluation of programs; or improve public health knowledge), simplicity (ease of understanding data processes), flexibility (ability of the system to adapt to changing needs), data quality (is the data complete), acceptability (the willingness of providers to participate in IDEA system processes), representativeness (is the data generalisable to the wider population), timeliness (speed of which data is provided at all stages), and stability (whether resourcing is sufficient). We did not aim to calculate positive predictive value and sensitivity due to lack of primary data to assess these attributes.

4.4.2 Study setting

4.4.2.1 Case ascertainment and eligibility

Cases are ascertained from the Disability Services Commission (DSC, now Department of Communities) through referrals to assess individuals for eligibility to access disability services. For the Department of Education cases are school aged children who are identified as potentially needing additional teaching support in relation to intellectual functioning and who have been assessed to determine the level of educational support required. Table 4.1 provides case eligibility for both DSC and Department of Education.

Table 4.1 Intellectual disability case definition

Government organisation	Definition
Disability Services Commission (13)	A person is considered to be intellectually disabled if they have scored more than two standard deviations below the mean on a recent formal assessment of intellectual functioning (within the past 3 years); or scored more than two standard deviations below the mean on a recognised measure of adaptive functioning with demonstrated deficits in two or more of the following skill domains conceptual, social or practical; or if their clinical presentation is consistent with an intellectual disability. The onset of these conditions needs to have manifested prior to 18 years of age.
Department of Education (14)	Intellectual disability is determined through a diagnostic report which has had all components completed within six months and has considered factors such as language, cultural background, learning opportunities, disabilities, motivation and cooperation. Determining intellectual disability includes an assessment of adaptive functioning using both clinical evaluation and standardised assessment with a significant impairment defined as two standard deviations below the mean on a standardised, culturally relevant assessment in at least one domain across multiple environments (e.g. home, school, community and work). Results and interpretations of assessments demonstrate a significant sub-average intellectual functioning of an intelligence quotient <70 on an individually administered appropriate IQ test; and evidence that academic achievement and progress is limited in comparison to age expectations. Prior to 2006 cases were classified as either a “mild or moderate” or “severe” level of intellectual disability. In 2006, the level of ID provided by the Department was modified to represent the child’s educational level of need, rated from 1 (low need) to 5 (high need). The IDEA surveillance data used the educational need (EN) data to estimate the level of intellectual disability. In 2016 the level of educational need was replaced with an Individual Disability Allocation (IDA) which was rated from 1 (mild ID) to 7 (severe and comorbid ID) and is used to estimate level of intellectual disability. The onset of these conditions needs to have manifested prior to 18 years of age.

Eligibility for IDEA has been extended to children < 6 years old who are considered ‘vulnerable’ by the DSC when a developmental assessment indicates a likelihood of ID although they are too young to have a formal IQ assessment. These children are included in the database but are reconsidered if assessments become available at school age. This represents only approximately 2% of cases (estimated for birth years 1990–2001).(9) Children identified through the Department of Education were accepted as having an ID unless there is conflicting evidence from DSC.

4.4.2.2 Case definition

A confirmed case from the DSC is i) an individual with a full IQ<70; ii) evidence of developmental delay at <18 years of age (where evidence is not available but there is no obvious cause for the ID after 18 years of age, it is accepted that the delay was probably present during childhood and the case will be eligible); or iii) where there is no

IQ test score available but the child has a known biomedical cause of ID, such as Down syndrome.

Prior to 2006, confirmed cases from the Department of Education were included if the assigned level of ID was ‘mild or moderate’ or severe. Subsequent to 2005 and in the absence of availability of information on ID level, cases with an educational need of 4-5 were considered to have an ID. An analysis of the correlation between the previously assigned level of ID and the level of educational need (EN) has shown that an EN score of 4 is correlated with a mild or moderate ID, and EN score of 5 with a severe ID.(9) In 2016 the level of educational need was replaced with an Individual Disability Allocation which was rated from 1 (mild ID) to 7 (severe and comorbid ID) and used to estimate level of intellectual disability. Further enhancement of data is undertaken by a medical officer, located at DSC, using the four digit American Association on Mental Retardation system to assign the most appropriate cause of ID to cases which can be later grouped into broader categories.(15)

4.4.2.3 Management of IDEA system

Currently there is funding provided by the DSC for personnel equivalent to 0.5 FTE and operating costs. Personnel costs cover liaising with departments for data, updating data within the IDEA system, supporting and completing epidemiological studies on ID and responding to requests for data. Operating costs need to cover future fees for data linkage by Department of Health WA. Funds have also provided some support for traditional research outputs such as conference fees and publication costs. However, there has been limited support for work related travel, communication and engagement activities, which have been covered from other sources including a philanthropic donation in 2013. In addition, there is a volunteer community advisory group which consists of researchers, advocates for ID, policy makers and the IDEA system data custodian. The aim of the advisory group is to review and approve projects applying for the use of ID data in their study and to provide support where applicable. Although the

advisory committee originally met annually in person, since 2011 communication between members has primarily been through email.

4.4.3 Patient and public involvement

Patient and public involvement was not completed for the study design or the development of outcome measures. A member of the public and an advocacy organisation for intellectual disability were recruited and provided their views on the IDEA system. The results will be disseminated through traditional journal publication, conference presentation and a lay summary, which will be sent to all individuals who participated in the project. We have acknowledged the time stakeholders spent in participating in the study.

4.4.4 Data collection

For privacy and confidentiality reasons there is a limited number of data variables that are collected as part of the IDEA system (Table 4.2). As a population-based data linkage surveillance system these data need to be linked to other WA administrative data collections.

Table 4.2 Data variables for IDEA surveillance system

Variable	Description
Unique ID	Unique identifier that can be used with other data linkage studies
Ascertainment source	Whether cases were ascertained through Department of Communities or Department of Education
IDEA eligibility	Described as Eligible, Eligible Department of Education, Eligible Vulnerable, not eligible. 1. Note: "Eligible Department of Education" are cases where there is insufficient information from Department of Communities to determine IDEA eligibility but sufficient information from Education is available. 2. "Eligible Vulnerable" are Department of Communities cases where level of ID is unknown but case has been deemed Vulnerable to ID.
ID level	Mild, mild or moderate, moderate, severe, unknown, Unknown but intellectually handicapped, borderline, Not intellectually handicapped
Sex	Male or Female
DOB Month	Month of birth
DOB Year	Year of birth
Client diagnosis	numeric Heber code for diagnosis – up to four can be recorded
Client diagnosis description	text description of diagnosis - up to four can be recorded
Autism Spectrum Disorder identified	Identifies clients with an autism spectrum disorder diagnosis
Cause of ID	Provides the broader group cause of ID if available. Described as biomedical, not medical – unknown, autism spectrum disorder with ID, insufficient information.

Note: ID (intellectual disability) and intellectual handicap are used interchangeably

The process of obtaining data for the IDEA system involves data contributions from two WA government departments, the DSC and the Department of Education. Figure 4.1

provides a flow diagram outlining the process from case ascertainment to finalising the IDEA system updates. Identifiable data on individuals with probable and suspected ID are provided to the Data Linkage Branch, Department of Health WA. These data are de-identified and only linkable through unique codes called root numbers, which are then provided back to the IDEA custodian and to the respective departments. Both departments then provide the IDEA management team with their de-identified datasets and data variables. This process is undertaken to safeguard privacy and confidentiality at all stages and takes approximately nine months to occur. Once the data are received by the IDEA team duplicates are combined into one record, new records are assessed for eligibility and the system updated (Figure 4.1). This latter process takes approximately four months to complete. Updates from DSC and the Education Department were initially undertaken every two years. However, there was four years between the last two updates (in 2013 and 2017). This delay was associated with the process of IDEA being converted to an Infrastructure Project.

4.4.5 Data analysis

To evaluate the IDEA surveillance system we took a three-pronged approach including process observation, in-depth interviews and secondary data analysis. Interviewees included representatives from the three WA government departments involved in the IDEA system, health service providers, community representatives and researchers using a 20-item semi-structured questionnaire. The aim of the interview was to discuss the usefulness, simplicity, flexibility, acceptability, timeliness, data quality, representativeness, and stability of the IDEA system through assessing and understanding responses of stakeholders. The questionnaire was administered face-to-face, took between 30-60 minutes and was recorded with participant's consent for further analysis. Some interviewees were not able to answer all questions depending on their level of involvement with the IDEA system. Thematic analysis according to the system attributes was completed.

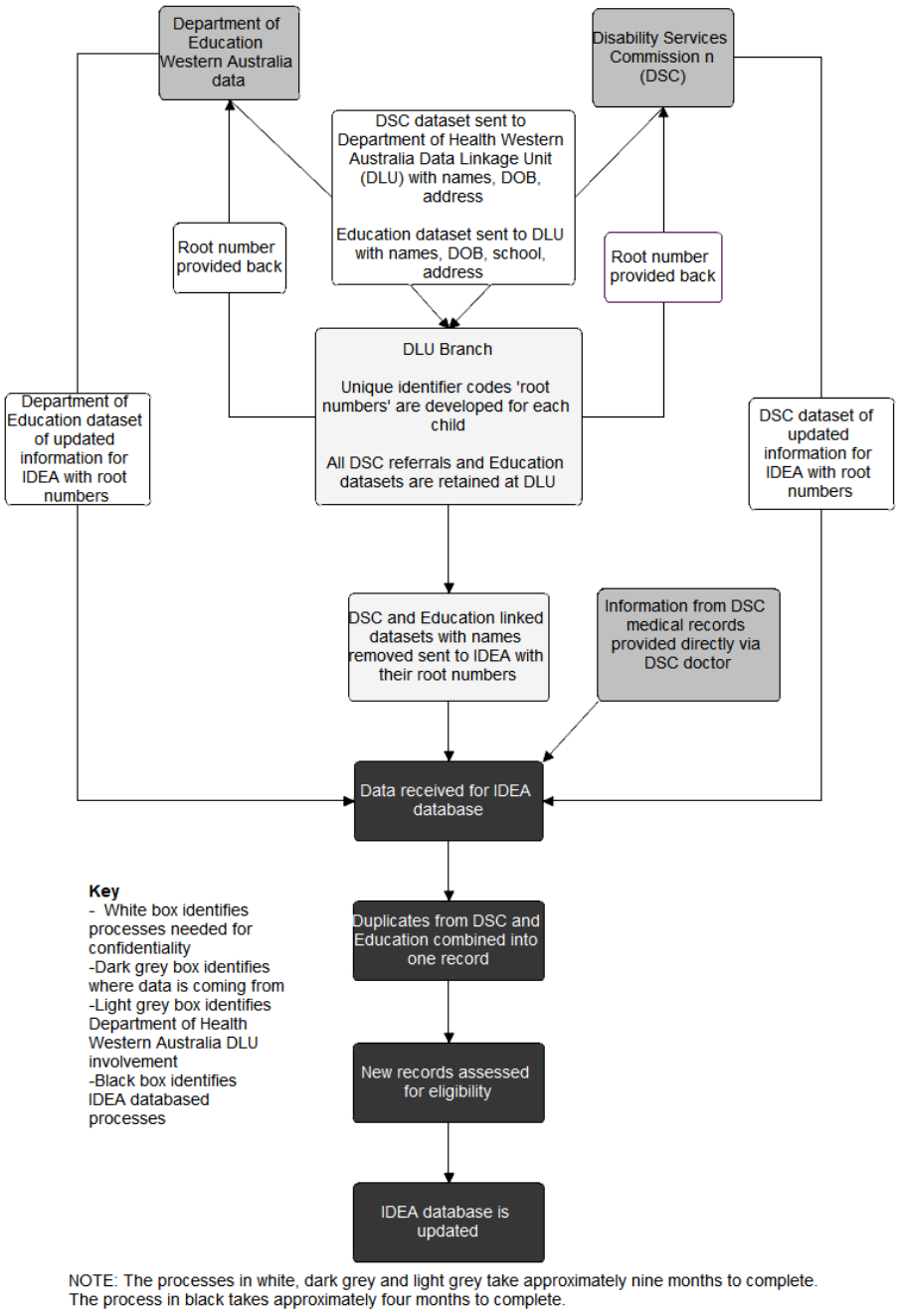

Figure 4.1 Flow diagram of process of data collection for IDEA surveillance system

Secondary data analysis was used to assess the data quality through determining the completeness of data. Cross-checking of individuals born between 1983—2014 from the mandatory WA Registry of Developmental Anomalies-Cerebral Palsy database (WARDA-CP) who have ID to the IDEA system was undertaken. ID for the WARDA-CP database is ascertained through medical records and is updated when a child is 5 years old. If there is no record of ID, the child's medical record will be checked again

once they have started school. All confirmed cases from the IDEA system from 1983-2014 were included. Children from the WARDA-CP database were included in the analysis if they had a mild impairment (IQ or development quotient (DQ) 50-69), moderate impairment (IQ/DQ 35-49) or severe impairment (IQ/DQ <35). Cross-tabulations were completed to determine the number of children from the WARDA-CP database that were not identified in the IDEA system. If there was a discrepancy between databases further investigation to determine reasons for missing cases was completed.

4.4.6 Ethics approval

This study was approved by the Department of Health Western Australia Human Research Ethics Committee (2014/24), The University of Western Australia (RA/4/20/4168) and The Australian National University (2017/567). Written consent was provided and all data collected was anonymous.

4.5 Results

4.5.1 Characteristics

Eleven interviews were completed. Three individuals were solely involved in reporting, analysing and/or interpreting of ID surveillance data. Two contributed to the data either directly or in an advisory capacity. Six were involved in both of these roles. Interviewees had been involved with the IDEA system for 3-17 years and many of them contributed to the system in a number of different areas (Table 4.3). Other roles that were identified included administrative support, reporting, communication and translation.

Table 4.3 Roles identified by interviewees within the IDEA surveillance system

Characteristics	Numbers (%)*
Analysing data	8 (73%)
Reporting data	8 (73%)
Interpreting data	9 (82%)
Maintenance of data	5 (45%)
Data quality	7 (64%)
Committee member	4 (36%)
Data entry	3 (27%)
Data linkage	3 (27%)
Data extraction	3 (27%)
Management of data	6 (55%)
Advocacy	5 (45%)

*The are multiple counts

4.5.2 Usefulness

Data on reasons for the importance of identifying and collecting ID data included:

- identifying prevalence and trends in ID
- using data for prevention of ID and to understand causes of ID, and management of care services
- identifying subgroups such as co-morbidity with mental illness, or child neglect for which ID is a very strong risk factor
- measuring and evaluating life outcomes for people with ID by being able to identify them as they move through the service system
- informing policy and practice particularly from a systems perspective for planning and resource allocation particularly as people with an ID are the largest single cohort of individuals receiving support through all disability services.

Concern about the stigma associated with identifying people as having an ID was expressed although services, funding and resource allocation decisions are made as a result of these processes. Ensuring appropriate identification was considered an important part of the data collection process.

Interviewees thought the IDEA surveillance system had either met or partially met the overall aim of the IDEA system; to provide high-quality, complete and population based information on ID in WA. The IDEA surveillance system was considered to be an

infrastructure which had provided a substantial amount of data to assess trends in the prevalence of ID, investigate health service use for people with ID, evaluate risks associated with having an ID and health and social determinants of ID. However, a major drawback in 2010 was the loss to the database of any information from the Western Australian Midwives database which provides an individual's basic birth data (born WA, race, birthweight etc.). As a result, other than through separate ethically approved data linkage projects, many of which have been undertaken, it is now difficult to provide many routine statistics. The system was also considered to be missing sub-groups of individuals such as the small number of people attending Catholic or independent schools for children born since 1992, individuals who were not receiving services from DSC or those not using the state education system. Additional data variables such as genetic information related to an individual's ID, co-morbidities, and in particular functional capacity, were commonly cited among interviewees as important information for IDEA. Interviewees agreed that evaluations of screening programs for prevention, early intervention or therapy programs for ID, or genetic research into the causes and prevention of ID had not been possible because of lack of availability of data or, if available, the presence of ethical and other constraints to its linkage. Lastly, it was acknowledged that although professional knowledge had increased about ID it was not known what impact this may have had on community awareness.

All interviewees had either used or read about the IDEA data in journal publications, annual reports, stakeholder reports, reports for consumers or the public, policy briefs, government reports, newsletters, minister reports, book chapters and conferences. There have been over 40 journal publications with approximately 740 citations and 70 conference presentations between 2004-2017 that have used IDEA surveillance data. Importantly, IDEA data have been widely used, cited and published in international literature including in international estimates of years lived with disabilities (2010).(16) However, there was unanimous agreement that there needs to be more publications,

particularly consumer and policy-driven, as well as regular biannual reports. Although there had been direct engagement with the DSC Director General through meetings every 3 months in 2013 facilitated with philanthropic funding to provide information on outcomes, it was considered by many interviewees that there had been little in the way of communicating results to the community and advocacy organisations. It was suggested knowing this information could be beneficial for community groups to advocate with and for families and individuals with ID.

4.5.3 Simplicity

There were conflicting responses when asked about the simplicity of the system. Respondents discussed the process for collecting data for the IDEA surveillance system inconsistently as simple; timely; complex; or taking too long (Figure 4.1). However, ultimately the process is largely based on safeguarding privacy therefore the nine months it takes for the IDEA team to receive data was deemed by those who have worked with and in the Department of Health to be in line with current data linkage processes. The four months for integrating data received by government departments into the IDEA system was considered reasonable especially as there is only one person working 0.5 full time equivalent (FTE). The process of providing ID data for research projects was also perceived as appropriate and completed in a timely manner (Figure 4.2).

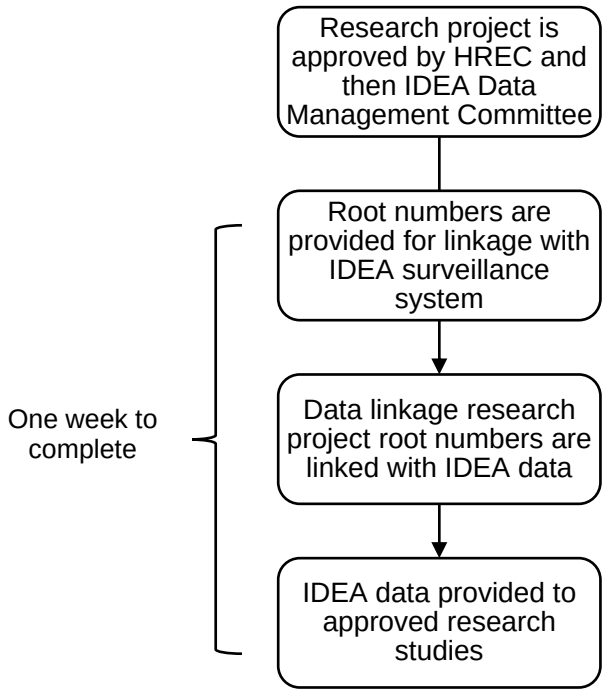

Figure 4.2 Internal data linkage process for IDEA surveillance data

4.5.4 Flexibility

The IDEA system was relatively flexible to changes in personnel and case definitions. Personnel and process changes have occurred at all stages within the data process, with the exception of the TKI team. The TKI team has largely remained the same since the inception of the system in 2002. As a result the process of data linkage and extraction from the larger dataset received from Department of Health to the TKI team has not been documented to date. Although having a consistent team has created a system that is flexible and stable, as part of good practice and sustainability, developing formalised documented processes would be valuable. Case definitions have also varied with changes in how the Department of Education have recorded ID. These changes have been recorded and the system adapted accordingly for data integrity.

4.5.5 Data quality

There was universal agreement that the system was not complete for ID in WA with children attending Catholic or independent schools and individuals who were not receiving services from DSC likely to be missing from the system. In addition since

mid-2014, individuals living in the Perth Hills region who were part of the NDIS pilot location had their data collected by the Australian Commonwealth government rather than the DSC WA.(17) Therefore there will be no data available on newly registered individuals with ID from this location at the next IDEA update.

Data quality is the responsibility of the two departments that assess individuals for ID. Each department has their own assessments for ID, reasons for collecting ID and ways in which the information is used. Ensuring data quality across organisations and that individuals with ID are correctly identified was seen as important for all people involved in collecting and using data.

We also assessed the completeness for individuals in the IDEA surveillance system to a sub-group of individuals, cerebral palsy with ID, from the mandatory reporting surveillance system WARDA-CP. Overall there were 10593 cases of ID in the IDEA system. 582 individuals were identified in the WARDA-CP surveillance system as having cerebral palsy and ID. Of those identified 501 (86.1%) were also in the IDEA system and 81 (13.9%) were not. In total 0.7% of cases (81/10674) with ID were not identified in the IDEA system. Potential reasons for the discrepancies between the two sources were children who had died prior to school entry may not be identified in IDEA (n=8) and that WARDA may be including cases with probable or borderline ID who would not be eligible for IDEA. It should also be noted that even though there was <1% of total cases missing when IDEA was compared to WARDA-CP, the latter database only represents 5.4% (582/10674) of the total cases and there was a total discrepancy of 13.9% of cases missing. Therefore, there is still some discrepancy between missing cases and the two databases. There were little differences in Indigenous status, sex and place of residence for cases not identified in the IDEA system (Table 4.4).

Table 4.4 Comparison of IDEA and WARDA-CP surveillance system data, 1982-2014

Variable	Total in WARDA-CP (n) %	Not in IDEA system (n) %	In both surveillance systems n (%)
Total	582	81 (13.9%)	501 (86.1%)
Alive	470 (80.8%)	69 (85.2%)	401 (80.0%)
Deceased	112 (19.2%)	12 (14.8%)	100 (20.0 %)
Indigenous status			
Indigenous	80 (13.7%)	15 (18.5%)	65 (13.0%)
Non-Indigenous	502 (86.3%)	66 (81.5%)	436 (87.0%)
Sex			
Male	346 (59.5%)	49 (60.5%)	297 (59.3%)
Female	236 (40.5%)	32 (39.5%)	204 (40.7%)
Location			
Metropolitan	363 (62.4%)	52(64.2%)	311 (62.1%)
Inner and outer regional areas	95 (16.3%)	10 (12.3%)	85 (17.0%)
Remote and very remote areas	53 (9.1%)	6 (7.4%)	47 (9.4%)
Missing	71 (12.2%)	13 (16.0%)	58 (11.6%)

4.5.6 Acceptability

There are four organisations (Telethon Kids Institute, Department of Health WA, DSC, Department of Education) within WA that voluntarily participate in the IDEA surveillance system. Unlike other surveillance systems there are no mandatory requirements for case notification and therefore no onus on clinicians and other public health practitioners to participate. The two departments which supply data for the IDEA system do so voluntarily and deem the collection of data to be important. Memoranda of understanding have been signed by DSC and Education with the Department of Health for the release of data. In addition, there is an agreement between Telethon Kids Institute and Department of Education outlining the provision of education data to IDEA and a Grant Agreement between Telethon Kids Institute and DSC.

4.5.7 Representativeness

ID data within the IDEA surveillance system is dependent on individuals being referred (by clinicians, psychologists, allied health, teachers or parents) for services and/or being identified through the public education system. Since the IDEA system does not have mandatory notifications, it is not surprising that there are certain subgroups of individuals who may not be represented. Despite this, there is no other equivalent system elsewhere in Australia and these data have been used as a key data source

for ID national estimates.(18) As a result the epidemiology findings are considered generalisable to the larger Australian population.

4.5.8 Timeliness

Overall the timeliness of the data was considered to be appropriate including the two year period between data extractions. The initial nine months for the data linkage process has previously been delayed through new staff having to extract the data from the two departments, resource limitations and priority delays within the departments. These barriers have resulted in delays at all stages of the nine month data extraction. It was also discussed that some of these time delays were the result of ensuring confidentiality, however, this is an important component of the system. Alternatively, it was mentioned that if individuals, organisations and policymakers valued the data then more frequent data extractions could occur.

4.5.9 Stability

Despite being a non-mandatory surveillance system, data has been regularly provided by departments and there has been ongoing funding negotiated. The funding provided has allowed for a 0.5 FTE position which supports personnel and operating costs. However, in-kind support from the TKI Disability team has also supported these activities and the day to day administrative tasks. The limited funding for the database has also restricted the amount of work that can be achieved within the IDEA system. Additional activities could include engaging with stakeholders, translation and communication of findings, use of IDEA data for supporting policy decisions and priority setting. It was estimated by those working directly with the system that 1.5FTE would be enough to complete the technical requirements of the IDEA surveillance system and be able to complete the additional tasks outlined.

4.6 Discussion

The IDEA system is the only Australian population-based ID surveillance system and one of few internationally.(19-21) Since 2002, the IDEA system has been successfully

funded and maintained by long-term collaborations with two WA departments. This has provided an infrastructure to understand prevalence rates and trends over time for ID, inform resource allocation, identify those at risk of negligence or other adverse events, identify risk and protective factors associated with ID and inform larger international studies on the global burden of disability.(1, 16, 22-25) Overall, the IDEA system was considered to be flexible, simple, acceptable, representative, timely and stable. However, components within these attributes such as insufficient engagement with stakeholders and community, lack of opportunities for translation and ensuring there is a workforce to deliver these initiatives could be improved.

Due to the IDEA system's data linkage capabilities, data from health, justice and child protection can be linked to determine important and complex associations both cross-sectionally and longitudinally for people living with intellectual disabilities. These data continue to provide important policy and program relevant implications and findings (Table 4.5). For example, the use of high quality administrative data has been used internationally to show the increased mortality rates due to potentially preventable conditions for people living with an ID compared to those without ID.(26, 27) Using the IDEA system it has also been demonstrated that this issue exists and needs to be addressed in WA.(28) It has highlighted the prevalence ID in WA has risen over the last 10 years from 14.3/1000 (births 1983-1992) to 17.0/1000 (births 1983-2005), representing an overall increase in prevalence of 19% from 1999 to 2010.(22) The use of high quality data is fundamental in dealing with the challenging health and social issues of people living with IDs, with the IDEA system addressing this need.

Table 4.5 Examples of policy and program relevant findings for people living with an intellectual disability

Program type	Important findings
Antenatal care	• Improved management of women with diabetes, epilepsy and/or anaemia during the antenatal period to reduce the risk of having a child with intellectual disabilities.(29) • Importance of monitoring maternal health due to poor fetal growth increasing the risk of intellectual disability.(30) • Health promotion and public health campaigns to prevent the use of alcohol during pregnancy.(31)
Service delivery	• Children with intellectual disability are also more likely to have birth defects resulting in increased health and social supports for children and additional services for families.(32) • The need for additional services and support for families in areas of social disadvantage who are at greater risk of having child with intellectual disability.(30) • Improved access, quality and coordination is needed for individuals with intellectual disability as they are more likely to experience potentially preventable conditions at the end of their lives.(28)

Many participants thought that sub-groups were missing within the IDEA system, however, this is likely to be a very small percentage of the population. Case ascertainment using the two Department resources is high with previous research showing that between 1983-2003 only 50% of cases were ascertained through the DSC Services, with the remaining 50% from the Department of Education.(33) In addition, when considering the quality and quantity of services provided, as seen in WA, using administrative data sources results in high ascertainment of cases and therefore sound reporting of prevalence rates.(34) When comparing whether the WARDA-CP system had any additional cases not in the IDEA system there was a small percentage of cases missing. This equated to <1% of total cases in the IDEA system and reflects the high quality data source. The IDEA system provides coverage of ID considerably superior to that from other administrative datasets such as the WA Hospital Morbidity Data System.(35) Overall, the completeness of the IDEA system was high when compared to potential missing population data.

A major concern and impetus for completing this evaluation is the roll-out of the NDIS. Pilot trials have been completed nationwide for the NDIS with individual states currently determining the finer details of how the scheme will work. A common perception of the scheme is that not all individuals will need to be assessed for their disability,

particularly ID, if they clearly meet the eligibility requirements. Although the collection of data may still occur at some level, it is possible that as a result of these changes, ascertainment of ID will no longer occur through DSC (now Department of Communities). Although it is difficult to determine how this situation can be resolved for the IDEA system, the community advisory group has substantial clinical, policy and research experience to determine how this could occur. It is recommended that the advisory group start discussing and planning these changes in the near future. The development of a mechanism to ascertain cases through the NDIS remains a pressing issue.

The IDEA surveillance system has provided important clinical data on the health and social needs of people living with ID. Despite this there are a number of areas that the IDEA team could undertake to strengthen the system. Based on this evaluation we recommend the following:

1. Discussion and engagement with the IDEA advisory group on how ID could be collected in the future given the changes in data ownership to the Australian Government.
2. The IDEA team has been involved in the system since its initiation in 2002. As a result there have been few protocols developed for how data are linked, extracted and maintained. It is recommended that internal protocols are developed for future personnel working on the system. An additional 1FTE is also recommended to support additional activities proposed in these recommendations.
3. Active engagement with community and relevant stakeholders including disability organisations, policy makers, researchers and service organisations is sorely needed to promote awareness of current research and to determine priority setting for future research. This can be achieved through the development of communication and translation strategies as well as priority setting workshops.

4. Currently the IDEA team uses the Heber classification for the level of disability. This is an outdated system with other classification systems more up to date with current practice. Determining whether there are other classification systems that could be used and if the data could be moved to this system would be beneficial.
5. An additional variable for functional ability was considered to be important for informing current practice. Enhanced surveillance on a sub-group of individuals could be considered. To determine whether these data are important and if so what data would be included should occur in consultation with stakeholders.
6. The community advisory group should consider meeting annually again. This increased level of active engagement and strategic planning could influence the current activities of IDEA and inform future directions. Leadership is needed and the community advisory group are well placed to take on this role.

4.7 Conclusion

The IDEA surveillance system provides crucial data about people living with ID. However, there remains significant challenges in the future of the IDEA system given recent funding and service delivery changes within Australia. Changes to engagement with the community and stakeholders could play an essential role in the sustainability of the IDEA system through advocacy for its continuation. Enhanced surveillance for functional capacity could also strengthen the system and provide important information for people living with ID and their families. The IDEA surveillance system is one of the few international ongoing data collections of ID. Discontinuing data collection and evaluation for this vulnerable population would be a disservice to society. Implementation of these recommendations will provide ways for the IDEA system to remain a successful source of important data for people living in with an ID.

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CHAPTER 5: UNDERSTANDING THE STRUCTURE AND PROCESSES OF CARE WITHIN PRIMARY HEALTH CARE FOR YOUNG INDIGENOUS CHILDREN

5.1 Prologue

5.1.1 My role

For the epidemiology project I:

- developed a data analysis plan that guided the analysis of the data
- made the appropriate changes to the data analysis plan based on feedback from co-authors
- created the master file for the cohort data and associated variables
- explored the data, completed the data analysis and interpreted the data
- drafted the first copy of the manuscript
- liaised with co-authors for feedback and comments, which led to changes I made to the manuscript.

5.1.2 Lessons learned

This was the first project I have worked on using primary health care audit data. I was able to learn how to use audit information including how to handle missing data, and how to create a master file to then generate new variables and recode. In particular, I learnt about using data to form indicators to assess the process of care delivered by organisations. This is first time I have combined variables to create indicators as a proxy for delivery of care. I would use this technique in the future studies as a way of determining whether comprehensive health care has been delivered. I also learnt about modelling proportions (‘glogit’ in STATA) and to query the output STATA gave. As I undertook the analysis, STATA was performing the analysis on some variables and dropping those that had a proportion of 0.00 and 1.00. Although I investigated why this was the case I was unable to determine why this was happening. As a result I decided

not to include this analysis in the chapter. My lesson was don't always believe the output and to check to make sure your output makes sense.

5.1.3 Public health implications

Anaemia in Aboriginal children, particularly in remote areas, has been a concern in primary health care centres. There has been an ongoing effort to improve anaemia in young Aboriginal children. Emphasis in recent years has been on secondary prevention through implementing CQI initiatives, health sector forums and community engagement to improve these rates. The results of this work highlight that elements of team structure and functioning including team leadership, defining roles and responsibilities, and building capacity as well as care planning which includes planning as part of routine practice, and consistency with best practice guidelines were shown to be positive in improving anaemia care in young Aboriginal children. These data provide evidence that the organisation of health services is associated with the prevention and management of anaemia for young Indigenous children.

5.1.4 Acknowledgements

I would like to acknowledge my co-authors and supervisors. Professor Karen Edmond (placement supervisor UNICEF), Professor Ross Bailie (University of Sydney), Drs Kimberley McAuley (UWA), Veronica Matthews (University of Sydnyy) and Dr Alice Richardson (primary supervisor ANU) who supported the conception and design of the evaluation. Drs Kimberley McAuley, Alice Richardson and Veronica Matthews supported the data analysis. Professor Karen Edmond, Professor Ross Bailie, Associate Dan McAullay (placement supervisor UWA), Drs Kimberley McAuley, Veronica Matthews, Jason Agostino and Alice Richardson all contributed intellectual input through comments and suggestions for improving the manuscript.

I would also like to thank the ABCD team, participating health services and CQI facilitators for the data collection for this project.

5.1.5 MAE core requirement

This chapter fulfils the design and conduct an epidemiological study component of the MAE. The chapter has been published in the Journal of Primary Health care which is provided in the Appendix C at the end of the thesis.

Citation: Strobel NA, McAuley K, Matthews V, Richardson A, Agostino J, Bailie R, et al. Understanding the structure and processes of primary health care for young indigenous children. J Prim Health Care. 2018;10(3):267-78.

5.2 Abstract

5.2.1 Introduction

Primary health care organisations need to continuously reform to more effectively address current health challenges, particularly for vulnerable populations. There is growing evidence that optimal health service structures are essential for producing positive outcomes.

5.2.2 Aim

To determine whether there was an association between process of care indicators (PoCIs) for important young Indigenous child health and social issues and i) primary health care service and child characteristics and ii) organisational health service structures.

5.2.3 Methods

This was a cross-sectional study of 1554 clinical child health audits and associated system assessments from 74 primary care services from 2012-2014. Composite PoCIs were developed for social and emotional wellbeing (SEWB), child neurodevelopment and anaemia. Crude and adjusted logistic regression models were fitted clustering for health services. Odds ratios and 95% confidence intervals were derived.

5.2.4 Results

Overall, 32.0% of records had a SEWB (449) PoCI, 56.6% (791) had an anaemia PoCI and 49.3% (430) had a child neurodevelopment PoCI. Children who were 12-23 months old were significantly more likely to receive all PoCIs compared to those aged 24-59 months. For every one point increase in assessment scores for team structure and function (aOR 1.14, 95% CI 1.01-1.27) and care planning (aOR1.14, 95% CI 1.01-1.29) items there was a 14% greater odds of a child having an anaemia PoCI. SEWB and child neurodevelopment PoCIs were not associated with system assessment scores.

5.2.5 Discussion

Ensuring young Indigenous children aged 24-59 months are receiving quality care for important social and health indicators is a priority. Processes of care and organisational systems within primary care services are important for the optimal management of anaemia in Indigenous children.

5.3 Introduction

Internationally the health and social wellbeing of young indigenous children are of major concern.(1) In Australia, young Aboriginal and/or Torres Strait Islander children (hereafter Indigenous) remain a high risk group for experiencing adverse health and social outcomes such as otitis media (2), child neurodevelopment (3), and birth outcomes (e.g. prematurity and low birth weight) (4) compared to non-Indigenous Australian children. Despite this, improvements in primary health care coupled with major policy and funding changes has resulted in an increase of important child health indicators including child health assessments and vaccination coverage.(4-7)

Primary health care plays an important role in the delivery of community and preventive health services. However, providing high quality care remains an ongoing challenge (8). Detailed measurement and evaluation of the quality of care delivered to Indigenous

children is needed to track and improve service delivery. This can be determined through understanding the relationship and interplay between the three categories of quality of care: structure (attributes and organisational structures which define a health system); processes (delivering and receiving care); and outcomes (the consequences or effect of care on health status).(9) It is expected that good structural systems will lead to good processes of care and ultimately improved outcomes.(9) As a result, it is important to objectively assess the relationship between these three categories and service delivery to children in real world situations.

The Assessment of Chronic Illness Care (ACIC) tool was developed to help health services understand the organisation of care within their systems, identify areas for improvement, and evaluate the level and nature of these changes for people living with a chronic disease (10). The ACIC team identified six areas of system change: delivery system design, self-management, clinical information systems, linkages to community resources, decision support, and organisation of the health system.(10) In 2005 the Audit and Best Practice for Chronic Disease (ABCD) program (a continuous quality improvement (CQI) program in Australia) modified the ACIC tool, added three items (cultural competence, laboratory management, and pharmacy management) and developed the Systems Assessment Tool (SAT).(11) The SAT has enabled Indigenous health services to assess their health care systems and improve the quality of care they provide.(11, 12)

To date the SAT tool has been used to assess the quality of care for diabetes and pregnancy.(11, 13, 14) However, the SAT tool has yet to be used to assess, on a broad scale, the quality of care delivered through organisation of care (structures) for Indigenous children and key process of care indicators (PoCIs) for important childhood health and social issues, in particular social and emotional wellbeing, anaemia and

child neurodevelopment. Therefore, the objectives of this study were to determine whether there was an association between social and emotional wellbeing (SEWB), anaemia and child neurodevelopment PoCIs and i) primary health care service and child characteristics, and ii) organisational health service structures. It was hypothesised that fully supported organisations, and structures within health services would result in increased improvement in processes of care for Indigenous children.

5.4 Methods

5.4.1 Study setting

This was a retrospective cross-sectional study of 1554 child health audits that included SAT data from 74 remote, rural and urban primary health care services that participated in the ABCD program in several Australian states and territories (Queensland, Northern Territory, South Australian and Western Australia) from 2012-2014. The most recent record for each child was included.

5.4.2 Data collection

5.4.2.1 ABCD audits

Annual child health audits from participating primary health care services were completed by primary care staff that had received training by ABCD educators.(15, 16) Files were required to meet the following criteria to be eligible for auditing: 1) child was aged between three months and 14 years at the audit date; 2) child was a resident in the community for at least six months (or half of the time since birth if aged under six months); and 3) child had no major health anomaly such as heart defects or inherited disorders.

A random sample of at least 30 files were selected for audit from each participating primary health care service. The sampling process included stratification of sex to ensure similar numbers. The auditors read each client file (electronic and paper) and

recorded information in a standardised pre-coded data collection tool. Child characteristics included: date of birth, age, sex, Indigenous status, attendance at the primary care centre in the previous 12 months, reason for the last attendance (acute care, health check, vaccination, other) and receipt of any child health checks in the last 12 months (Australian Commonwealth funded [Medicare 715] or other child health check). Health centre characteristics included governance (Aboriginal community controlled health service or government operated), location (urban, rural or remote), and number of CQI audits the primary care centre had completed. The auditors scored 'yes' in the audit tool if there had been any documentation in the client file in the last 12 months, 'no' if there was no documentation and 'not applicable' if a service was not recommended or scheduled within that jurisdiction.

The ABCD audit tool included eleven pre-coded items about SEWB services, seven on anaemia and six on child neurodevelopment. Descriptions of these items are provided in Table 5.1.

Table 5.1 Pre-coded items for social and emotional wellbeing, anaemia and child neurodevelopment based on national best practice guidelines and indicators that were common to all jurisdictions.

Social and emotional wellbeing
1. Assessment of parent-child interaction
2. Advice about domestic/social environment*
3. Advice about social/family support*
4. Advice about financial situation
5. Advice about housing condition*
6. Advice about food security
7. Advice about physical and mental stimulation of child*
8. Advice about child behaviour
9. Clinic follow up and/or referral for problems with domestic environment
10. Clinic follow up and/or referral for family and financial support
11. Clinic follow up and/or referral for housing condition or food security
Anaemia
1. Advice about breastfeeding (< 2 years)
2. Advice about nutrition*
3. Advice about food security
4. A record of haemoglobin at least once in the last 12 months*
5. If there is evidence of anaemia, is there a record of dietary/nutrition advice given
6. A record of prescription of iron supplement
7. A record of follow-up FBE or haemoglobin within 2 months
Child neurodevelopment
1. Assessment of developmental milestones*
2. Assessment of vision*
3. Assessment of hearing*
4. Assessment of parent-child interaction*
5. Advice about physical and mental stimulation of child*
6. Clinic follow up and/or referral regarding concerns about a finding of developmental delay

*Items included in their respective process of care indicator

5.4.2.2 SAT audit

The SAT (Table 5.2) included five components (delivery system design; information systems and decision support; self-management support; links with community, other health service and other services; and organisational influence and integration) with multiple items for each component. The SAT was self-completed within each primary health care service by staff and a trained CQI facilitator. Each item within a component was scored as 0-2 (limited), 3-5 (basic), 6-8 (good) and 9-11 (fully developed) by the health service. The tool included a brief description of each component and item to help health service staff decide on the existing support they have. The CQI facilitator helps health service staff reach an agreement about what best represents their health system. Each component score was calculated as the mean of the individual items. The overall organisation of the health system score was the mean of the four component scores. We did not include the self-management component of the SAT due to perceptions that this was of limited relevance to the study outcomes.

Table 5.2 Systems Assessment Tool

Component	Item for each component
Delivery system design	1. Team structure and function 2. Clinical leadership 3. Appointments and scheduling 4. Care Planning 5. Systematic approach to follow-up 6. Continuity of care 7. Client access/cultural competence 8. Physical infrastructure, supplies and equipment
Information systems and decision support	1. Maintenance and use of electronic client lists 2. Evidence based guidelines 3. Specialist-generalist collaborations
Links with community, other health services and other services	1. Communication and cooperation on governance and operation of the health centre and other community based organisations and programs 2. Linking health centre clients to outside resources 3. Working in the community 4. Communication and cooperation on regional health planning and development of health resources
Organisational influence and integration	1. Organisational commitment 2. Quality improvement strategies 3. Integration of health system components
Self-management support	1. Assessment and documentation 2. Self-management education and support, behaviour risk reduction and peer support

5.4.3 Definitions

We defined PoCIs as:

- social and emotional wellbeing using four items comprising of advice provided to parents or carers at least once in the last 12 months about: domestic environment, social support, housing condition and child stimulation for all children 3-59 months
- anaemia using two items comprising of advice provided at least once in the last 12 months on nutrition and haemoglobin documented in last 12 months for all children 6-59 months
- child neurodevelopment using five items comprising of assessment provided in the last 12 months for: parent-child interaction (<2 years), developmental milestones, vision and hearing for all children 3-59 months. Advice about physical and mental stimulation of the child was also included for all children 3-59 months.

PoCIs were developed using the Primary Clinical Care Manual for Queensland (17, 18), the Central Australian Rural Practitioners Association (CARPA) standard treatment manuals for Northern Territory and South Australia (19) and the Kimberley Aboriginal Medical Service guidelines (20, 21). The Medicare Benefits Schedule (MBS) 715 (child health check) (22) and the National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people (23) were also consulted in the development of the PoCIs. To develop the PoCIs there had to be commonality in individual items between jurisdictions. The PoCIs were dichotomised into a score of 'yes' if an audit record showed evidence that all items had been completed or 'no' if records were partially or not completed (Table 5.3).

Table 5.3 Indigenous children aged 3-59^ months receiving services and process of care indicators including denominators

	Number of primary health care services that included care in their protocols	Total number of audits assessed	Total number receiving
Assessment of SEWB care			
Advice about physical and mental stimulation of child	72/74 (97.3%)	1514/1554 (97.4%)	831/1514 (54.9%)
Advice about domestic/social environment	74 /74(100.0%)	1545/1554 (99.4%)	978/1545 (63.3%)
Advice about social/family support	73/74 (98.6%)	1436/1554 (92.4%)	867/1436 (60.4%)
Advice about housing condition	74 /74(100.0%)	1545/1554 (99.4%)	691/1545 (44.7%)
Composite measure of quality of care	71/74 (95.9%)	1405/1554 (90.4%)	449/1405 (32.0%)
Assessment of anaemia care			
Nutrition anticipatory guidance	74/74 (100.0%)	1545/1554 (99.4%)	1174/1545 (76.0%)
Haemoglobin documented in last 12 months	72/74 (97.3%)	1397/1554 (89.9%)	1012/1397 (72.4%)
Composite measure of quality of care	72/74 (97.3%)	1397/1554 (89.9%)	791/1397 (56.6%)
Assessment of Developmental Care			
Assessment of parent-child interaction	72/74 (97.3%)	1000/1554 (64.4%)	764/1000 (76.4%)
Assessment of developmental milestones	73/74 (98.6%)	1291/1554 (83.1%)	991/1291 (76.8%)
Assessment of vision	72/74 (97.3%)	1416/1554 (91.1%)	965/1416 (68.1%)
Assessment of hearing	74/74 (100.0%)	1497/1554 (96.3%)	1107/1497 (73.9%)
Advice about physical and mental stimulation of child	72/74 (97.3%)	1514/1554 (97.4%)	831/1514 (54.9%)
Composite measure of quality of care	70/74 (94.6%)	873/1554 (56.5%)	430/873 (49.3%)

^Anaemia composite measure completed on children aged 6-59

5.4.4 Statistical analysis

Descriptive statistics were calculated as count and percentages for all categorical data, and median and interquartile ranges (IQR, 75% percentile - 25% percentile) for continuous data. Data analyses were conducted using STATA 13.1.

5.4.4.1 PoCIs and child and primary health service characteristics

To examine the effect of primary health care service and child characteristics on the probability of having a PoCI, multilevel binomial models with an exchangeable correlation structure and robust standard errors were used. Adjusted logistic regression models were fitted using generalised estimating equations and the primary health care service as the clustering variable. Odds ratios and 95% confidence intervals (95% CI) were derived. Important explanatory variables were constructed *a priori* and included: sex, year of data collection, geographic location, governance, and CQI participation.

5.4.4.2 PoCIs and SAT components

To assess the association between SAT components and the three PoCIs, crude and adjusted logistic regression models were fitted using generalised estimating equations and the primary health care service as the clustering variable. Multilevel binomial models with an exchangeable correlation structure and robust standard errors were also constructed and odds ratios and 95% CIs were derived. Important explanatory variables were constructed *a priori* and included: year of data collection, geographical location, governance, CQI participation, the number of health areas SAT was related too.

5.4.5 Ethics approval

Ethics approval was obtained from all Human Research Ethics Committees (HRECs) in the states and territories involved: the Human Research Ethics Committee (HREC) of the Northern Territory Department of Health and Menzies School of Health Research (HREC-EC00153); Central Australian HREC (HREC-12-53); Queensland HREC Darling Downs Health Services District (HREC/11/QTDD/47); South Australian Indigenous Health Research Ethics Committee (04-10-319); Curtin University HREC (HR140/2008); Western Australian Country Health Services Research Ethics Committee (2011/27); Western Australian Aboriginal Health Ethics Committee (111-8/05); University of Western Australia HREC (RA/4/1/5051); and the Australian National University (2017/560).

5.5 Results

During 2012-2014, there were 1554 records audited from 74 primary health care services that completed the SAT (Table 5.4). The majority of health services were government run (94.6%, 70), serviced a population of < 500 people (58.1%, 43), located in remote locations (87.8%, 65) and had participated in three or more CQI cycles (73.0%, 54) (Table 5.4). 54.6% (848) of records audited were for children aged between 24-59 months.

Table 5.4 Key characteristics by audits and health care centres in Indigenous children aged 3-59 months

	Number of audits (n=1554)	Number of health services (n=74)
Health service characteristics		
Governance		
Aboriginal community controlled	105 (6.8%)	4 (5.4%)
Government	1449 (93.2%)	70 (94.6%)
Year of data collection		
2012	320 (20.6%)	15 (20.3%)
2013	902 (58.0%)	41 (55.4%)
2014	332 (21.4%)	18 (24.3%)
Population size		
<500	698 (44.9%)	43 (58.1%)
500-999	530 (34.1%)	17 (23.0%)
>=1000	326 (21.0%)	14 (18.9%)
Location		
Remote	1373 (88.4%)	65 (87.8%)
Rural	120 (7.7%)	6 (8.1%)
Urban	61 (3.9%)	3 (4.1%)
Continuous quality improvement participation (number of audits completed)		
1	293 (18.8%)	11 (14.9%)
2	194 (12.5%)	9 (12.2%)
≥3	1067 (68.7%)	54 (73.0%)
Systems assessment participation (number of assessments completed)		
1	439 (28.2%)	19 (25.7%)
2	94 (6.1%)	4 (5.4%)
≥3	1021 (65.7%)	51 (68.9%)
Health service provider who first saw the child		
Indigenous health worker	169 (10.9%)	N/A
Nurse	1128 (72.6%)	N/A
General practitioner	170 (10.9%)	N/A
Other	87 (5.6%)	N/A
Child characteristics		
Sex of child		
Male	797 (51.3%)	N/A
Female	757 (48.7%)	N/A
Age (months)		
3-11	368 (23.7%)	N/A
12-23	338 (21.8%)	N/A
24-59	848 (54.5%)	N/A
Type of child health check completed in the last 12 months		
Medical benefits schedule (MBS) 715	662 (42.6%)	N/A
Other child health check	439 (28.2%)	N/A
Not known / not recorded	453 (29.2%)	N/A
Reason for last clinic attendance		
Acute care	780 (50.2%)	N/A
Immunisation	212 (13.7%)	N/A
Child health check	361 (23.2%)	N/A
Other	201 (12.9%)	N/A

5.5.1 PoCIs and child and primary health service characteristics

Less than a third of records had a social and emotional wellbeing (32.0%, 449) PoCI, 56.6% (791) had an anaemia PoCI and just under half (49.3%, 430) had a child neurodevelopment PoCI (Table 5.5). Children aged 12-23 months had increased odds of receiving a PoCI for SEWB (aOR 1.35, 95% CI 1.01–1.49), anaemia (aOR 1.68, 95% CI 1.30-2.18) and child neurodevelopment (aOR 1.80, 95% CI 1.12–2.90) compared to children aged 24-59 months (Table 5.5). Children who received acute care were less likely to have a PoCI for SEWB (aOR 0.74, 95% CI 0.57–0.96),

anaemia (aOR 0.62, 95% CI 0.49-0.77) and child neurodevelopment (aOR 0.61, 95% CI 0.44–0.85) than those that received a child health check (Table 5.5).

5.5.2 PoCIs and SAT components

Two items within the delivery system design SAT component were significantly associated with the anaemia PoCI. For every one point increase in the team structure and function item there was a 14% greater odds of having an anaemia PoCI (aOR 1.14, 95% CI 1.01-1.27) (Table 5.6). A similar trend was shown for care planning where for every one point increase in the care planning item there was also 14% greater odds of having the anaemia PoCI (aOR1.14, 95% CI 1.01-1.29) (Table 5.6). Social and emotional well-being and child neurodevelopment PoCIs were not influenced by delivery systems design (Table 5.6). There was no association between information systems and decision support, links with community and other health and non-health services, or organisational influence and integration on any of the three PoCIs (Table 5.6).

For all three PoCIs there was little difference in the median and interquartile ranges for each system assessment item and component between those that received the PoCI and those that did not (Table 5.7).

Table 5.5 Associations between key characteristics and process of care indicators in Indigenous children aged 3-59^ months

	Social and emotional wellbeing				Anaemia				Neurodevelopment			
	Total audits n	**PoCIs received n (%)**	**aOR* 95% CI**	**P value**	**Total audits n**	**PoCIs received n (%)**	**aOR* 95% CI**	**P value**	**Total audits n**	**PoCIs received n (%)**	**aOR* 95% CI**	**P value**
Total	1405	449 (32.0%)			1397	791 (56.6%)			873	430 (49.3%)		
Health service characteristics												
Governance												
Aboriginal community controlled	105	32 (30.5%)	0.70 (0.23-2.13)	0.530	79	40 (50.6%)	0.87 (0.19-0.87)	0.853	66	33 (50.0%)	3.07 (0.91-10.3)	0.070
Government	1300	417 (32.1%)	1.00		1318	751 (57.0%)	1.00		807	397 (49.2%)	1.00	
Year of data collection												
2012	270	103 (38.1%)	1.00		257	161 (62.6%)	1.00		178	92 (51.7%)	1.00	
2013	814	220 (27.0%)	0.50 (0.26-1.00)	0.050	826	435 (52.7%)	0.58 (0.31-1.08)	0.087	541	269 (49.7%)	1.02 (0.50-2.10)	0.956
2014	321	126 (39.3%)	0.97 (0.42-2.26)	0.947	314	195 (62.1%)	0.96 (0.44-2.11)	0.925	154	69 (44.8%)	1.29 (0.51-3.29)	0.588
Population size												
<500	645	203 (31.5%)	1.00		656	341 (52.0%)	1.00		374	185 (49.5%)	1.00	
500-999	281	97 (34.5%)	1.33 (0.56-3.11)	0.517	293	169 (57.7%)	1.69 (0.81-3.56)	0.164	182	89 (48.9%)	1.13 (0.48-2.65)	0.780
>=1000	479	149 (31.1%)	1.32 (0.55-3.16)	0.527	448	281 (62.7%)	2.18 (1.24-3.84)	0.007	317	156 (49.2%)	1.46 (0.95-3.27)	0.360
Location												
Remote	1275	405 (31.8%)	1.00		1270	737 (58.0%)	1.00		779	396 (50.8%)	1.00	
Rural	100	29 (29.0%)	0.64 (0.19-2.12)	0.463	87	35 (40.2%)	0.37 (0.09-1.57)	0.179	70	23 (32.9%)	0.25 (0.06-1.03)	0.055
Urban	30	15 (50.0%)	3.47 (0.89-13.51)	0.073	40	19 (47.5%)	0.37 (0.54-2.47)	0.302	24	11 (45.8%)	0.32 (0.07-1.44)	0.136

CQI participation (number of audits completed)												
1	253	64 (25.3%)	1.00		245	132 (53.9%)	1.00		128	39 (30.5%)	1.00	
2	182	45 (24.7%)	0.98 (0.25-3.84)	0.980	176	84 (47.7%)	0.74 (0.26-2.06)	0.561	77	41 (53.2%)	2.33 (0.51-10.56)	0.273
≥3	970	340 (35.1%)	1.54 (0.50-4.73)	0.454	976	575 (58.9%)	1.33 (0.57-3.07)	0.509	668	350 (52.4%)	2.09 (0.68-6.38)	0.196
Systems Assessment participation (number of assessments completed)												
1	389	109 (28.0%)	1.00		382	206 (53.9%)	1.00		170	58 (34.1%)	1.00	
2	92	11 (12.0%)	0.25 (0.06-1.01)	0.052	84	31 (36.9%)	0.43 (0.17-1.13)	0.086	47	26 (55.3%)	1.12 (0.17-7.43)	0.905
≥3	924	329 (35.6%)	0.66 (0.12-3.63)	0.633	931	554 (59.5%)	1.16 (0.44-3.09)	0.764	656	346 (52.7%)	1.09 (0.15-7.72)	0.930
Health service provider who first saw the child												
Indigenous health worker	139	44 (31.7%)	0.88 (0.62-1.24)	0.460	136	59 (43.4%)	0.83 (0.59-1.16)	0.273	105	50 (47.6%)	0.74 (0.53-1.04)	0.080
Nurse	1039	335 (32.2%)	1.00		1030	604 (58.6%)	1.00		611	303 (49.6%)	1.00	
General practitioner	149	39 (26.2%)	0.71 (0.47-1.05)	0.088	152	80 (52.6%)	1.19 (0.79-1.78)	0.402	114	58 (50.9%)	1.16 (0.66-2.02)	0.600
Other	78	31 (39.7%)	1.31 (0.72-2.36)	0.375	79	48 (60.8%)	1.10 (0.61-1.98)	0.759	43	19 (44.2%)	0.96 (0.50-1.85)	0.913
Child characteristics												
Sex of child												
Male	723	238 (32.9%)	1.00		717	410 (57.2%)	1.00		461	227 (49.2%)	1.00	
Female	682	211 (30.9%)	0.92 (0.73-1.16)	0.484	680	381 (56.0%)	0.98 (0.80-1.19)	0.806	412	203 (49.3%)	0.94 (0.71-1.26)	0.690
Age (months)												
3-11	356	147 (41.3%)	2.07 (1.53-2.81)	<0.001	254	119 (46.9%)	0.60 (0.38-0.95)	0.028	258	155 (60.1%)	2.68 (1.69-4.25)	<0.001
12-23	331	107 (32.3%)	1.35 (1.01-1.79)	0.040	330	222 (67.3%)	1.68 (1.30-2.18)	<0.001	331	162 (48.9%)	1.80 (1.12-2.90)	0.015
24-59	718	195 (27.2%)	1.00		813	450 (55.4%)	1.00		284	113 (39.8%)	1.00	

Type of child health check completed in the last 12 months												
Medical benefits schedule (MBS 715)	626	261 (41.7%)	1.00		608	420 (69.1%)	1.00		384	241 (62.8%)	1.00	
Other child health check	382	102 (26.7%)	0.78 (0.51-1.18)	0.235	388	228 (58.8%)	0.97 (0.65-1.45)	0.889	267	134 (50.2%)	1.02 (0.66-1.59)	0.926
Not known / not recorded	397	86 (21.7%)	0.41 (0.30-0.58)	<0.001	401	143 (35.7%)	0.33 (0.24-0.46)	<0.001	222	55 (24.8%)	0.23 (0.15-0.35)	<0.001
Reason for last clinic attendance												
Acute care	721	218 (30.2%)	0.74 (0.57-0.96)	0.022	722	388 (53.7%)	0.62 (0.49-0.77)	<0.001	457	207 (45.3%)	0.61 (0.44-0.85)	0.003
Immunisation	176	47 (26.7%)	087 (0.61-1.24)	0.439	172	74 (43.0%)	0.56 (0.43-0.74)	<0.001	143	73 (51.0%)	0.78 (0.53-1.14)	0.197
Child health check	320	111 (34.7%)	1.00		320	204 (63.8%)	1.00		186	103 (55.4%)	1.00	
Other	188	73 (38.8%)	0.93 (0.73-1.16)	0.736	183	125 (68.3%)	0.84 (0.57-1.25)	0.395	87	47 (54.0%)	0.85 (0.52-1.41)	0.535

PoCIs (process of care indicators); aOR (adjusted odds ratio); CI (confidence interval); CQI (continuous quality improvements).
†Anaemia composite measure completed for children aged 6–59 months.
*Adjusted for sex, year of data collection, geographic location, governance, CQI participation.

Table 5.6 Association between delivery systems design and process of care indicators in Indigenous children aged 3-59^ months

	Social and emotional wellbeing (n=449/1405)*				Anaemia (n=791/1397)*				Neurodevelopment (430/873)*			
	OR (95% CI)	P value	aOR** (95% CI)	P value	OR (95% CI)	P value	aOR** (95% CI)	P value	OR (95% CI)	P value	aOR** (95% CI)	P value
Delivery systems design												
Team structure and function	1.04 (0.91-.18)	0.564	1.05 (0.91-.22)	0.516	1.12 (1.01-1.24)	0.026	1.14 (1.011.27)	0.028	0.98 (0.87-1.11)	0.788	1.00 (0.87-1.16)	0.965
Clinical leadership	1.01 (0.91-.13)	0.777	1.04 (0.92-.18)	0.499	1.02 (0.93-1.12)	0.725	1.04 (0.94-.15)	0.434	0.94 (0.85-1.04)	0.241	0.94 (0.84-1.05)	0.288
Appointments and scheduling	0.95 (0.86-.06)	0.356	0.94 (0.85-.05)	0.300	1.04 (0.94-1.15)	0.432	1.01 (0.92-.10)	0.830	1.01 (0.90-1.14)	0.843	0.98 (0.87-1.11)	0.758
Care Planning	0.96 (0.82-.12)	0.594	0.96 (0.82-0.13)	0.651	1.12 (0.98-1.27)	0.085	1.14 (1.01-.29)	0.034	0.97 (0.83-1.14)	0.725	0.97 (0.84-1.11)	0.613
Systematic approach to follow-up	1.01 (0.86-.16)	0.930	1.00 (0.86-1.17)	0.973	0.99 (0.88-1.12)	0.917	1.00 (0.88-.13)	0.997	1.02 (0.88-1.19)	0.762	1.01 (0.87-1.17)	0.922
Continuity of care	0.99 (0.88-.12)	0.891	0.98 (0.86-1.13)	0.795	1.01 (0.91-1.13)	0.821	0.99 (0.87-.12)	0.856	1.00 (0.89-1.12)	0.936	0.98 (0.86-1.12)	0.814
Client access/cultural competence	1.01 (0.89-0.16)	0.836	1.01 (0.89-1.16)	0.834	1.04 (0.94-1.16)	0.446	1.04 (0.94-.16)	0.440	1.02 (0.90-1.16)	0.738	1.02 (0.89-1.17)	0.776
Physical infrastructure, supplies and equipment	1.09 (0.96-1.24)	0.180	1.11 (0.98-1.26)	0.109	1.00 (0.90-1.12)	0.958	1.01 (0.91-.12)	0.807	0.94 (0.83-1.05)	0.268	0.95 (0.84-1.07)	0.363
Overall component	1.02 (0.87-1.19)	0.836	1.02 (0.86-1.23)	0.768	1.07 (0.93-1.24)	0.333	1.08 (0.92-.27)	0.345	0.97 (0.82-1.14)	0.714	0.96 (0.81-1.15)	0.667
Information systems and decision support												
Maintenance and use of electronic client lists	1.07 (0.92-1.25	0.388	1.07 (0.90-1.26)	0.437	1.06 (0.91-1.24)	0.456	1.04 (0.90-0.21)	0.579	1.02 (0.87-1.22)	0.752	0.99 (0.84-1.16)	0.863
Evidence based guidelines	1.04 (0.89-1.22)	0.616	1.03 (0.88-1.21)	0.733	1.12 (0.95-1.33)	0.169	1.09 (0.93-0.28)	0.304	0.98 (0.82-1.15)	0.773	0.90 (0.78-1.04)	0.163
Specialist-generalist collaborations	0.97 (0.86-1.10)	0.613	0.95 (0.84-1.07)	0.414	1.01 (0.90-1.14)	0.817	0.98 (0.88-1.09)	0.712	0.97 (0.85-1.12)	0.627	0.92 (0.82-1.07)	0.212
Overall component	1.02 (0.86-1.21)	0.815	1.00 (0.84-1.19)	0.981	1.08 (0.91-1.29)	0.391	1.03 (0.87-1.23)	0.694	0.98 (0.81-1.18)	0.829	0.91 (0.77-1.07)	0.242
Community, other health services and other services												
Communication and cooperation on governance and operation of the health centre and other community based organisations and programs	1.00 (0.88-1.15)	0.952	0.98 (0.85-1.13)	0.777	0.98 (0.89-1.08)	0.728	0.96 (0.87-1.06)	0.424	0.99 (0.86-1.14)	0.880	0.95 (0.83-1.10)	0.492
Linking health centre clients to outside resources	0.97 (0.88-1.08)	0.631	0.96 (0.86-1.07)	0.470	0.97 (0.88-1.07)	0.579	0.93 (0.84-1.03)	0.167	0.96 (0.85-1.08)	0.458	0.92 (0.82-1.04)	0.165

Working in the community	0.98 (0.89-1.08)	0.674	0.97 (0.88-1.08)	0.609	0.96 (0.87-1.06)	0.438	0.94 (0.85-1.04)	0.221	1.02 (0.91-1.14)	0.771	0.98 (0.87-1.11)	0.798
Communication and cooperation on regional health planning and development of health resources	1.02 (0.92-1.13)	0.766	1.0 (0.89-1.11)	0.969	1.00 (0.91-1.10)	0.986	0.96 (0.88-1.06)	0.449	1.02 (0.92-1.13)	0.736	0.98 (0.88-1.09)	0.678
Overall component	0.99 (0.87-1.12)	0.877	0.96 (0.85-1.11)	0.633	0.97 (0.86-1.08)	0.565	0.92 (0.82-1.04)	0.190	1.00 (0.86-1.16)	0.956	0.94 (0.81-1.09)	0.408
Organisational influence and integration												
Organisational commitment	0.97 (0.84-1.11)	0.637	0.96 (0.83-1.11)	0.565	1.01 (0.91-1.12)	0.873	0.99 (0.88-1.11)	0.877	0.92 (0.81-1.06)	0.258	0.90 (0.78-1.05)	0.172
Quality improvement strategies	1.06 (0.92-1.22)	0.446	1.08 (0.92-1.25)	0.355	1.03 (0.91-1.17)	0.655	1.05 (0.92-1.20)	0.462	0.92 (0.79-1.07)	0.295	0.89 (0.77-1.03)	0.124
Integration of health system components	1.00 (0.89-1.12)	0.949	0.98 (0.88-1.11)	0.793	1.06 (0.95-1.17)	0.285	1.03 (0.93-1.15)	0.516	0.94 (0.83-1.07)	0.345	0.91 (0.80-1.07)	0.163
Overall component	1.00 (0.87-1.16)	0.955	1.00 (0.86-1.16)	0.993	1.04 (0.92-1.19)	0.505	1.03 (0.90-1.18)	0.644	0.91 (0.78-1.06)	0.231	0.88 (0.75-1.02)	0.097

aOR = adjusted odds ratio
^Anaemia composite measure completed on children aged 6-59 months
*Number of children who received process of care indicators /total number who were assessed as having a process of care indicators
**Adjusted for year of data collection, geographical location, governance, CQI participation, number of health areas SAT was related too

Table 5.7 Median and interquartile range for each system assessment component and item by process of care indicators

	Social and emotional wellbeing (n=449/1405)		Anaemia (n=791/1397)		Neurodevelopment (n=430/873)	
	Received PoCI Median (IQR)	Did not receive PoCI Median (IQR)	Received PoCI Median (IQR)	Did not receive PoCI Median (IQR)	Received PoCI Median (IQR)	Did not receive PoCI Median (IQR)
Delivery system design						
Team structure and function	7.0 (6.0-9.0)	7.0 (6.0-8.0)	7.0 (6.0-9.0)	7.0 (5.0-8.0)	7.0 (5.0-9.0)	7.0 (6.0-9.0)
Clinical leadership	7.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)	7.0 (6.0-9.0)	8.0 (6.0-10.0)	8.0 (7.0-10.0)
Appointments and scheduling	8.0 (6.0-8.0)	8.0 (6.0-9.0)	8.0 (7.0-9.0)	8.0 (6.0-9.0)	8.0 (7.0-9.0)	8.0 (6.0-9.0)
Care Planning	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (7.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)
Systematic approach to follow-up	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)
Continuity of care	7.0 (6.0-8.0)	7.0 (5.0-8.0)	7.0 (5.0-8.0)	7.0 (5.0-8.0)	7.0 (6.0-8.0)	7.0 (5.0-9.0)
Client access/cultural competence	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-10.0)	8.0 (6.0-9.0)	8.0 (6.0-10.0)	8.0 (6.0-9.0)
Physical infrastructure, supplies and equipment	7.0 (6.0-8.0)	6.0 (5.0-8.0)	7.0 (5.0-9.0)	7.0 (5.0-8.0)	7.0 (5.0-8.0)	7.0 (5.0-9.0)
Overall component	7.0 (6.0-9.0)	8.0 (6.0-9.0)	7.0 (6.0-9.0)	7.0 (6.0-9.0)	7.0 (6.0-9.0)	8.0 (6.0-9.0)
Information systems and decision support						
Maintenance and use of electronic client lists	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)
Evidence based guidelines	9.0 (8.0-9.0)	9.0 (8.0-10.0)	9.0 (8.0-9.0)	9.0 (7.0-9.0)	8.0 (7.0-9.0)	9.0 (7.0-10.0)
Specialist-generalist collaborations	7.0 (6.0-8.0)	8.0 (6.0-9.0)	7.0 (6.0-8.0)	7.0 (5.0-9.0)	7.0 (5.0-8.0)	8.0 (6.0-9.0)
Overall component	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)
Community linkages						
Communication and cooperation on governance and operation of the health centre and other community based organisations and programs	5.0 (4.07-7.0)	5.0 (4.0-7.0)	5.0 (4.0-7.0)	5.0 (4.0-7.0)	5.0 (4.0-7.0)	5.0 (4.0-7.0)
Linking health centre clients to outside resources	6.0 (4.0-9.0)	7.0 (6.0-9.0)	6.0 (5.0-8.0)	6.0 (5.0-9.0)	6.0 (4.0-9.0)	6.0 (5.0-9.0)
Working in the community	6.0 (3.0-8.0)	6.0 (4.0-8.0)	6.0 (3.0-8.0)	6.0 (4.0-8.0)	7.0 (4.0-8.0)	6.0 (4.0-8.0)
Communication and cooperation on regional health planning and development of health resources	5.0 (2.0-7.0)	5.0 (3.0-7.0)	5.0 (2.0-7.0)	5.0 (3.0-7.0)	5.0 (3.0-7.0)	4.0 (2.0-7.0)
Overall component	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)
Organisational influence and integration						
Organisational commitment	6.0 (4.0-7.0)	6.0 (5.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-8.0)	6.0 (5.0-7.0)
Quality improvement strategies	8.0 (6.0-9.0)	8.0 (7.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (7.0-9.0)
Integration of health system components	7.0 (5.0-8.0)	7.0 (6.0-8.0)	7.0 (6.0-8.0)	7.0 (5.0-8.0)	7.0 (4.0-8.0)	7.0 (5.0-8.0)
Overall component	7.3 (5.7-8.0)	7.3 (6.0-8.0)	7.0 (6.0-8.0)	7.0 (6.0-8.0)	6.0 (5.0-8.0)	7.0 (6.0-8.0)

PoCI = Process of care indicator, IQR = Interquartile range

5.6 Discussion

There was wide variation on the delivery of PoCIs with 32.0% of children receiving PoCIs for social and emotional well-being, 56.6% for anaemia, and 49.3% for child neurodevelopment. Children who were aged 12-23 months old were more likely to receive the PoCIs than children aged 24-59 months. Contrary to our expectations, there was little association between an organisation's health structures and processes of care for SEWB and child neurodevelopment. However, we found that the delivery system design component which included items for team structure and function and care planning, were associated with the process of care provided for anaemia.

Based on the reporting of child health indicators, CQI has improved the delivery of many child health milestones and brief interventions over time.(4) As a result we anticipated that 50% of records would achieve our PoCIs. However, social and emotional well-being (32%) fell well short of this. In contrast, anaemia (60%) and child neurodevelopment (49%) reached the expected target. Our data also indicate that the provision of care varies greatly depending on the routine service provided.

There has been much concern in primary health care centres about the high levels of iron-deficiency anaemia in young Indigenous children.(24) Substantial emphasis in recent years on improving these rates in remote regions has included improving primary and secondary prevention through implementing CQI initiatives, health sector forums and community engagement. In our study, elements of team structure and functioning including team leadership, defining roles and responsibilities, and building capacity as well as care planning which includes planning as part of routine practice, and consistency with best practice guidelines were shown to be positive in improving

anaemia care. Capacity building with health service providers for anaemia care has fostered important changes within health services and provided quality care to children (25). Alternatively non-adherence to guidelines has resulted in poor management of children with anaemia.(26) In contrast there has been little focus on the more complex processes of care needed for social and emotional wellbeing and child neurodevelopment and this is reflected in the lower PoCIs that we reported for these two conditions.(27) The delivery of child neurodevelopment assessments has been shown to vary across primary health care services and researchers have recently called for more system-wide approach to improve the delivery, recording and monitoring.(28) There has been a recent emphasis on the importance of child neurodevelopment and the delivery of social and emotional services in family centred care practice. Thus it is expected that we will see improvements in the provision of care for these important areas in the coming years.(29, 30)

It is our understanding that this is the first study that has investigated the association between a standardised SAT assessment of quality of care and the processes of care delivered to Indigenous children within the primary health care setting. It has previously been shown that a health care system's organisational influence and integration was positively associated with the quality of care provided to adults for diabetes control (HbA1C), blood pressure and total cholesterol levels.(31) However, we found no association between the organisation of health systems and the provision of care for children as measured by our neurodevelopment and SEWB PoCIs. Almost 70% of the health services had completed at least three or more SAT cycles, thus this may have improved the organisation of all the health care systems in terms of these PoCIs over time. It is also possible that a number of other factors have resulted in this lack of association including lack of assessment of communication and patient-centred care

which were not included in our analysis and the potential for under-reporting in health records. Despite this processes of care and organisational systems within primary care services were shown to be important for the optimal management of anaemia in Indigenous children and should be enhanced.

There are several limitations to this study. Although guidance and facilitation was provided to local health centre staff and managers to complete the SAT, in practice they were largely completed by front line primary health care teams without direct standardised support. This is likely to influence how the tool was completed. We only included records as a 'yes' for a PoCI if all elements of our measures were documented. It was decided that the process of care delivered should be maximal and therefore include all elements documented. Although the PoCIs have not been validated, we believe this study has demonstrated an important use of them. In addition, we constructed them through ensuring that they were specific, measurable, attainable, relevant and trackable. It is also possible that for some levels of care, there was little or no documentation of this in the health care records.

This was a cross-sectional study and therefore we could only report associations and could not assess causality. The positive results seen in our analyses may be the result of type 1 error, however, given that our p values were not borderline and we have narrow confidence intervals we are confident in our analysis. Due to the voluntary nature of participation by primary health care services in this study, the findings are not necessarily generalisable to all primary health care services. Most of the health services were government run (94.6%), located in remote areas (87.8%) and serviced populations <500 (58.1%) people. This also limited the potential generalisability to

other health services in particular Aboriginal Community Controlled Health Organisations.

5.7 Conclusion

Our study found that organisational health service structures which included items for team structure and function and care planning, was associated with quality of anaemia care. This study provides evidence that organisation of health services is associated with the prevention and management of anaemia for young Indigenous children. In addition, our young Indigenous children aged 24-59 months are not receiving care for important social and health indicators. Child health checks are an important avenue to ensuring quality of care is provided.

5.8 References

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CHAPTER 6: LESSONS FROM THE FIELD

6.1 Prologue

6.1.1 My role and lessons learnt

As a core competency of the MAE, Lessons From the Field (LFF), provides an opportunity for scholars to teach their peers an aspect about epidemiology they have learnt during their MAE. The LFF I provided wasn't an example from my MAE but one from the previous year to my enrolment. I used this example in my LFF as it represents a mammoth learning curve for me including learning how to link different datasets, knowing your population so you complete the correct analysis and learning how to use STATA. There were so many different aspects to use for my MAE that my first draft of the LFF was very long. After whittling it down to a reasonable amount I decided that my LFF would be understanding your population for data analysis to know what analysis should be completed.

6.2 Understanding your population for data analysis

6.2.1 Learning objectives

The objectives of this LFF are to:

- understand when to use count data in your analysis
- understand when to use time at-risk data in your analysis
- develop knowledge about preterm infants

6.2.2 Background

You are an epidemiologist working in the Department of Health and have been handed a project that has been requested from the Board's of the major birthing hospital and children's hospital in the state. They are concerned that infants who are Aboriginal and

born prematurely (i.e. <37 weeks) are being admitted to hospital more than non-Aboriginal preterm infants in their first year of life (i.e. <12 months old). They would also like to know whether there are differences between important variables such as gender, geographic location, and socio-economic status so they can help families who may need additional support.

You have been provided with birth data for all infants born in 'The State' between 2014-2015 and all of their hospitalisation data to date. There are two datasets that you have been given to you with some explanation about the datasets:

- Midwives dataset – all birth variables including sex, date of birth, prematurity, birthweight, place of residence
- Hospital dataset – each line represents a hospital admission and includes date of admission, diagnosis and how the person is admitted ie through emergency department, between hospital transfer, aged care etc

Someone very nicely offered to merge the datasets and clean them for you (yay!). They have provided you with a excel data file and data dictionary for you to work from.

Note: Although there are many variables that you could work with you have only been provided with those relevant to the LFF. These data have been created therefore the results may differ from what you expect.

6.2.3 Task 1: Data analysis plan

Based on the information provided you thought it would be a good idea to do a data analysis plan. Fill in the sections in italics.

DATA ANALYSIS PLAN			
Reference No.	*N/A*	Study name	Natalie LFF_Preterm
Date of plan		Chief investigator	
Person conducting analysis		Telephone	*N/A*
Analysis team members			
Background to the study and analysis (Please use plain language)			
No need to do.			
Number study subjects	n=1050		
Study research questions	Are Aboriginal preterm infants more likely to be admitted to hospital in the first year of life compared to non-aboriginal infants? Are socio-economic status, sex and geographic location associated with the incidence of hospital admissions of preterm infants during the first year of life?		
Specific hypothesis under study	Aboriginal preterm infants have a greater incidence of being admitted to hospital in the first year of life compared to non-Aboriginal infants.		
Objectives	The primary objective is to determine the incidence of hospital admission between Aboriginal and non-Aboriginal preterm infants in the first year of life. Secondary objective is to assess incidence of hospital admission on other risk factors such as socio-economic status, sex and geographic location.		
Data details			
Study type	Prospective cohort design		
Data sets used	Midwives and Hospital datasets		
Analysis package	STATA		
Study population	All preterm babies born between 2014-2015 in the State		
Exposure variables	Based on the data provided: Aboriginal status, SES, geographic location and sex		
Outcome variables	All-cause hospitalisations in the first year of life		
Potential confounders	In the paper we adjusted for: Adjusted for Indigenous status, IRSD (Index of Relative Socio-Economic Disadvantage), maternal age, gravidity, gender of child, birth weight Prematurity as the exposure variable was not adjusted for birth weight due to collinearity.		
Data cleaning			
Already done for you and data dictionary provided.			
Descriptive and univariate analyses			
We will do this within the LFF.			
Multivariable analyses			
Statistical significance	p<0.05		

NOTE: Answers were provided after the LFF was finished

6.2.4 Task 2: Data exploring

You would now like to know the numbers and percentages of your cohort for the variables listed below. Please fill in Table 6.1 below.

Action: Import your excel file into Stata.

Stata code: See do file

Table 6.1 Socio demographic characteristics in the study population, 2010-2011

Characteristics	Total number of infants n (%) n = 1050	Number of Indigenous infants n(%) n = 118	Number of non-Indigenous infants n(%) n =932	OR 95% CI	P value
Child sex					
Male	457 (43.5)	52 (44.0)	405 (43.5)	1.03 (0.70-1.51)	0.899
Female	593 (56.5)	66 (56.0)	527 (56.6)	0.98 (0.66-1.43)	0.899
Socio-economic status					
Most disadvantaged	698 (66.48)	49 (41.5)	649 (69.6)	0.31 (0.21-0.46)	<0.001
Least disadvantaged	352 (33.5)	69 (58.5)	283 (30.4)	3.23 (2.18-4.78)	<0.001
Geographic location					
Urban	932 (88.8)	58 (49.2)	874 (93.8)	0.60 (0.04-0.10)	<0.001
Remote	118 (11.2)	60 (50.9)	58 (6.2)	15.59 (9.96-24.40)	<0.001

Describe the data in Table 6.1

Answer: There were twice as many disadvantaged infants (66.5%) compared to least disadvantaged infants (33.5%). In total, Indigenous preterm infants (41.5%) were less likely to be in the most disadvantaged areas compared to non-Indigenous infants (69.6%) (OR 0.31; 95% CI 0.21-0.46). Indigenous infants (58.5%) had 3.2 times higher odds (OR 3.23; 95% CI 2.18-4.78) of being in the least disadvantaged bracket compared to non-Indigenous infants (30.4%).

Of the total preterm infants, a higher proportion lived in urban areas (88.8%) compared to remote areas (11.2%). Indigenous infants were 94% less likely to live in urban areas compared to non-Indigenous infants (93.8%) (OR 0.06; 95% CI 0.04-0.1). Indigenous infants (50.9%) were 15.6 time more likely to live in remote areas compare non-

Indigenous preterm infants (6.2%) (OR 15.58 95% CI 9.96-24.4). Overall, there were slightly more female preterm infants (56.5%) than male preterm infants (43.5%). There was no association between Indigenous status and sex.

6.2.5 Task 3: logistic regression

After chatting to some people about the analysis someone suggests to you that you should do a logistic regression where the outcome is whether a preterm infant has had at least one hospitalisation in their first year of life. Your exposure variables are Indigenous status, socio-economic status, geographic location and child sex. Is this the right analysis to do? (tick the check box)

☒ Yes

☐ No

Why have you provided the answer above? If you answered 'no' what analysis would you do?

Answer: A logistic regression requires a binary outcome variable. Exposures variables can be categorical, binary or continuous. The data provided has a binary outcomes and binary exposure variables. Based on our objectives it would be appropriate to do a logistic regression.

However, as you go further through the LFF it will become clear that actually this type of regression isn't appropriate for our population.

6.2.6 Task 4: Preterm infants

Unlike other infants after birth, pre-term infants in their first year of life may have a normal birth length of stay in hospital which is considered zero number of days as the length of stay. Or they have a substantial length of stay which may be anything from 0-365 days. The length of time spent in hospital depends on their age of prematurity and

any arising complications. Knowing this extra information does this change your answer above? If so, how?

Answer: Yes. The time-at risk for each infant to have a hospitalisation will be different. Therefore we need to include this information in the regression. A more appropriate regression would be a count regression for the number of hospital admissions with the time-at-risk for hospital adimission included.

6.2.7 Task 5: Creating a new time at risk variable

After much deliberation you have decided that the best analysis is a count regression using the frequency of hospitalisation with person-days-at-risk as your denominator. Your at-risk period is the time a preterm infant has available in the first year of life after their initial birth hospitalisation to have a hospital presentation.

First you need to create a ‘time at risk’ variable. You know that infant’s time spent in hospital is the ‘blos’ (baby length of stay) variable. Create a new variable for the time at risk if the time at risk is the infants first year of life (<12 months). What is the stata code you used to create the variable? Note: name your new variable ‘blos_new’

Answers: gen blos_new=(365-blos)

2014 and 2015 were not leap years, therefore 365 days/year.

Action: Now fill in the first three columns in Table 6.2 below.

Stata code: See do file. There is no code provided for the third column. Do this on your own.

Table 6.2 Frequency of hospital utilisation in preterm infants post discharge from birth hospital to 11 months by socio demographic characteristics, 2010-2011

Characteristics	Events	Time at risk	(Events/Risk)*1000	unadjusted IRR (95% CI)	*p value*
Infant					
Indigenous status					
Indigenous	190	41994	4.53	1.36 (1.14-1.61)	<0.001
Non-Indigenous	1099	329756	3.33	1.00	
Child sex					
Male	511	161238	3.12	0.86 (0.76-0.97)	0.013
Female	778	210512	3.70	1.00	
Socio-economic status					
Most disadvantaged	819	247584	3.31	1.14 (1.01-1.30)	0.033
Least disadvantaged	470	124166	3.79	1.00	
Remoteness					
Urban	1122	329807	3.40	1.00	
Remote	167	41943	3.98	1.17(0.98-1.40)	0.087

6.2.8 Task 6: Determining goodness of fit

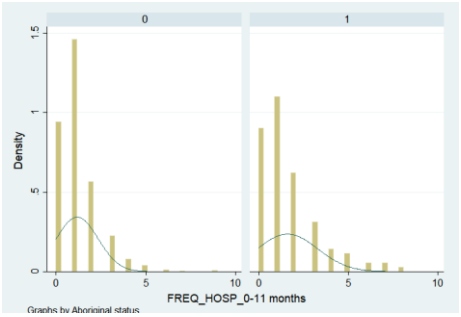
You are now ready to run your analysis but firstly you want to make sure the model is a good fit for your data. So you run the analysis you are most interested in which is how hospitalisations differ according to Indigenous status.

You run the following code:

hist FREQ_HOSP_011months , normal by(, legend(off)) by(Aboriginalstatus)

What do these histograms tell you?

Answer: The data is not normally distributed for Indigenous or non-Indigenous infants and is skewed to the right (positively skewed). This would indicate that Poisson regression is an appropriate regression for this data.



You decide to go ahead with a Poisson regression and run the following code

Code:

poisson FREQ_HOSP_011months i.Aboriginalstatus, exposure(blos_new) irr allbase
estat gof

What does this analysis tell you? What analysis should you do instead?

Answer: There is a highly significant lack of fit with the

Pearson goodness-of-fit = 1306.003

Prob > chi2 (1048) = 0.0000

This is because there is over-dispersion of the data most likely too many zeros. A quasi-poisson regression or a negative binomial regression would be best. For the paper we did negative binomial regression.

Complete the final analysis for Table 6.2 and add the results into the table. The code for the final analysis is in the do file.

What do the final results in tell you?

Answer: Indigenous preterm infants had a higher incidence of hospital admission (4.5/1000 person days) compared with non-Indigenous preterm infants (3.3/1000 person days, IRR 1.35, 95% CI 1.14 -161).

Male preterm infants had a lower incidence of hospital admission (3.1/1000 person days) compared with female preterm infants (3.7/1000 person days; IRR 0.86, 95% CI 0.76-0.97).

Preterm infants living in the most disadvantaged areas had an increased incidence of hospital admissions (3.3/1000 person days) compared with the most advantaged preterm infants (3.8/1000 person days; IRR 1.14, 95% CI 1.01-1.30)

There was no difference between remoteness and the incidence of hospital for preterm infants.

If you are interested the final publication is:

Strobel NA, Peter S, McAuley KE, McAullay DR, Marriott R, Edmond KM. Effect of socioeconomic disadvantage, remoteness and Indigenous status on hospital usage for Western Australian preterm infants under 12 months of age: a population-based data linkage study. BMJ Open. 2017;7(1):e013492.

See here for publication history and all the mistakes I made!:

http://bmjopen.bmj.com/content/7/1/e013492.info

6.3 Feedback and reflections

I developed a survey to which four MAE students people responded. Table 6.3 provides feedback on the lessons learnt by participants and feedback on how to improve my teaching lessons in the future. Although I reduced the LFF to what I thought was a manageable size it still appeared to still be too long. Next time I would consider starting easier and moving through a bit slower so that people would be able to spend more time understanding the basics without getting confused.

Table 6.3 Feedback about lesson's learnt and future improvements from the LFF

Lesson's learnt by participants
How to appropriately do a count regression and some of the obstacles that might come up.
Aside from performing count regression itself, I found the logical steps to arrive at which test was appropriate to be very helpful.
Many things, but one thing that stuck out was around confounders and that you really need to understand your dataset and that you wouldn't be able to adjust for a number of confounders as this data is just not available. Also that for retrospective or prospective designs, it's based on timing of data collection (good thing to remember!)
The purpose of using count data in analysis.
Future improvements
It took me longer than I expected but that was more likely due to my inexperience in the area.
The initial recoding was a bit confusing, and I suspect that may have contributed to some of the mistakes that people made later on in the interpretation of the regression outcomes.
Can't really think of anything. It was really good. It was a pretty complicated data analysis to get my head around!
I felt it may have been a tad long.

Overall, most people either agreed or strongly agreed that the LFF met its purpose or objectives, understood count regression and that they had a better understanding of how to complete a count regression (Figure 6.1).

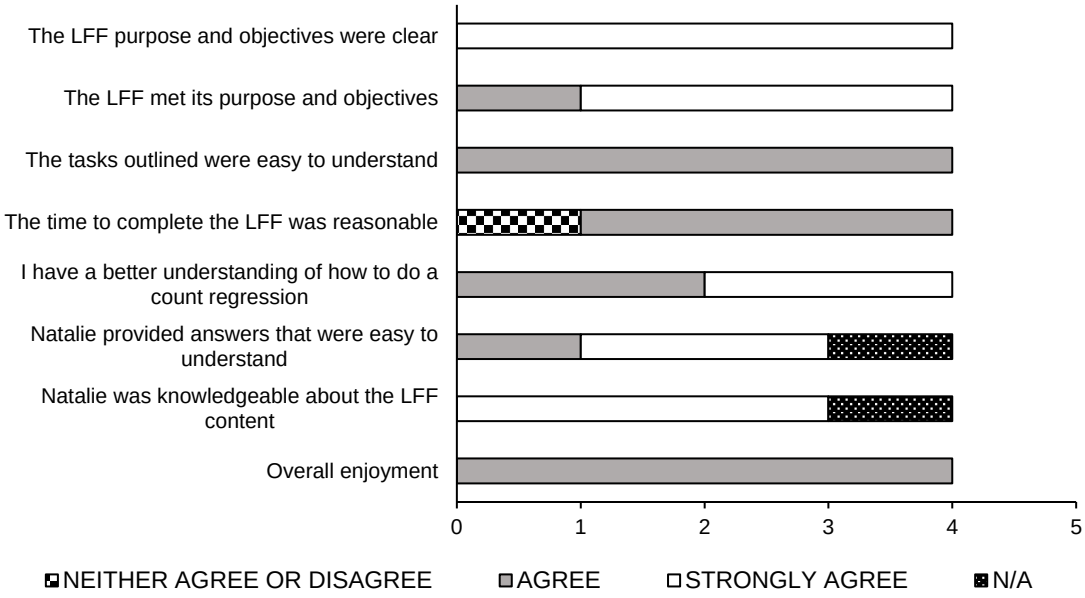


Figure 6.1 Overall feedback from the LFF

CHAPTER 7: APPENDICES

7.1 Appendix A

7.1.1 Abstract - Australian Epidemiology Conference 2018, Perth (Australia)

Factors influencing developmental vulnerability in Aboriginal and Torres Strait Islander children

Natalie Strobel, Alice Richardson, Kimberley McAuley, Carrington Shepherd, Karen Edmond, Rhonda Marriott, Dan McAullay

Background

The Australian Early Developmental Census (AEDC) provides a measure of early child health and development. Understanding the factors that influence child development among Aboriginal children is important to inform policy and practice.

Aim

To investigate risk factors that are associated with developmental vulnerability at school-entry among Western Australian (WA) Aboriginal children.

Method

This is a prospective population-based birth cohort study using linked datasets with information on cohort children, and their mothers and siblings. The 2009 and 2012 AEDC was used to assess developmental vulnerability in Aboriginal children born in WA across five domains of development. Adjusted logistic regression models used to determine salient risks.

Results

49.3% of Aboriginal children were vulnerable on at least one developmental domain and 30.4% were vulnerable on two or more. Children developmentally vulnerable on one or more domains were more likely to have at least one contact with child protection services compared to those with no contacts (aOR 1.47, 95% CI 1.21-1.78). Developmentally vulnerable children were also more likely to have a mother with at least one mental health admission compared to mothers with no admissions (aOR 1.51, 95% CI 1.28-1.78). Aboriginal children with at least one developmental vulnerability experienced a range of adverse health and social outcomes. Similar risks were evident for children with two or more vulnerabilities.

Conclusions

Many Aboriginal children in WA are entering school with at least one developmental vulnerability. Addressing child protection issues and supporting maternal mental health are important for improving the early development of young Aboriginal children.

7.1.2 Presentation - Australian Epidemiology Association 2018

FACTORS INFLUENCING DEVELOPMENTAL VULNERABILITY IN ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN

Natalie Strobel[1,2], Alice Richardson[2], Carrington Shepherd[3], Kimberley McAuley[1], Karen Edmond[4], Rhonda Marriott[5], Dan McAullay[1]

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[4]Unicef Afghanistan, Kabul, Afghanistan
[5]Murdoch University, Australia

AUSTRALIAN EARLY DEVELOPMENTAL CENSUS (AEDC)

- A developmental census that is conducted every three years, with data collected by teachers.
- Five developmental domains:
  - physical health and wellbeing
  - social competence
  - emotional maturity
  - Language and cognitive
  - Communication skills.

In our cohort of 2715 Western Australian Aboriginal children aged 5 years old who completed the 2009 or 2012 AEDC 49.3% of children had at least one developmental vulnerability and 30.4% had at least two developmental vulnerabilities.

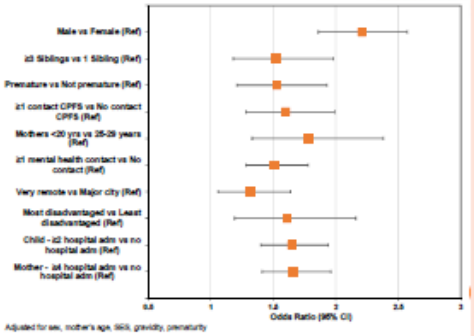
OBJECTIVES

- Our primary objective was to use latent class analysis (LCA) to model AEDC profiles and identify the highest risk profiles.
- Our secondary objective was to determine the impact of these high risk profiles on the likelihood of a child becoming developmentally vulnerable.

LATENT CLASS ANALYSIS – A PERSON CENTRED APPROACH

- Identifies patterns in individuals that may be experiencing similar combinations of risk or protective factors.
- Profiles can be ascertained that provide interpretable groups which can than be used to identify those at risk of a particular outcome.

At least one developmental vulnerability



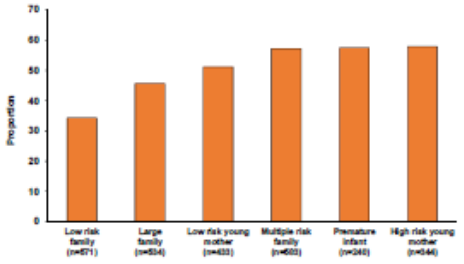
Latent class variables

Variable	No risk (coded 0)	Risk (coded 1)
Child sex	Female	Male
Prematurity	Not premature	<37 weeks gestational age
Birth weight	≥2500g weight	<2500g weight
APGAR 5 score	Healthy ≥7	Unhealthy <7
Contact with Child Protection	Not removed	Had contact or was removed
Siblings	0-2 Siblings	≥3 siblings
Disabled siblings	No disabled siblings	Disabled siblings
Maternal Age	≥20 years old	<20 years old
Gravidity	<3 pregnancies	≥3 pregnancies
Mental health contact	No mental health contact	At least one mental health contact
Geographic location (ARIA)	Major cities to remote	Very remote
Socio-economic status	2-5 ISRD	1 ISRD
Child hospitalisation	<2 hospitalisations	≥2 hospitalisations
Child emergency	<2 emergency presentations	≥2 emergency presentations
Mother hospitalisation	<4 hospitalisations	≥4 hospitalisations
Mother emergency	<2 emergency presentations	≥2 emergency presentations

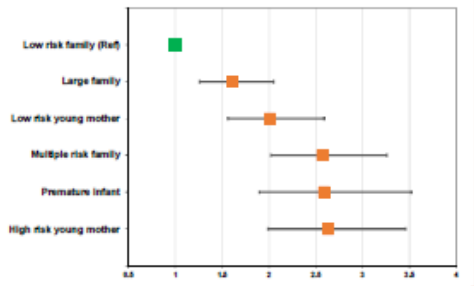
Conditional probabilities and distributions of risk

	Low risk family	Multiple risk family	Premature infant	High risk young mother	Low risk young mother	Large family
Male	0.532	0.505	0.418	0.451	0.558	0.456
Being premature	0.042	0.113	0.974	0.054	0.048	0.027
Being <2500g birthweight	0.000	0.059	0.911	0.115	0.047	0.023
Unhealthy APGAR <7	0.010	0.006	0.063	0.036	0.005	0.023
Child protection contact	0.001	0.472	0.338	0.483	0.152	0.103
≥3 siblings	0.000	0.881	0.406	0.115	0.243	0.764
Having disabled siblings	0.020	0.103	0.129	0.091	0.067	0.126
Teenage mother	0.267	0.011	0.223	0.878	0.476	0.007
Having ≥3 pregnancies	0.006	0.019	0.340	0.000	0.019	0.779
At least one mental health contact	0.129	0.699	0.519	1.000	0.186	0.201
Very remote location	0.494	0.697	0.564	0.709	0.815	0.541
Most disadvantaged quintile	0.190	0.257	0.241	0.396	0.173	0.165
Child - ≥2 hospitalisations	0.294	0.617	0.849	0.812	0.445	0.270
Child - ≥2 emergency presentations	0.831	0.963	0.901	0.915	0.976	0.799
Mother - ≥4 hospitalisations	0.126	0.945	0.700	0.795	0.717	0.203
Mother - ≥2 emergency presentations	0.819	0.990	0.896	0.974	1.000	0.697
			Class membership			
Probabilities	0.19	0.21	0.09	0.11	0.19	0.20
Standard error	0.02	0.02	0.01	0.02	0.02	0.02

Proportion of children who had at least one developmental vulnerability in each latent class



Association between class membership developmental vulnerability



Key messages

- This is the first study to identify important configurations of risk that were associated to early developmental vulnerabilities in Aboriginal children.
- Multiple risk family, High risk young mother and Premature infant comprised 49% of the cohort and were considered to have high risk configurations.
- These class were more than twice as likely to have children who had at least one developmental vulnerabilities compared to the Low risk family class.

Strengths and limitations

- Strengths
  - Large population based study with minimal missing data
  - We linked our cohort to their mothers and siblings
- Limitations
  - We did not include important social variables that are often available in survey data. As a result, we have not captured the full spectrum of stressors and protective factors a family may have.

Next steps

1. Preterm infants and transition of care
2. Explore why some young mothers remote area mothers are experiencing more risk than others

- Disclaimer - This presentation used data from the Australian Early Development Census. The AEDC is funded by the Australian Government Department of Education and Training. The findings and views reported are those of the author and should not be attributed to the Department or the Australian Government.
- Funding - This research is supported by an Australian Government Research Training Program (RTP) Scholarship. The funders had no role in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript.

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7.2 Appendix B

7.2.1 Abstract - 2018 International Population Data Linkage Network Conference, Banff (Canada)

Evaluation of the Western Australian population based data linkage Intellectual Disability Exploring Answers (IDEA) surveillance system

Natalie Strobel, Jenny Bourke Helen Leonard[3], Alice Richardson, Karen Edmond and Dan McAullay

Introduction (What is Known)

The IDEA surveillance system is a population-based data linkage system for intellectual disability, which combines data from two state government departments. Due to recent policy changes the future of the IDEA system is unknown. Understanding the IDEA system's strengths and limitations will provide data custodians with the opportunity to re-design the system.

Objectives and Approach

An evaluation of the IDEA surveillance system was undertaken to assess the quality, efficiency and usefulness of the system. The primary objectives were to evaluate systematically and objectively the attributes of the system and provide recommendations to data custodians and stakeholders to strengthen the surveillance system.

The evaluation was based on the methods from the 2001 U.S. Centers for Disease Control and Prevention guidelines on evaluation of public health surveillance systems. We assessed the following system attributes: usefulness, simplicity, flexibility, data quality, acceptability, representativeness, timeliness, and stability. This was completed by process observation, semi-structured interviews and data analysis.

Results

Our results found the IDEA system was flexible, acceptable, representative, timely and stable. Given data linkage process and maintaining confidentiality the data linkage process was considered relatively simple. We compared individuals in the IDEA surveillance system to a sub-group of individuals, cerebral palsy with ID, to the mandatory reporting surveillance system WARDA-CP. There were 582 individuals identified in the WARDA-CP surveillance system as having cerebral palsy and ID. Of those identified 501 (86.1%) were also in the IDEA database and 81 (13.9%) were not. There were little differences in Indigenous status, sex and place of residence for cases not identified in the IDEA system.

Conclusion/Implications

The IDEA system has successfully been used to understand prevalence rates, inform resource allocation, and identify those at risk of negligence or other adverse events for intellectual disability. Changes to engagement with community and stakeholders could play an essential role in the sustainability of the IDEA system. Additional variables or enhanced surveillance for functional capacity could also strengthen the system and provide important information for people living with ID and their families.

7.2.2 Presentation - 2018 International Population Data Linkage Network Conference

ISAC

EVALUATION OF THE WESTERN AUSTRALIAN POPULATION BASED INTELLECTUAL DISABILITY EXPLORING ANSWERS (IDEA) SURVEILLANCE SYSTEM

Natalie Strobel[1,2], Jenny Bourke[3], Helen Leonard[3], Alice Richardson[3], Karen Edmond[4] and Dan McAullay[1]

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[4]Unicef Afghanistan, Kabul, Afghanistan

The Context

- The Australian National Disability Insurance Scheme:
  - Provides support for Australians with disability, their families and carers
  - Takes a lifetime approach through investing in people with a disability early to improve outcomes later in life
  - Improves access to services and provides financial support

Aims and objectives

- Our overall aim was to evaluate the Western Australian 'Intellectual Disability Exploring Answers' (IDEA) surveillance system.
- The primary objective was to evaluate the attributes of the system.
- The secondary objective was to provide recommendations to data custodians and stakeholders to strengthen the system.

Methods

Attributes	Measure
Usefulness	How important is the collection of ID
Simplicity	Ease of understanding data processes
Flexibility	Ability of the system to adapt to changing needs
Data quality	Is the data complete?
Acceptability	The willingness of providers to participate in IDEA system processes
Representativeness	Generalisable to wider population
Timeliness	Speed of which data is provided at all stages
Stability	Whether resourcing is sufficient

Usefulness

- Data collection
  - Interviews using a 20-item semi-structured questionnaire
  - Representatives from the three WA government departments, health service providers, community representatives and researchers
- Analysis
  - Thematic analysis according to the system attributes was completed.

Data quality

- Data collection
  - Individuals born between 1982—2014 from the mandatory WA Registry of Developmental Anomalies-Cerebral Palsy database (WARDA-CP) who have ID and compared these data to the IDEA system
- Analysis
  - Cross-tabulations to determine the number of children from the WARDA-CP database that were not identified in the IDEA system.
  - Differences were explored

Usefulness 'the successes'

- Monitored trends and investigating changes in the prevalence of ID
- Provided an infrastructure for research into the health status and service needs of children and adults with ID
- Allowed the identification of population based subgroups with specific characteristics who might benefit from new scientific advances
- Increased professional knowledge about ID

The successes

- Journal publications, annual reports, stakeholder reports, reports for consumers or the public, policy briefs, government reports, newsletters, minister reports, book chapters and conferences.
- There have been over 40 journal publications with approximately 740 citations and 70 conference presentations between 2004-2017 that have used IDEA surveillance data.
- IDEA data have been widely used, cited and published in international literature including in international estimates of years lived with disabilities (2010).

Vos T, Flaxman AD, Naghavi M, Lozano R, Michaud C, Ezzati M, et al. Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380(9859):2163-96.

Examples of policy and program relevant findings for people living with an intellectual disability

Antenatal care

- Improved management of women with diabetes, epilepsy and/or anaemia during the antenatal period to reduce the risk of having a child with intellectual disabilities.[1]
- Importance of monitoring maternal health due to poor fetal growth increasing the risk of intellectual disability.[2]
- Health promotion and public health campaigns to prevent the use of alcohol during pregnancy.[3]

Service delivery

- Children with intellectual disability are also more likely to have birth defects resulting in increased health and social supports for children and additional services for families.[4]
- The need for additional services and support for families in areas of social disadvantage who are at greater risk of having child with intellectual disability.[2]
- Improved access, quality and coordination is needed for individuals with intellectual disability as they are more likely to experience potentially preventable conditions at the end of their lives.[5]

Usefulness 'Desired Improvements'

- Needs to be more publications, particularly consumer and policy-driven, as well as regular biannual reports
- Little in the way of communicating results to the community and advocacy organisations.
- Functional capacity was considered important information for ID.

Data Quality

- 582 individuals were identified in the WARDA-CP surveillance system as having cerebral palsy and ID.
- Of those identified 501 (86.1%) were also in the IDEA system and 81 (13.9%) were not.
- 10,593 cases of ID in the IDEA system.
- In total 0.7% of cases (81/10674) with ID were not identified in the IDEA system.

Comparison of IDEA and WARDA-CP surveillance system data, 1982-2014

Variable	Not in IDEA (n) %	In both systems n (%)
Total	81 (13.9%)	501 (86.1%)
Alive	69 (85.2%)	401 (80.0%)
Deceased	12 (14.8%)	100 (20.0 %)
Indigenous status		
Indigenous	15 (18.5%)	65 (13.0%)
Non-Indigenous	66 (81.5%)	436 (87.0%)
Sex		
Male	49 (60.5%)	297 (59.3%)
Female	32 (39.5%)	204 (40.7%)
Location		
Metropolitan	52(64.2%)	311 (62.1%)
Inner and outer regional areas	10 (12.3%)	85 (17.0%)
Remote and very remote areas	6 (7.4%)	47 (9.4%)
Missing	13 (16.0%)	58 (11.6%)

Results

- The IDEA system has been successfully funded and maintained by long-term collaborations with two WA departments.
- Using high-quality data is has provided an infrastructure to understand prevalence rates and trends over time for ID, inform resource allocation, identify those at risk of negligence or other adverse events, identify risk and protective factors associated with ID and inform larger international studies on the global burden of disability
- The IDEA system was considered to be flexible, simple, acceptable, representative, timely and stable.

What's needed

Discussion and engagement with the IDEA advisory group on how ID could be collected in the future given the changes in data ownership to the Australian Government.

Recommendations

- Changes to engagement with the community and stakeholders could play an essential role in the sustainability of the IDEA system through advocacy for its continuation.
- Enhanced surveillance for functional capacity could also strengthen the system and provide important information for people living with ID and their families.

- **Acknowledgements**

  We would like to acknowledge the time of our stakeholders in providing their thoughts on the IDEA system. We are very grateful to DSC and Department of Education for their ongoing support of the IDEA database.
- **Competing interests**

  Author JB is employed to work on the IDEA system. Author HL is the data custodian of the IDEA system.
- **Funding**

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7.2.3 Lay summary

The evaluation of The Intellectual Disability Exploring Answers (IDEA) surveillance system

INTELLECTUAL DISABILITY AND THE IDEA SYSTEM

People living with an intellectual disability have impaired thought processes, learning, communication, and remembering. They are a vulnerable group who are at risk of maltreatment as children, have more co-morbidities and mental health problems than people without an intellectual disability. The IDEA system is a unique resource that collects data on the number of people living with a severe intellectual disability in Western Australia.

WHY EVALUATE THE IDEA SYSTEM?

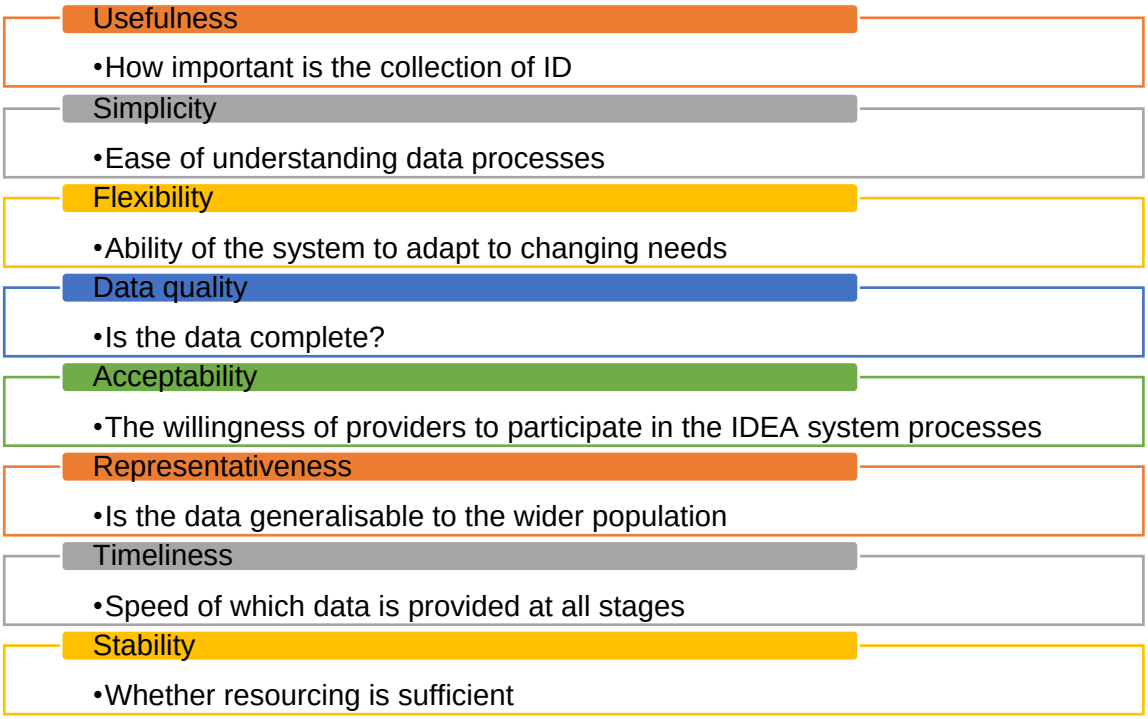
The new National Disability Insurance Scheme will help families and people living with an intellectual disability. However, data will now be collected by the Australian Government which means that data on intellectual disability will be missing in State Government data collections.

We wanted to know what the current strengths and limitations of the IDEA surveillance system. This way we could help stakeholders and data custodians understand how the system has been used and how important it is to maintain.

WHAT WE DID?

We interviewed stakeholders and looked at the data to determine whether the system was working well. We looked at eight different ‘attributes’ of the system (see below) to

see if the system was working well.



IDEA ACHIEVEMENTS

- There were journal publications, annual reports, stakeholder reports, reports for consumers or the public, policy briefs, government and minister reports, newsletters, book chapters and conferences abstracts.
- There have been over 40 journal publications with approximately 740 citations and 70 conference presentations between 2004-2017 that have used IDEA surveillance data.
- IDEA data have been widely used in the international literature including the international estimates of years lived with disabilities published in the high quality journal Lancet 2012.
- In total, the dataset was pretty complete with 0.7% of cases (81/10674) with ID were not identified in the IDEA system when compared to the WARDA-CP system.

IDEA IMPROVEMENTS

Data from the IDEA system has resulted in

- Develop communication and translation strategies to promote outcomes from IDEA data

- Increase engagement with community and relevant stakeholders to promote awareness of current research.
- Use stakeholders and community organisations to generate priority setting for future research

WHAT THIS MEANS?

The IDEA management team believe that discussion and engagement with the IDEA advisory group on how we can bridge the gap between Australian and Western Australian data collection is necessary.

Engagement between IDEA management team, stakeholders and community organisations is fundamental to the future of the IDEA system. Advocating for the continuation of the IDEA system can have real world impact on the lives of people living with intellectual disability and their families.

7.3 Appendix C

Journal publication for Chapter 5 is provided on the next page.

Citation: Strobel NA, McAuley K, Matthews V, Richardson A, Agostino J, Bailie R, et al. Understanding the structure and processes of primary health care for young indigenous children. J Prim Health Care. 2018;10(3):267-78.

Understanding the structure and processes of primary health care for young indigenous children

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ABSTRACT

INTRODUCTION: Primary health care organisations need to continuously reform to more effectively address current health challenges, particularly for vulnerable populations. There is growing evidence that optimal health service structures are essential for producing positive outcomes.

AIM: To determine if there is an association between process of care indicators (PoCIs) for important young indigenous child health and social issues and: (i) primary health-care service and child characteristics; and (ii) organisational health service structures.

METHODS: This was a cross-sectional study of 1554 clinical child health audits and associated system assessments from 74 primary care services from 2012 to 2014. Composite PoCIs were developed for social and emotional wellbeing, child neurodevelopment and anaemia. Crude and adjusted logistic regression models were fitted, clustering for health services. Odds ratios and 95% confidence intervals were derived.

RESULTS: Overall, 32.0% (449) of records had a social and emotional wellbeing PoCI, 56.6% (791) had an anaemia PoCI and 49.3% (430) had a child neurodevelopment PoCI. Children aged 12–23 months were significantly more likely to receive all PoCIs compared to children aged 24–59 months. For every one point increase in assessment scores for team structure and function (aOR 1.14, 95% CI 1.01–1.27) and care planning (aOR 1.14, 95% CI 1.01–1.29) items, there was a 14% greater odds of a child having an anaemia PoCI. Social and emotional wellbeing and child neurodevelopment PoCIs were not associated with system assessment scores.

DISCUSSION: Ensuring young indigenous children aged 24–59 months are receiving quality care for important social and health indicators is a priority. Processes of care and organisational systems in primary care services are important for the optimal management of anaemia in indigenous children.

KEYWORDS: Indigenous health; health services; health systems; paediatrics; epidemiology

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Introduction

Internationally, the health and social wellbeing of young indigenous children are of major concern.[1] In Australia, young Aboriginal and Torres Strait Islander children (hereafter 'indigenous') remain a high-risk group for experiencing adverse health and social outcomes such as otitis media,[2] child neurodevelopment delay[3] and birth outcomes such as prematurity and low birthweight[4] compared to non-indigenous Australian children. Despite this, improvements in primary health care, coupled with major policy and funding changes, has resulted in an increase of important

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WHAT GAP THIS FILLS

What is already known: Organisational health service structures have enabled primary health-care services to improve their quality of care for indigenous adult chronic disease management and maternal care; however, there is little information on how the organisation of health systems structures influences the processes of care for important health and wellbeing indicators for young indigenous children.

What this study adds: This research highlights that organisational health service structures are important for the delivery and management of anaemia for indigenous children. Primary health-care services should be supported in delivering social and emotional wellbeing, child neurodevelopment and anaemia care for children aged 25–59 months.

child health indicators including child health assessments and vaccination coverage.[4–7]

Primary health care plays an important role in the delivery of community and preventive health services. However, providing high-quality care remains an ongoing challenge.[8] Detailed measurement and evaluation of the quality of care delivered to indigenous children is needed to track and improve service delivery. This can be determined through understanding the relationship and interplay between the three categories of quality of care: structure (attributes and organisational structures that define a health system); processes (delivering and receiving care); and outcomes (the consequences or effect of care on health status).[9] Good structural systems are expected to lead to good processes of care and ultimately improved outcomes.[9] It is therefore important to objectively assess the relationship between these three categories and service delivery to children in real world situations.

The Assessment of Chronic Illness Care (ACIC) tool was developed to help health services understand the organisation of care within their systems, identify areas for improvement and evaluate the level and nature of these changes for people living with a chronic disease.[10] The ACIC team identified six areas of system change: delivery system design, self-management, clinical information systems, linkages to community resources, decision support, and organisation of the health system.[10] In 2005, the Audit and Best Practice for Chronic Disease (ABCD) programme (a continuous quality improvement (CQI) programme in Australia) modified the ACIC tool, added three items (cultural competence, laboratory management and pharmacy management) and developed the Systems Assessment Tool (SAT).[11] The SAT has enabled indigenous health services to assess their health-care systems and improve the quality of care they provide.[11,12]

To date, the SAT has been used to assess the quality of care for diabetes and pregnancy.[11,13,14] The SAT has yet to be used to assess on a broad scale the quality of care delivered through organisations of care (structures) for indigenous children and key process of care indicators (PoCIs) for important childhood health and social issues, in particular, social and emotional wellbeing, anaemia and child neurodevelopment. Therefore, the objectives of this study were to determine whether there was an association between social and emotional wellbeing, anaemia and child neurodevelopment PoCIs and: (i) primary health-care service and child characteristics; and (ii) organisational health service structures. It was hypothesised that fully supported organisations and structures within health services would result in increased improvement in processes of care for indigenous children.

Methods

Study setting

This was a retrospective cross-sectional study of 1554 child health audits that included SAT data from remote, rural and urban primary health-care services that participated in the ABCD programme in Queensland, Northern Territory, South Australia and Western Australia from 2012 to 2014. The most recent record for each child was included.

Data collection

ABCD audits

Annual child health audits from participating primary health-care services were completed by

primary care staff who had received training by ABCD educators.[15,16] Files had to meet the following criteria to be eligible for auditing: (1) child is aged 3 months to 14 years at the audit date; (2) child is a resident in the community for at least 6 months (or half of the time since birth if aged <6 months); and (3) child has no major health anomalies such as heart defects or inherited disorders.

A random sample of at least 30 files was selected for audit from each participating primary health-care service. The sampling process included stratification of sex to ensure similar numbers. The auditors read each client file (electronic and paper) and recorded information in a standardised pre-coded data collection tool. Child characteristics included: date of birth, age, sex, indigenous status, attendance at the primary care centre in the previous 12 months, reason for the last attendance (acute care, health check, vaccination, other) and receipt of any child health checks in the last 12 months (Australian Commonwealth funded [Medicare 715] or other child health check). Health centre characteristics included governance (Aboriginal community-controlled health service or government operated), location (urban, rural or remote) and number of CQI audits the primary care centre had completed. The auditors scored 'yes' in the audit tool if there had been any documentation in the client file in the last 12 months, 'no' if there was no documentation and 'not applicable' if a service was not recommended or scheduled within that jurisdiction.

The ABCD audit tool included 11 pre-coded items about social and emotional wellbeing services, seven on anaemia and six on child neurodevelopment. Descriptions of these items are provided in Supplementary material table 1 (available at journal's website).

SAT audit

The SAT (Supplementary material table 2) included five components (delivery system design; information systems and decision support; self-management support; links with community, other health service and other services; and organisational influence and integration), with multiple items for each

Table 1. Key characteristics of audits and health-care centres for indigenous children aged 3–59 months

	Number of audits (*n* = 1554)	Number of health services (*n* = 74)
Health service characteristics		
Governance		
Aboriginal community controlled	105 (6.8)	4 (5.4)
Government	1449 (93.2)	70 (94.6)
Year of data collection		
2012	320 (20.6)	15 (20.3)
2013	902 (58.0)	41 (55.4)
2014	332 (21.4)	18 (24.3)
Population size		
<500	698 (44.9)	43 (58.1)
500–999	530 (34.1)	17 (23.0)
≥1000	326 (21.0)	14 (18.9)
Location		
Remote	1373 (88.4)	65 (87.8)
Rural	120 (7.7)	6 (8.1)
Urban	61 (3.9)	3 (4.1)
Continuous quality improvement participation (number of audits completed)		
1	293 (18.8)	11 (14.9)
2	194 (12.5)	9 (12.2)
≥3	1067 (68.7)	54 (73.0)
Systems assessment participation (number of assessments completed)		
1	439 (28.2)	19 (25.7)
2	94 (6.1)	4 (5.4)
≥3	1021 (65.7)	51 (68.9)
Health service provider who first saw the child		
Indigenous health worker	169 (10.9)	N/A
Nurse	1128 (72.6)	N/A
General practitioner	170 (10.9)	N/A
Other	87 (5.6)	N/A
Child characteristics		
Sex of child		
Male	797 (51.3)	N/A
Female	757 (48.7)	N/A
Age (months)		
3–11	368 (23.7)	N/A
12–23	338 (21.7)	N/A
24–59	848 (54.6)	N/A
Type of child health check completed in the last 12 months		
Medical benefits schedule (MBS) 715	662 (42.6)	N/A
Other child health check	439 (28.2)	N/A
Not known / not recorded	453 (29.2)	N/A
Reason for last clinic attendance		
Acute care	780 (50.2)	N/A
Immunisation	212 (13.7)	N/A
Child health check	361 (23.2)	N/A
Other	201 (12.9)	N/A

Data are presented as *n* (%).
N/A (not applicable).

Table 2. Associations between key characteristics and process of care indicators in indigenous children aged 3–59† months

	Social and emotional wellbeing				Anaemia				Neurodevelopment			
	Total audits n	PoCIs received n (%)	aOR* 95% CI	P value	Total audits n	PoCIs received n (%)	aOR* 95% CI	P value	Total audits n	PoCIs received n (%)	aOR* 95% CI	P value
Total	1405	449 (32.0)			1397	791 (56.6)			873	430 (49.3)		
Health service characteristics												
Governance												
Aboriginal community controlled	105	32 (30.5)	0.70 (0.23–2.13)	0.530	79	40 (50.6)	0.87 (0.19–3.87)	0.853	66	33 (50.0)	3.07 (0.91–10.3)	0.070
Government	1300	417 (32.1)	1.00		1318	751 (57.0)	1.00		807	397 (49.2)	1.00	
Year of data collection												
2012	270	103 (38.1)	1.00		257	161 (62.6)	1.00		178	92 (51.7)	1.00	
2013	814	220 (27.0)	0.50 (0.26–1.00)	0.050	826	435 (52.7)	0.58 (0.31–1.08)	0.087	541	269 (49.7)	1.02 (0.50–2.10)	0.956
2014	321	126 (39.3)	0.97 (0.42–2.26)	0.947	314	195 (62.1)	0.96 (0.44–2.11)	0.925	154	69 (44.8)	1.29 (0.51–3.29)	0.588
Population size												
<500	645	203 (31.5)	1.00		656	341 (52.0)	1.00		374	185 (49.5)	1.00	
500–999	281	97 (34.5)	1.33 (0.56–3.11)	0.517	293	169 (57.7)	1.69 (0.81–3.56)	0.164	182	89 (48.9)	1.13 (0.48–2.65)	0.780
>=1000	479	149 (31.1)	1.32 (0.55–3.16)	0.527	448	281 (62.7)	2.18 (1.24–3.84)	0.007	317	156 (49.2)	1.46 (0.95–3.27)	0.360
Location												
Remote	1275	405 (31.8)	1.00		1270	737 (58.0)	1.00		779	396 (50.8)	1.00	
Rural	100	29 (29.0)	0.64 (0.19–2.12)	0.463	87	35 (40.2)	0.37 (0.09–1.57)	0.179	70	23 (32.9)	0.25 (0.06–1.03)	0.055
Urban	30	15 (50.0)	3.47 (0.89–13.51)	0.073	40	19 (47.5)	0.37 (0.54–2.47)	0.302	24	11 (45.8)	0.32 (0.07–1.44)	0.136
CQI participation (number of audits completed)												
1	253	64 (25.3)	1.00		245	132 (53.9)	1.00		128	39 (30.5)	1.00	
2	182	45 (24.7)	0.98 (0.25–3.84)	0.980	176	84 (47.7)	0.74 (0.26–2.06)	0.561	77	41 (53.2)	2.33 (0.51–10.56)	0.273
≥3	970	340 (35.1)	1.54 (0.50–4.73)	0.454	976	575 (58.9)	1.33 (0.57–3.07)	0.509	668	350 (52.4)	2.09 (0.68–6.38)	0.196
Systems Assessment participation (number of assessments completed)												
1	389	109 (28.0)	1.00		382	206 (53.9)	1.00		170	58 (34.1)	1.00	
2	92	11 (12.0)	0.25 (0.06–1.01)	0.052	84	31 (36.9)	0.43 (0.17–1.13)	0.086	47	26 (55.3)	1.12 (0.17–7.43)	0.905
≥3	924	329 (35.6)	0.66 (0.12–3.63)	0.633	931	554 (59.5)	1.16 (0.44–3.09)	0.764	656	346 (52.7)	1.09 (0.15–7.72)	0.930

Continued

	Social and emotional wellbeing				Anaemia				Neurodevelopment			
	Total audits n	PoCIs received n (%)	aOR* 95% CI	P value	Total audits n	PoCIs received n (%)	aOR* 95% CI	P value	Total audits n	PoCIs received n (%)	aOR* 95% CI	P value
Health service provider who first saw the child												
Indigenous health worker	139	44 (31.7)	0.88 (0.62–1.24)	0.460	136	59 (43.4)	0.83 (0.59–1.16)	0.273	105	50 (47.6)	0.74 (0.53–1.04)	0.080
Nurse	1039	335 (32.2)	1.00		1030	604 (58.6)	1.00		611	303 (49.6)	1.00	
General practitioner	149	39 (26.2)	0.71 (0.47–1.05)	0.088	152	80 (52.6)	1.19 (0.79–1.78)	0.402	114	58 (50.9)	1.16 (0.66–2.02)	0.600
Other	78	31 (39.7)	1.31 (0.72–2.36)	0.375	79	48 (60.8)	1.10 (0.61–1.98)	0.759	43	19 (44.2)	0.96 (0.50–1.85)	0.913
Child characteristics												
Sex of child												
Male	723	238 (32.9)	1.00		717	410 (57.2)	1.00		461	227 (49.2)	1.00	
Female	682	211 (30.9)	0.92 (0.73–1.16)	0.484	680	381 (56.0)	0.98 (0.80–1.19)	0.806	412	203 (49.3)	0.94 (0.71–1.26)	0.690
Age (months)												
3–11	356	147 (41.3)	2.07 (1.53–2.81)	<0.001	254	119 (46.9)	0.60 (0.38–0.95)	0.028	258	155 (60.1)	2.68 (1.69–4.25)	<0.001
12–23	331	107 (32.3)	1.35 (1.01–1.79)	0.040	330	222 (67.3)	1.68 (1.30–2.18)	<0.001	331	162 (48.9)	1.80 (1.12–2.90)	0.015
24–59	718	195 (27.2)	1.00		813	450 (55.4)	1.00		284	113 (39.8)	1.00	
Type of child health check completed in the last 12 months												
Medical benefits schedule (MBS 715)	626	261 (41.7)	1.00		608	420 (69.1)	1.00		384	241 (62.8)	1.00	
Other child health check	382	102 (26.7)	0.78 (0.51–1.18)	0.235	388	228 (58.8)	0.97 (0.65–1.45)	0.889	267	134 (50.2)	1.02 (0.66–1.59)	0.926
Not known / not recorded	397	86 (21.7)	0.41 (0.30–0.58)	<0.001	401	143 (35.7)	0.33 (0.24–0.46)	<0.001	222	55 (24.8)	0.23 (0.15–0.35)	<0.001
Reason for last clinic attendance												
Acute care	721	218 (30.2)	0.74 (0.57–0.96)	0.022	722	388 (53.7)	0.62 (0.49–0.77)	<0.001	457	207 (45.3)	0.61 (0.44–0.85)	0.003
Immunisation	176	47 (26.7)	0.87 (0.61–1.24)	0.439	172	74 (43.0)	0.56 (0.43–0.74)	<0.001	143	73 (51.0)	0.78 (0.53–1.14)	0.197
Child health check	320	111 (34.7)	1.00		320	204 (63.8)	1.00		186	103 (55.4)	1.00	
Other	188	73 (38.8)	0.93 (0.73–1.16)	0.736	183	125 (68.3)	0.84 (0.57–1.25)	0.395	87	47 (54.0)	0.85 (0.52–1.41)	0.535

PoCIs (process of care indicators); aOR (adjusted odds ratio); CI (confidence interval); CQI (continuous quality improvements).

† Anaemia composite measure completed for children aged 6–59 months.

* Adjusted for sex, year of data collection, geographic location, governance, CQI participation.

component. The SAT was self-completed in each primary health-care service by staff and a trained CQI facilitator. Each item within a component was scored as 0–2 (limited), 3–5 (basic), 6–8 (good) and 9–11 (fully developed) by the health service. The tool included a brief description of each component and item to help health service staff decide on their existing support. The CQI facilitator helps health service staff reach agreement about what best represents their health system. Each component score was calculated as the mean of the individual items. The overall organisation of the health system score was the mean of the four component scores. We did not include the self-management component of the SAT due to perceptions that this was of limited relevance to the study outcomes.

Definitions

We defined PoCIs as:

Social and emotional wellbeing: using four items comprising advice provided to parents or carers at least once in the last 12 months about: domestic environment, social support, housing condition and child stimulation for all children aged 3–59 months.

Anaemia: using two items comprising advice provided at least once in the last 12 months about nutrition and haemoglobin, documented in the last 12 months for all children aged 6–59 months.

Child neurodevelopment: using five items comprising assessment provided in the last 12 months for parent–child interaction (<2 years), developmental milestones, vision and hearing testing for all children aged 3–59 months. Advice about physical and mental stimulation of the child was also included for all children aged 3–59 months.

The PoCIs were developed using the Primary Clinical Care Manual for Queensland,[17,18] the Central Australian Rural Practitioners Association (CARPA) standard treatment manuals for Northern Territory and South Australia[19] and the Kimberley Aboriginal Medical Service guidelines.[20,21] The Medicare Benefits Schedule (MBS) child health check[22] and the National guide to a preventive health assessment for Aboriginal and Torres Strait Islander people[23] were also consulted in the development of the PoCIs. To develop the PoCIs, there had to be commonality in individual items between jurisdictions. The PoCIs were dichotomised into a score of 'yes' if an audit record showed evidence that all items had been completed or 'no' if records were partially or not completed (Supplementary material table 3).

Statistical analysis

Descriptive statistics were calculated as counts and percentages for all categorical data, and median and interquartile ranges (IQR, 75% percentile – 25% percentile) for continuous data. Data analyses were conducted using STATA 13.1 (StataCorp, College Station, TX, USA).

PoCIs and child and primary health service characteristics

To examine the effect of primary health-care service and child characteristics on the probability of having a PoCI, multilevel binomial models with an exchangeable correlation structure and robust standard errors were used. Adjusted logistic regression models were fitted using generalised estimating equations and the primary health-care service as the clustering variable. Odds ratios and 95% confidence intervals (95% CI) were derived. Important explanatory variables were constructed *a priori* and included: sex, year of data collection, geographic location, governance and CQI participation.

PoCIs and SAT components

To assess associations between SAT components and the three PoCIs, crude and adjusted logistic regression models were fitted using generalised estimating equations and the primary health-care service as the clustering variable. Multilevel binomial models with an exchangeable correlation structure and robust standard errors were also constructed, and odds ratios and 95% CIs were derived. Important explanatory variables were constructed *a priori* and included: year of data collection, geographical location, governance, CQI participation and the number of health areas SAT was related to.

Table 3. Association between delivery systems design and process of care indicators in indigenous children aged 3–59† months

	Social and emotional wellbeing (*n* = 449/1405)*				Anaemia (*n* = 791/1397)*				Neurodevelopment (*n* = 430/873)*			
	OR (95% CI)	*P*- value	aOR‡ (95% CI)	*P*- value	OR (95% CI)	*P*- value	aOR‡ (95% CI)	*P*- value	OR (95% CI)	*P*- value	aOR‡ (95% CI)	*P*- value
Team structure and function	1.04 (0.91–1.18)	0.564	1.05 (0.91–1.22)	0.516	1.12 (1.01–1.24)	0.026	1.14 (1.01–1.27)	0.028	0.98 (0.87–1.11)	0.788	1.00 (0.87–1.16)	0.965
Clinical leadership	1.01 (0.91–1.13)	0.777	1.04 (0.92–1.18)	0.499	1.02 (0.93–1.12)	0.725	1.04 (0.94–1.15)	0.434	0.94 (0.85–1.04)	0.241	0.94 (0.84–1.05)	0.288
Appointments and scheduling	0.95 (0.86–1.06)	0.356	0.94 (0.85–1.05)	0.300	1.04 (0.94–1.15)	0.432	1.01 (0.92–1.10)	0.830	1.01 (0.90–1.14)	0.843	0.98 (0.87–1.11)	0.758
Care planning	0.96 (0.82–1.12)	0.594	0.96 (0.82–1.13)	0.651	1.12 (0.98–1.27)	0.085	1.14 (1.01–1.29)	0.034	0.97 (0.83–1.14)	0.725	0.97 (0.84–1.11)	0.613
Systematic approach to follow up	1.01 (0.86–1.16)	0.930	1.00 (0.86–1.17)	0.973	0.99 (0.88–1.12)	0.917	1.00 (0.88–1.13)	0.997	1.02 (0.88–1.19)	0.762	1.01 (0.87–1.17)	0.922
Continuity of care	0.99 (0.88–1.12)	0.891	0.98 (0.86–1.13)	0.795	1.01 (0.91–1.13)	0.821	0.99 (0.87–1.12)	0.856	1.00 (0.89–1.12)	0.936	0.98 (0.86–1.12)	0.814
Client access/ cultural competence	1.01 (0.89–1.16)	0.836	1.01 (0.89–1.16)	0.834	1.04 (0.94–1.16)	0.446	1.04 (0.94–1.16)	0.440	1.02 (0.90–1.16)	0.738	1.02 (0.89–1.17)	0.776
Physical infrastructure, supplies and equipment	1.09 (0.96–1.24)	0.180	1.11 (0.98–1.26)	0.109	1.00 (0.90–1.12)	0.958	1.01 (0.91–1.12)	0.807	0.94 (0.83–1.05)	0.268	0.95 (0.84–1.07)	0.363
Overall component	1.02 (0.87–1.19)	0.836	1.02 (0.86–1.23)	0.768	1.07 (0.93–1.24)	0.333	1.08 (0.92–1.27)	0.345	0.97 (0.82–1.14)	0.714	0.96 (0.81–1.15)	0.667

OR (odds ratio); aOR (adjusted odds ratio); CI (confidence interval).

† Anaemia composite measure completed for children aged 6–59 months.

* Number of children who received process of care indicators/total number who were assessed as having a process of care indicator.

‡ Adjusted for year of data collection, geographical location, governance, continuous quality improvement participation, number of health areas the Systems Assessment Tool was related to.

Ethics approval

Ethics approval was obtained from all Human Research Ethics Committees in the states and territories involved: the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (HREC-205 EC00153); Central Australian Human Research Ethics Committee (HREC-12–53); Queensland Human Research Ethics Committee of the Darling Downs Health Services District (HREC/11/QTDD/47); South Australian Indigenous Health Research Ethics Committee (04–10–319); Curtin University Human Research Ethics Committee (HR140/2008); Western Australian Country Health Services Research Ethics Committee (2011/27); Western Australian Aboriginal Health Ethics Committee (111–8/05); University of Western Australia Human Research Ethics Committee (RA/4/1/5051); and the Australian National University (2017/560).

Results

During 2012–14, there were 1554 records audited from 74 primary health-care services that completed the SAT (Table 1). Most health services (94.6%, 70/74) were government run, serviced a population of <500 people (58.1%, 43/74), were in remote locations (87.8%, 65/74) and had participated in three or more CQI cycles (73.0%, 54/74) (Table 1). Approximately half (54.6%, 848/1554) of records audited were for children aged between 24 and 59 months.

PoCIs and child and primary health service characteristics

Less than one-third of records (32.0%, 449) had a social and emotional wellbeing PoCI, 56.6% (791) had an anaemia PoCI and just under half (49.3%, 430) had a child neurodevelopment PoCI (Table 2). Children aged 12–23 months had increased odds of receiving a PoCI for social and emotional wellbeing (aOR 1.35, 95% CI 1.01–1.49), anaemia (aOR 1.68, 95% CI 1.30–2.18) and child neurodevelopment (aOR 1.80, 95% CI 1.12–2.90) compared to children aged 24–59 months (Table 2). Children who received acute care were less likely to have a PoCI for social and emotional wellbeing (aOR 0.74, 95% CI 0.57–0.96), anaemia (aOR 0.62, 95% CI 0.49–0.77) and child neurodevelopment (aOR 0.61, 95% CI 0.44–0.85) than children who received a child health check (Table 2).

PoCIs and SAT components

Two items within the delivery system design SAT component were significantly associated with the anaemia PoCI. For every one point increase in the team structure and function item, there was a 14% greater odds of having an anaemia PoCI (aOR 1.14, 95% CI 1.01–1.27) (Table 3). A similar trend was shown for care planning where for every one point increase in the care planning item, there was also a 14% greater odds of having the anaemia PoCI (aOR1.14, 95% CI 1.01–1.29) (Table 3). Social and emotional wellbeing and child neurodevelopment PoCIs were not influenced by delivery systems design (Table 3). There was no association between information systems and decision support, links with community and other health and non-health services or organisational influence and integration on any of the three PoCIs (Table 4–6). For all three PoCIs, there was little difference in the median and interquartile ranges for each system assessment item and component between children receiving the PoCI and children who did not (Supplementary material table 4).

Discussion

There was wide variation on the delivery of PoCIs, with 32.0% of children receiving PoCIs for social and emotional wellbeing, 56.6% for anaemia and 49.3% for child neurodevelopment. Children who were aged 12–23 months were more likely to receive the PoCIs than children aged 24–59 months. Contrary to our expectations, there was little association between an organisation's health structures and processes of care for social and emotional wellbeing and child neurodevelopment. However, we found that the delivery system design component, which included items for team structure and function and care planning, were associated with the process of care provided for anaemia.

Based on the reporting of child health indicators, CQI has improved the delivery of many child health milestones and brief interventions over

time.[4] As a result, we anticipated that 50% of records would achieve our PoCIs. However, social and emotional wellbeing (32%) fell well short of this. In contrast, anaemia (60%) and child neurodevelopment (49%) reached the expected target. Our data also indicate that the provision of care varies greatly, depending on the routine service provided.

There has been much concern in primary healthcare centres about the high levels of iron-deficiency anaemia in young indigenous children.[24] Substantial emphasis in recent years on improving these rates in remote regions has included improving primary and secondary prevention through implementing CQI initiatives, health sector forums and community engagement. In our study, elements of team structure and functioning including team leadership, defining roles and responsibilities and building capacity, as well as care planning that includes planning as part of routine practice, and consistency with best practice guidelines, were shown to be positive in improving anaemia care. Capacity building with health service providers for anaemia care has fostered important changes in health services and provided quality care to children.[25] Alternatively, non-adherence to guidelines has resulted in poor management of children with anaemia.[26]

In contrast, there has been little focus on the more complex processes of care needed for social and emotional wellbeing and child neurodevelopment, and this is reflected in the lower PoCIs that we reported for these two conditions.[27] The delivery of child neurodevelopment assessments has been shown to vary across primary healthcare services, and researchers have recently called for a more system-wide approach to improve delivery, recording and monitoring.[28] There has been a recent emphasis on the importance of child neurodevelopment and the delivery of social and emotional services in family-centred care practice. Thus, it is expected that we will see improvements in the provision of care for these important areas in the coming years.[29,30]

It is our understanding that this is the first study to investigate associations between a standardised SAT assessment of quality of care and the

Table 4. Association between information systems and decision support and process of care indicators in indigenous children aged 3–59† months

	Social and emotional wellbeing (*n* = 449/1405)*				Anaemia (*n* = 791/1397)*				Neurodevelopment (430/873)*			
	OR (95% CI)	*P*-value	aOR‡ (95% CI)	*P*-value	OR (95% CI)	*P*-value	aOR‡ (95% CI)	*P*-value	OR (95% CI)	*P*-value	aOR‡ (95% CI)	*P*-value
Maintenance and use of electronic client lists	1.07 (0.92–1.25	0.388	1.07 (0.90–1.26)	0.437	1.06 (0.91–1.24)	0.456	1.04 (0.90–1.21)	0.579	1.02 (0.87–1.22)	0.752	0.99 (0.84–1.16)	0.863
Evidence-based guidelines	1.04 (0.89–1.22)	0.616	1.03 (0.88–1.21)	0.733	1.12 (0.95–1.33)	0.169	1.09 (0.93–1.28)	0.304	0.98 (0.82–1.15)	0.773	0.90 (0.78–1.04)	0.163
Specialist–generalist collaborations	0.97 (0.86–1.10)	0.613	0.95 (0.84–1.07)	0.414	1.01 (0.90–1.14)	0.817	0.98 (0.88–1.09)	0.712	0.97 (0.85–1.12)	0.627	0.92 (0.82–1.07)	0.212
Overall component	1.02 (0.86–1.21)	0.815	1.00 (0.84–1.19)	0.981	1.08 (0.91–1.29)	0.391	1.03 (0.87–1.23)	0.694	0.98 (0.81–1.18)	0.829	0.91 (0.77–1.07)	0.242

OR (odds ratio); aOR (adjusted odds ratio); CI (confidence interval).
† Anaemia composite measure completed for children aged 6–59 months.
* Number of children who received process of care indicators/total number who were assessed as having a process of care indicator.
‡ Adjusted for year of data collection, geographical location, governance, continuous quality improvement participation, number of health areas the Systems Assessment Tool was related to.

Table 5. Association between links with community, other health services and other services and process of care indicators in indigenous children aged 3–59† months

	Social and emotional wellbeing (*n* = 449/1405)*				Anaemia (*n* = 791/1397)*				Neurodevelopment (430/873)*			
	OR (95% CI)	*P*-value	aOR‡ (95% CI)	*P*-value	OR (95% CI)	*P*-value	aOR‡ (95% CI)	*P*-value	OR (95% CI)	*P*-value	aOR‡ (95% CI)	*P*-value
Communication and cooperation on governance and operation of the health centre and other community-based organisations and programs	1.00 (0.88–1.15)	0.952	0.98 (0.85–1.13)	0.777	0.98 (0.89–1.08)	0.728	0.96 (0.87–1.06)	0.424	0.99 (0.86–1.14)	0.880	0.95 (0.83–1.10)	0.492
Linking health centre clients to outside resources	0.97 (0.88–1.08)	0.631	0.96 (0.86–1.07)	0.470	0.97 (0.88–1.07)	0.579	0.93 (0.84–1.03)	0.167	0.96 (0.85–1.08)	0.458	0.92 (0.82–1.04)	0.165
Working in the community	0.98 (0.89–1.08)	0.674	0.97 (0.88–1.08)	0.609	0.96 (0.87–1.06)	0.438	0.94 (0.85–1.04)	0.221	1.02 (0.91–1.14)	0.771	0.98 (0.87–1.11)	0.798
Communication and cooperation on regional health planning and development of health resources	1.02 (0.92–1.13)	0.766	1.0 (0.89–1.11)	0.969	1.00 (0.91–1.10)	0.986	0.96 (0.88–1.06)	0.449	1.02 (0.92–1.13)	0.736	0.98 (0.88–1.09)	0.678
Overall component	0.99 (0.87–1.12)	0.877	0.96 (0.85–1.11)	0.633	0.97 (0.86–1.08)	0.565	0.92 (0.82–1.04)	0.190	1.00 (0.86–1.16)	0.956	0.94 (0.81–1.09)	0.408

OR (odds ratio); aOR (adjusted odds ratio); CI (confidence interval).
† Anaemia composite measure completed for children aged 6–59 months.
* Number of children who received process of care indicators/total number who were assessed as having a process of care indicator.
‡ Adjusted for year of data collection, geographical location, governance, continuous quality improvement participation, number of health areas the Systems Assessment Tool was related to.

Table 6. Association between organisational influence and integration and process of care indicators in indigenous children aged 3–59† months

	Social and emotional wellbeing (*n* = 449/1405)*				Anaemia (*n* = 791/1397)*				Neurodevelopment (430/873)*			
	OR (95% CI)	*P*-value	aOR‡ (95% CI)	*P*-value	OR (95% CI)	*P*-value	aOR‡ (95% CI)	*P*-value	OR (95% CI)	*P*-value	aOR‡ (95% CI)	*P*-value
Organisational commitment	0.97 (0.84–1.11)	0.637	0.96 (0.83–1.11)	0.565	1.01 (0.91–1.12)	0.873	0.99 (0.88–1.11)	0.877	0.92 (0.81–1.06)	0.258	0.90 (0.78–1.05)	0.172
Quality improvement strategies	1.06 (0.92–1.22)	0.446	1.08 (0.92–1.25)	0.355	1.03 (0.91–1.17)	0.655	1.05 (0.92–1.20)	0.462	0.92 (0.79–1.07)	0.295	0.89 (0.77–1.03)	0.124
Integration of health system components	1.00 (0.89–1.12)	0.949	0.98 (0.88–1.11)	0.793	1.06 (0.95–1.17)	0.285	1.03 (0.93–1.15)	0.516	0.94 (0.83–1.07)	0.345	0.91 (0.80–1.07)	0.163
Overall component	1.00 (0.87–1.16)	0.955	1.00 (0.86–1.16)	0.993	1.04 (0.92–1.19)	0.505	1.03 (0.90–1.18)	0.644	0.91 (0.78–1.06)	0.231	0.88 (0.75–1.02)	0.097

OR (odds ratio); aOR (adjusted odds ratio); CI (confidence interval).
† Anaemia composite measure completed for children aged 6–59 months.
* Number of children who received process of care indicators/total number who were assessed as having a process of care indicator.
‡ Adjusted for year of data collection, geographical location, governance, continuous quality improvement participation, number of health areas the Systems Assessment Tool was related to.

processes of care delivered to indigenous children in primary health care. It has previously been shown that a health-care system's organisational influence and integration is positively associated with the quality of care provided to adults for diabetes control (HbA1C), blood pressure and total cholesterol levels.[31] However, we found no association between the organisation of health systems and the provision of care for children as measured by our neurodevelopment and social and emotional wellbeing PoCIs. Almost 70% of the health services had completed at least three or more SAT cycles, thus this may have improved the organisation of all the health-care systems in terms of these PoCIs over time. It is also possible that other factors have resulted in this lack of association, including lack of assessment of communication and patient-centred care, which were not included in our analysis and the potential for under-reporting in health records. Despite this, processes of care and organisational systems in primary care services were shown to be important for the optimal management of anaemia in indigenous children and should be enhanced.

There are several limitations to this study. Although guidance and facilitation was provided to local health centre staff and managers to complete the SAT, in practice, they were largely completed by front-line primary health-care teams without direct standardised support. This is likely to influence how the tool was completed. It was decided that the process of care delivered should be maximal and therefore included all elements documented. Although the PoCIs have not been validated, we believe this study has demonstrated an important use of them. In addition, we constructed them through ensuring that they were specific, measurable, attainable, relevant and trackable. It is also possible that for some levels of care, there was no or little documentation of this in the health-care records.

This was a cross-sectional study so we could only report associations and could not assess causality. The positive results seen in our analyses may be the result of type 1 error; however, given that our *P* values were not borderline and we have narrow confidence intervals, we are confident in our results. Due to the voluntary nature of participation by primary health-care services in this study, the findings are not necessarily generalisable to all primary health-care services. Most of the health services were government-run (94.6%), located in remote areas (87.8%) and serviced populations of <500 (58.1%) people. This also limits the potential generalisability of findings to other health services, in particular Aboriginal Community-Controlled Health Organisations.

Conclusion

Our study found that organisational health service structures, which included items for team structure and function and care planning, were associated with quality of anaemia care. This study provides evidence that organisation of health services is associated with the prevention and management of anaemia for young indigenous children. In addition, our young indigenous children aged 24–59 months are not receiving care for important social and health indicators. Child health checks are an important avenue to ensuring quality care is provided.

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COMPETING INTERESTS
The authors declare that they have no competing interests.

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Supplement table 1: Pre-coded items for social and emotional wellbeing, anaemia and child neurodevelopment based on national best practice guidelines and indicators that were common to all jurisdictions.

Social and emotional wellbeing
1. Assessment of parent-child interaction
2. Advice about domestic/social environment*
3. Advice about social/family support*
4. Advice about financial situation
5. Advice about housing condition*
6. Advice about food security
7. Advice about physical and mental stimulation of child*
8. Advice about child behaviour
9. Clinic follow up and/or referral for problems with domestic environment
10. Clinic follow up and/or referral for family and financial support
11. Clinic follow up and/or referral for housing condition or food security
Anaemia
1. Advice about breastfeeding (< 2 years)
2. Advice about nutrition*
3. Advice about food security
4. A record of haemoglobin at least once in the last 12 months*
5. If there is evidence of anaemia, is there a record of dietary/nutrition advice given
6. A record of prescription of iron supplement
7. A record of follow-up FBE or haemoglobin within 2 months
Child neurodevelopment
1. Assessment of developmental milestones*
2. Assessment of vision*
3. Assessment of hearing*
4. Assessment of parent-child interaction*
5. Advice about physical and mental stimulation of child*
6. Clinic follow up and/or referral regarding concerns about a finding of developmental delay

*Items included in their respective process of care indicator

Supplement table 2: Systems Assessment Tool

Component	Item for each component
Delivery system design	1. Team structure and function 2. Clinical leadership 3. Appointments and scheduling 4. Care Planning 5. Systematic approach to follow-up 6. Continuity of care 7. Client access/cultural competence 8. Physical infrastructure, supplies and equipment
Information systems and decision support	1. Maintenance and use of electronic client lists 2. Evidence based guidelines 3. Specialist-generalist collaborations
Links with community, other health services and other services	1. Communication and cooperation on governance and operation of the health centre and other community based organisations and programs 2. Linking health centre clients to outside resources 3. Working in the community 4. Communication and cooperation on regional health planning and development of health resources
Organisational influence and integration	1. Organisational commitment 2. Quality improvement strategies 3. Integration of health system components
Self-management support	1. Assessment and documentation 2. Self-management education and support, behaviour risk reduction and peer support

Supplement table 3: Number and proportions of Indigenous children aged 3-59^ months receiving services and process of care indicators

Process measures	Eligible primary care centres n (%)	Number of primary health care services that included care in their protocols n (%)	Total number of audits assessed n (%)	Total number receiving care n (%)
Total	**74**	**74**	**1545**	**1545**
Assessment of SEWB care				
Advice about physical and mental stimulation of child	74 (100%)	72 (97.3%)	1514 (98.0%)	831 (54.9%)
Advice about domestic/social environment	74 (100%)	74 (100%)	1545 (100.0%)	978 (63.3%)
Advice about social/family support	74 (100%)	73 (98.6%)	1436 (92.9%)	867 (60.4%)
Advice about housing condition	74 (100%)	74 (100%)	1545 (100.0%)	691 (44.7%)
Composite measure of quality of care	74 (100%)	71 (95.9%)	1405 (90.9%)	449 (32.0%)
Assessment of anaemia care				
Nutrition anticipatory guidance	74 (100%)	74 (100%)	1545 (100.0%)	1174 (76.0%)
Haemoglobin documented in last 12 months	74 (100%)	72 (97.3%)	1397 (90.4%)	1012 (72.4%)
Composite measure of quality of care	74 (100%)	72 (97.3%)	1397 (90.4%)	791 (56.6%)
Assessment of Developmental Care				
Assessment of parent-child interaction	74 (100%)	72 (97.3%)	1000 (64.7%)	764 (76.4%)
Assessment of developmental milestones	74 (100%)	73 (98.6%)	1291 (83.6%)	991 (76.8%)
Assessment of vision	74 (100%)	72 (97.3%)	1416 (91.7%)	965 (68.1%)
Assessment of hearing	74 (100%)	74 (100%)	1497 (96.9%)	1107 (73.9%)
Advice about physical and mental stimulation of child	74 (100%)	72 (97.3%)	1514 (98.0%)	831 (54.9%)
Composite measure of quality of care	74 (100%)	70 (94.6%)	873 (56.5%)	430 (49.3%)

^Anaemia composite measure completed on children aged 6-59

Supplement table 4: Median and interquartile range for each system assessment component and item by process of care indicators

	Social and emotional wellbeing (n=449/1405)		Anaemia (n=791/1397)		Neurodevelopment (430/873)	
	Received PoCI Median (IQR)	Did not receive PoCI Median (IQR)	Received PoCI Median (IQR)	Did not receive PoCI Median (IQR)	Received PoCI Median (IQR)	Did not receive PoCI Median (IQR)
Delivery system design						
Team structure and function	7.0 (6.0-9.0)	7.0 (6.0-8.0)	7.0 (6.0-9.0)	7.0 (5.0-8.0)	7.0 (5.0-9.0)	7.0 (6.0-9.0)
Clinical leadership	7.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)	7.0 (6.0-9.0)	8.0 (6.0-10.0)	8.0 (7.0-10.0)
Appointments and scheduling	8.0 (6.0-8.0)	8.0 (6.0-9.0)	8.0 (7.0-9.0)	8.0 (6.0-9.0)	8.0 (7.0-9.0)	8.0 (6.0-9.0)
Care Planning	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (7.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)
Systematic approach to follow-up	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)
Continuity of care	7.0 (6.0-8.0)	7.0 (5.0-8.0)	7.0 (5.0-8.0)	7.0 (5.0-8.0)	7.0 (6.0-8.0)	7.0 (5.0-9.0)
Client access/cultural competence	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-10.0)	8.0 (6.0-9.0)	8.0 (6.0-10.0)	8.0 (6.0-9.0)
Physical infrastructure, supplies and equipment	7.0 (6.0-8.0)	6.0 (5.0-8.0)	7.0 (5.0-9.0)	7.0 (5.0-8.0)	7.0 (5.0-8.0)	7.0 (5.0-9.0)
Overall component	7.0 (6.0-9.0)	8.0 (6.0-9.0)	7.0 (6.0-9.0)	7.0 (6.0-9.0)	7.0 (6.0-9.0)	8.0 (6.0-9.0)
Information systems and decision support						
Maintenance and use of electronic client lists	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)
Evidence based guidelines	9.0 (8.0-9.0)	9.0 (8.0-10.0)	9.0 (8.0-9.0)	9.0 (7.0-9.0)	8.0 (7.0-9.0)	9.0 (7.0-10.0)
Specialist-generalist collaborations	7.0 (6.0-8.0)	8.0 (6.0-9.0)	7.0 (6.0-8.0)	7.0 (5.0-9.0)	7.0 (5.0-8.0)	8.0 (6.0-9.0)
Overall component	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)	8.0 (7.0-9.0)
Community linkages						
Communication and cooperation on governance and operation of the health centre and other community based organisations and programs	5.0 (4.07-7.0)	5.0 (4.0-7.0)	5.0 (4.0-7.0)	5.0 (4.0-7.0)	5.0 (4.0-7.0)	5.0 (4.0-7.0)
Linking health centre clients to outside resources	6.0 (4.0-9.0)	7.0 (6.0-9.0)	6.0 (5.0-8.0)	6.0 (5.0-9.0)	6.0 (4.0-9.0)	6.0 (5.0-9.0)
Working in the community	6.0 (3.0-8.0)	6.0 (4.0-8.0)	6.0 (3.0-8.0)	6.0 (4.0-8.0)	7.0 (4.0-8.0)	6.0 (4.0-8.0)
Communication and cooperation on regional health planning and development of health resources	5.0 (2.0-7.0)	5.0 (3.0-7.0)	5.0 (2.0-7.0)	5.0 (3.0-7.0)	5.0 (3.0-7.0)	4.0 (2.0-7.0)
Overall component	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)
Organisational influence and integration						
Organisational commitment	6.0 (4.0-7.0)	6.0 (5.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-7.0)	6.0 (4.0-8.0)	6.0 (5.0-7.0)
Quality improvement strategies	8.0 (6.0-9.0)	8.0 (7.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (6.0-9.0)	8.0 (7.0-9.0)
Integration of health system components	7.0 (5.0-8.0)	7.0 (6.0-8.0)	7.0 (6.0-8.0)	7.0 (5.0-8.0)	7.0 (4.0-8.0)	7.0 (5.0-8.0)
Overall component	7.3 (5.7-8.0)	7.3 (6.0-8.0)	7.0 (6.0-8.0)	7.0 (6.0-8.0)	6.0 (5.0-8.0)	7.0 (6.0-8.0)

PoCI = Process of care indicators