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MChD BMSc (Hons)

Health Service Use and Needs of Aboriginal Children in the Remote Fitzroy Valley

A thesis submitted for the degree of Doctor of Philosophy (Medicine)

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Declaration of Originality

This thesis is submitted to the Australian National University, School of Medicine within the College of Health and Medicine in fulfilment of the requirements for the degree of Doctor of Philosophy.

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that this thesis is solely my own, with guidance and supervision from Professor Kirsty Douglas, Professor Alexandra Martiniuk, Associate Professor David Harley, Associate Professor Kathryn Glass and Professor Heather Jeffery and support from the communities in the Fitzroy Valley and the Lililwan Project team: Dr. James Fitzpatrick, Professor Elizabeth Elliott, Dr. Jane Latimer, Maureen Carter, June Oscar, Marmingee Hand, Dr. Emily Fitzpatrick, Dr. John Boulton and Dr Kathryn Thorburn. Statements of contribution are included prior to each published paper with supporting signatures from co-authors.

I declare that this material has not been submitted, either in full or part, for a degree at this or any other institution.

Signature of candidate: Philippa Jane Dossetor

Date: 1/4/2022

Preface

The United Nations Convention for the Rights of the Child states that *"every child has the right to the highest attainable standard of health care" (Article 24), including children from minority groups (Article 2) and children with disabilities (Article 2) (1)."*

In Australia, Aboriginal and Torres Strait Islander children have significantly worse health outcomes than non-Indigenous children, however there are few population-based data that describe the quality and availability of child health services. These issues are addressed in this thesis, with a specific focus on health service access and utilisation by Aboriginal children residing in very remote communities spread across the Fitzroy Valley of northern Western Australia. Study participants were identified through the Lililwan study, which examined the prevalence of fetal alcohol spectrum disorder, and many live with chronic, complex disabilities (2).

This thesis is arranged in six chapters, each written so that they can be read independently. The Australian National University permits published manuscripts arising from the candidature to be included in the thesis. Three published papers and one manuscript prepared for submission for publication form four chapters of this thesis, each addressing a specific aim.

Chapter 1 is an introduction to the thesis and provides context to the thesis within the Lililwan Project. **Chapter 2** is an overview of the relevant literature on health services in remote Australia and their utilisation by children. This will be submitted to the *Rural and Remote Health* for review for publication. **Chapter 3** maps the existing services available for children in the remote Fitzroy Valley and is presented in its published form in *BMC Health Services Research*. **Chapter 4** describes lifetime hospitalisation rates in the Lililwan cohort (aged 0-7 years) and reasons for admission. This was published in *BMC Pediatrics*. **Chapter 5** reports emergency department utilisation over a five-year period by the cohort, as published in *Global Pediatric Health.* **Chapter 6** provides a summary of the principal findings of the thesis, describes the implications of these findings and proposes some recommendations and directions for future research.

Each chapter contains its own reference list. Appendices that were published online as supplementary materials are included at the end of the relevant chapters.

Ethics approval was gained for all studies prior to data collection from the following Human Research Ethics Committees: The University of Sydney Human Research Ethics Committee; Western Australian Aboriginal Health Information and Ethics Committee; Western Australian County Health Service Board Research Ethics Committee; and Kimberley Aboriginal Health Planning Forum Research Sub-Committee. Written informed consent was obtained from all participants at three time points during the study. Participant anonymity is preserved in reporting of results. Publications and Presentations resulting from this thesis are listed, as are Scholarships awarded in support of this thesis.

Finally, material published for community organisation feedback on the outcomes of this body of work is presented as Appendix 1 to demonstrate the dissemination and impact of this work.

Abstract

Despite a national focus on closing the gap between Aboriginal and Torres Strait Islander and non-Indigenous child health outcomes in Australia, there remain significant challenges to health service provision in very remote communities. The Fitzroy Valley is home to ~4500 people, the majority (81%) Aboriginal and from five language groups. In 2009, Indigenous leaders initiated a research partnership to conduct The Lililwan Project to address community priorities linked to identification, management and prevention of prenatal alcohol exposure (PAE) and fetal alcohol spectrum disorders (FASD). Data collection began after comprehensive community consultation, community consent and the development of a memorandum of understanding that includes Aboriginal custodianship of data.

Of all 134 eligible children in two age cohorts (born 2002-3), 95% participated. In the Lililwan cohort (n=127), 55% had high risk PAE and 19% had FASD, with associated physical, learning and behavioural problems. Over 400 referrals were made to health services for ongoing assessment and care (2). The community were concerned that service capacity was inadequate and invited me to explore the use and adequacy of child health services in the Fitzroy Valley.

I hypothesised that the need for and use of health services would be high; services would be inadequate to serve children with acute and complex chronic disorders and disabilities; many health conditions would be preventable; and that social disadvantage contributes to health service use. This thesis provides the first population-based data on access to and lifetime utilisation of health services in remote Australia by predominantly Aboriginal, primary school aged children. In this PhD, I aimed to identify service use, gaps, and barriers to access

to inform future policy and planning for the Fitzroy Valley and similar remote Australian communities.

Chapter 1 provides an introduction and places the work in the context of the Lililwan Project.

Chapter 2 includes a comprehensive literature review that highlights the paucity of published information on access to and utilisation of child health services across remote Australia. It underscores difficulties in delivering services in remote locations and identifies knowledge gaps which are addressed in subsequent chapters.

Chapter 3 documents existing paediatric services in the Fitzroy Valley following the Lililwan project (2013). Data were collected using semi-structured interviews with clinicians or service managers from 17 key service providers. I identified that service delivery is impacted by inadequate staffing and infrastructure, funding complexities, lack of service coordination, large geographic areas, and an extreme environment. There is a critical shortage of Aboriginal Health Workers (AHW) and a dearth of comprehensive preventative and primary health care. This work will inform future health service planning.

In **Chapter 4,** I report lifetime (0-7 years) hospital admissions to Fitzroy Crossing Hospital for the Lililwan cohort: 70% had at least one admission (total 314, median 5, range 1-12). Infants (N=56) accounted for 38.6% of admissions. Primary reasons for admission were infections including lower respiratory, gastrointestinal, upper respiratory. Comorbidities were common. Many hospitalisations were feasibly preventable. High hospitalisation rates reflected disadvantage and limited access to outpatient and preventative health services.

Chapter 5 reports emergency department (ED) presentations to the Fitzroy Crossing Hospital (between 2007-11) for the Lililwan cohort. There were 1058 presentations over 5 years. Most children (81%) had at least one presentation (median 9.0, range 1-50), commonly for screening/follow-up/social reasons, injury, and diseases of the ear, skin, or respiratory tract. Higher presentation rates were associated with PAE and socio-economic disadvantage. Many presentations were potentially preventable. There is a need for culturally appropriate public health prevention strategies and improved access to primary health services.

Chapter 6 provides a summary of the principal findings of this thesis and their implications and proposes directions for service development and future research.

In summary, this comprehensive review of access and utilisation of health services by children in the Lililwan Project cohort for over a decade, from 2002-2013 inclusive, demonstrates the significant challenges faced by children with complex chronic and acute health needs in remote Australia. Future health service planning for remote Australia must include capacity-building in the Aboriginal workforce, strategies to attract and retain skilled health professionals, better co-ordination of services to prevent duplication and enhance communication and collaboration, increased use of telehealth, and a focus on primary and preventative health care. Unless the health and wellbeing need of vulnerable groups of children are met, outcome gaps will not be closed.

Acknowledgements

I thank everyone who made this thesis possible. I firstly thank the people of the Fitzroy Valley, in particular the children that participated in the Lililwan Project. Throughout this experience I have learnt an incredible amount about Australian Aboriginal culture, history and enduring resilience. I would like to thank June Oscar, Maureen Carter, Emily Carter and Marmingee Hand for their ongoing support throughout this project.

To my supervisors Professor Kirsty Douglas, Professor Alexandra Martiniuk, Associate Professor David Harley, Associate Professor Kathryn Glass and Professor Heather Jeffery, thank you so much for providing an immense amount of guidance, patience, encouragement, feedback and humour throughout this project. You are all incredible and inspiring role models and mentors for me. Your work within the field of public health inspires me to continue future work in this area of medicine.

Thank you to Rochelle Watkins, Kathryn Glass and Tracey Tsang for teaching me to use SPSS. Without you none of the data analysis in this thesis would have been possible.

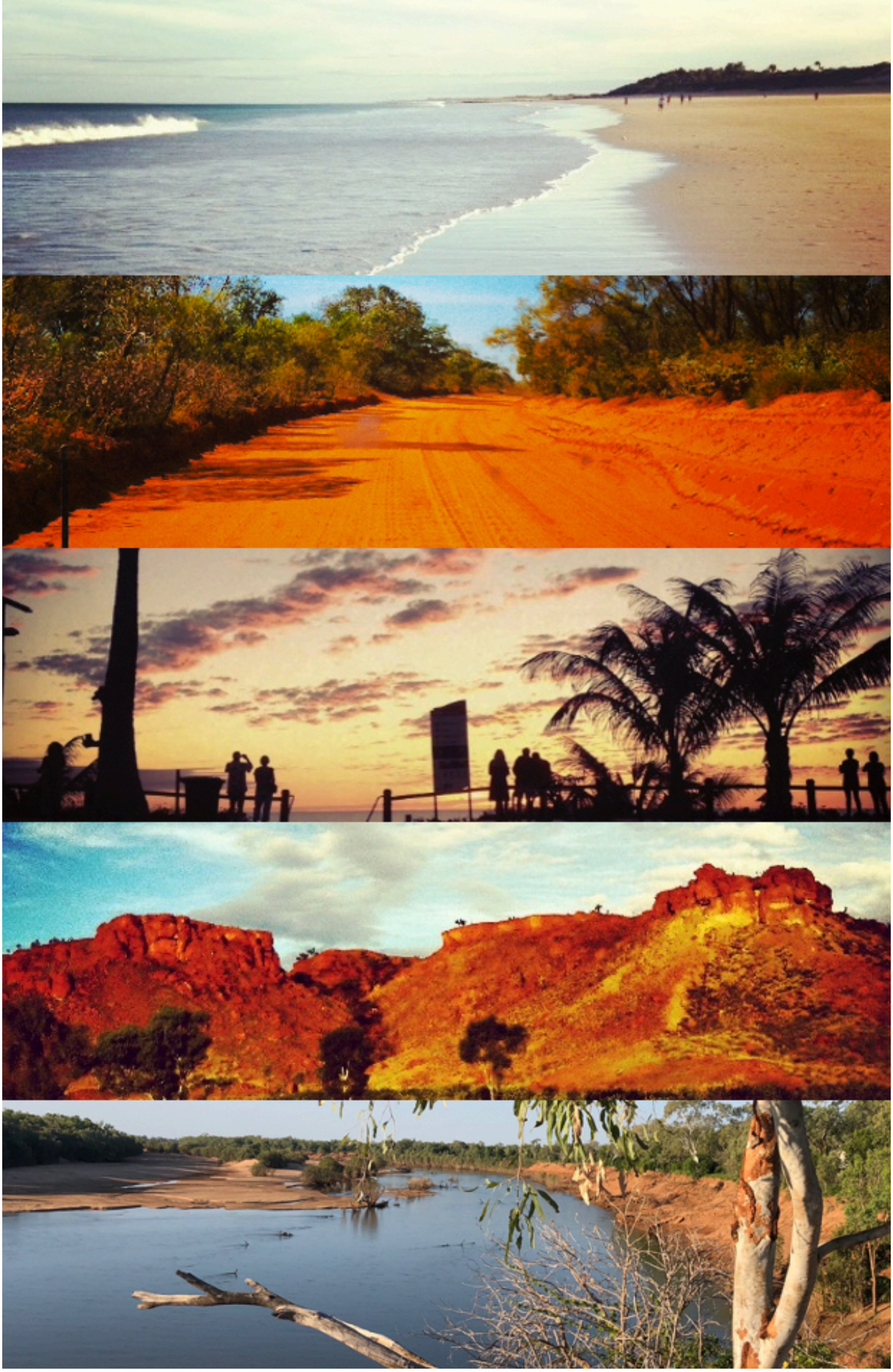
Thanks to Dr Kathryn Thorburn and Dr Emily Fitzpatrick who were wonderful co-workers, motivators and friends. Professor Elizabeth Elliott’s assistance throughout the project was invaluable.

Thank you to my parents, siblings and friends for keeping me sane and providing unfailing encouragement throughout my PhD. You all mean a great deal to me and have shaped me into the person I am today. I am privileged to have parents who provided me with deep

support and who are inspiring role models that have showed us the value of being compassionate and to committing to a lifetime of working in medicine. You encourage me to be the best I can be every day.

Acknowledgement and thanks also to the Poche Centre for Indigenous Health, within the Sydney University Faculty of Medicine, for the Student Research Scholarship, to the Avant Doctors in Training program, and to the Australian National University for financial support throughout this degree. Without these scholarships and stipends this thesis would never have been completed.

I dedicate this thesis to the Aboriginal children of the Fitzroy Valley, I hope that one day soon the disparity and inequality experienced by you in terms of health and welfare is alleviated and that you pave the way for future children living in remote areas to live rich and full lives, free of a burden of illness.



Photographs of the Fitzroy Valley and Broome by Philippa Dossetor

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Abbreviations and Definitions

ABS	Australian Bureau of Statistics
AEDC	Australian Early Development Census
AHW	Aboriginal Health Worker
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
AMS	Aboriginal medical services
ARF	Acute rheumatic fever
ARIA	Accessibility/Remoteness Index of Australia
ASGC	Australian Standard Geographical Classification
ATSI	Aboriginal and Torres Strait Islander
AUDIT-C	Alcohol Use Disorders Identification Test - Consumption
Bigiswun	Kimberley Kriol for all the bigger ones. The Bigiswun Kid Project is the follow up study of the Lililwan cohort into adolescence.
BMC	BioMed Central
BMI	Body mass index
CAMHS	Child and Adolescent Mental Health Service
CI	Confidence interval
CNS	Central nervous system
CoAG	Council of Australian Governments
COVID-19	Coronovirus-19; severe acute respiratory syndrome coronavirus 2
CQI	Continuous quality improvement
DOCP	Department of Child Protection
DoE	Department of Education
DOHaD	Developmental Origins of Health and Disease
ED	Emergency department
ENT	Ear, nose and throat
FAS	Fetal alcohol syndrome
FASD	Fetal alcohol spectrum disorders
FIFO	Fly-in fly-out
FTE	Full-time equivalent
GP	General practitioner
Hib	*Haemophilus influenza* type b
HIV	Human immunodeficiency virus
HWA	Heath Worker Association
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th Revision
IMR	Infant Mortality Ratio: the number of deaths of children under 1 year of age in a calendar year per 1,000 live births in the same calendar year. The rate ratio is Indigenous rate over non-Indigenous rate.

IQR	Inter-quartile range
KAMSC	Kimberley Aboriginal Medical Services Council
KPHU	Kimberley Population Health Unit
KPI	Key performance indicator
LBW	Low birth weight (<2500g)
Lililwan	Meaning all the little ones in Kimberley Kriol and representing the cohort who underwent complex multi-disciplinary assessments for fetal alcohol spectrum disorders.
LRTI	Lower respiratory tract infection
MWRC	Marninwarntikura Women's Resource Centre
NACCHO	National Aboriginal Controlled Community Health Organisation
NCHS	Nindilingarri Cultural Health Services
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGOs	Non-government organisations
NHMRC	National Health and Medical Research Council
NRHC	National Rural Health Conference
NSW	New South Wales
NT	Northern Territory
Overcrowding	Determined by number living in household and whether the parent or caregiver of the child felt there were too many people living in one house
PAE	Prenatal alcohol exposure
pFAS	partial fetal alcohol syndrome
PHC	Primary Health Care
PJD	Philippa Jane Dossetor
PNP	Paediatric nurse practitioner
QLD	Queensland
RAN	Remote area nurse
RCH	Royal Children’s Hospital
RFDS	Royal Flying Doctors Service
RRHA	Rural and Regional Health Australia
RSE	Relative standard error
SA	South Australia
SES	Socioeconomic status
UN	United Nations
URTI	Upper respiratory tract infection
WA	Western Australia
WACHS	Western Australia Country Health Service
WHO	World Health Organization
YLL	Years of life lost

Remoteness: ARIA is a geographic accessibility index that aims to reflect the ease or difficulty people face accessing services in non–metropolitan Australia. ARIA is a continuous index that allows comparison of remoteness within Australia with values ranging from 0 (high accessibility) to 15 (high remoteness). Our population is deemed very remote based on ARIA classifications (23).

A note on terminology:

In accordance with the terminology guidelines suggested by the Australian Institute of Aboriginal and Torres Strait Islander Studies we have chosen to utilize the following terms. Indigenous Australians is used to encompass both Aboriginal and Torres Strait Islander peoples, although we note that in doing so, we have grouped together two very distinct cultural groups. Aboriginal has been used when specifically discussing our cohort of children as is the preference of the Fitzroy Valley community. Where possible, we have avoided the use of acronyms (e.g., ATSI).

Publications

Dossetor PJ, Thorburn K, Oscar J, Carter M, Fitzpatrick J, Bower C, et al. Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions. BMC Health Serv Res. 2019;19(1):758.

Dossetor PJ, Martiniuk ALC, Fitzpatrick JP, Oscar J, Carter M, Watkins R, et al. Pediatric hospital admissions in Indigenous children: a population-based study in remote Australia. BMC Pediatr. 2017;17(1):195.

Dossetor PJ, Fitzpatrick EFM, Glass K, Douglas K, Watkins R, Oscar J, et al. Emergency Department Presentations by Children in Remote Australia: A Population-based Study. Glob Pediatr Health. 2021;8:2333794X21991006.

Dossetor PJ, Thorburn K, Jeffery HE, Harley D, Elliott EJ, Martiniuk ALC. Health services for Aboriginal children in remote Australia: a literature review. Manuscript prepared for submission to Rural and Remote Health for review for publication in June 2021.

Presentations

Oral Presentations

2017 Dossetor PJ, *Preventable paediatric hospitalisations among remote Indigenous Australian Children,* World Congress for Public Health, Melbourne (International)

2014 Dossetor PJ**,** *Health Service Use and Needs of Aboriginal Children in the Remote Fitzroy Valley: The Lililwan Project*, Australian Medical Students Association Convention, Three Minute Thesis Competition, Adelaide (National)

2014 Dossetor PJ, *Health Service Use and Needs of Aboriginal Children in the Remote Fitzroy Valley: The Lililwan Project,* The National Australian Indigenous Health Conference, Cairns (National)

2014 Dossetor PJ, *Health Service Use and Needs of Aboriginal Children in the Remote Fitzroy Valley: The Lililwan Project,* The Poche Centre for Indigenous Health Executive Academic Working Group Meeting, The University of Sydney

2014 Dossetor PJ et al., *Burden of Illness in Aboriginal Children in the Remote Fitzroy Valley: The Lililwan Project,* The Poche Centre for Indigenous Health Symposium, The University of Sydney

Poster Presentations

2018 Dossetor PJ et al. *Lifetime hospital admissions and emergency department presentations of The Lililwan cohort and the interrelation with fetal alcohol spectrum disorders (FASD) and Prenatal Alcohol Exposure (PAE),* 2nd Australasian FASD Conference 2018, Perth, Western Australia, November. (International)

2017 Dossetor PJ et al., *Emergency Department presentations in a paediatric cohort in remote Australia,* Canberra Health Annual Research Meeting (CHARM), Canberra, August.

Scholarships

2018 - 2019	Avant Doctors in Training Part-time Research Scholarship | *Avant*
2014 - 2018	Part-time PhD Scholarship | *Australian National University*
2013 - 2014	Poche Scholar | The Poche Centre for Indigenous Health | *The University of Sydney*

Chapter 1: Introduction

1.1. Introduction

Four hours and 400km inland, eastward from Broome, along a straight, narrow, long and red dust covered road, with barely another soul in sight, I found myself arriving in Fitzroy Crossing. The heart and soul of the Fitzroy Valley.

Here the beauty of simplicity resonates. Pleasure is found in activities that connect people: swimming in a croc infested river, filled with 'freshies'; children joyfully squealing as they taunt each other with a dead goanna; catching yabbies by the riverbed; bumping around over pothole ridden roads; or having a yarn to share stories under the glow of the star lit sky with a warm tea, cupped in your palms. The importance of family is paramount.

Here I learnt of a culture that carries a vast richness and lessons of history. Of lives that have demanded resilience to survive repeated layers of trauma and tragedy that have been thrown their way over the last 250 years.

The children of these very remote communities captured my heart, and I was struck by the health inequalities they experienced due to the arbitrariness of their birth.

The United Nations convention for the rights of the child states that every child has the right to "the highest attainable standard of health care" (Article 24), including children from minority groups (Article 2) and children with disabilities (Article 2) (1)."

The human right for health and health care motivated me to sign up for a project that I hoped would have a meaningful impact on the lives of these children and future generations. – PJD

1.2. Context for the study

1.2.1. Indigenous Australians

Aboriginal and Torres Strait Islanders have inhabited Australia and cared for the land for over 60,000 years. Today, they comprise approximately 3% of Australia's population (4). Of Indigenous Australians, 43% live in regional centres and 27% live in remote and very remote locations. Indigenous Australians account for 45% of the population in very remote locations, including the Kimberley region of Western Australia (5, 6).

Indigenous Australians have different and significantly greater health needs than other Australians. These increased needs are evidenced, across all age groups, by higher rates of health services usage compared with non-Indigenous Australians (7-9). This in turn is indicative of the disparity in health-burden and ongoing inequalities experienced by Indigenous compared to non-Indigenous Australians. Closing the gap in health outcomes between Aboriginal and Torres Strait Islanders and non-Indigenous Australians remains a national priority (10).

Key health-related targets established in the 'Closing the Gap' action plan included halving the gap in Indigenous child (under five-years) mortality within a decade (by 2018, not met) and closing the life expectancy gap within a generation (by 2031) (10). Although the gap in life expectancy between Indigenous and non-Indigenous Australians has narrowed over the last 40 years, we are not on track to meet the 2031 target (10). Currently, the life expectancy is 8.6 years shorter for Indigenous compared with non-Indigenous men (71.6 v 80.2 years) and 7.8 years shorter for women (75.6 v 83.4 years) (10). Over a third (34%) of this gap is deemed attributable to social determinants of health (e.g., education, employment status, housing, income) (10). Low life expectancy has resulted in an Indigenous population age structure and profile with a lower median age than non-Indigenous Australians (23 versus 28 years in 2016) (4).

1.2.2. Indigenous Australian child health

The National Health and Medical Research Council (NHMRC) of Australia has emphasized the need for research on children to promote a *Healthy Start to Life* (11). Birth weight and mortality in children aged under five years are important indicators of child population health (12). Children born with low birth rate (LBW [1]) are at greater risk of early death and other health problems (13). In 2010, the prevalence of LBW for Indigenous babies (12%) was twice that of non-Indigenous Aboriginal babies (6%) (13).

The under-five-years mortality in Indigenous Australians remains high (141 versus 67 per 100,000 for non-Indigenous children, 2018) (10). From 2014-2018, 85% of child deaths occurred in infancy (the first year of life), many attributable to perinatal conditions (49%) including pregnancy complications, birth trauma, fetal growth disorders, and respiratory and cardiovascular conditions (10). Nearly half of the remaining causes of death (15%) were accidents, drowning or injury (10). Many deaths in infancy and early childhood are potentially preventable. The infant mortality rate (IMR[2]) in Indigenous Australian infants is similarly higher than in non-Indigenous infants (3.1 times for males and 1.4 times for Indigenous females in Western Australia) (14).

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[1] Low Birth Rate (LBW): defined as a weight of less than 2500g at birth

[2] Infant Mortality Rate (IMR): the number of deaths of children under 1 year of age in a calendar year per 1,000 live births in the same calendar year. The rate ratio is the Indigenous rate divided by the non-Indigenous rate

The last four decades have shown improvement in these statistics, with a study conducted in the Northern Territory revealing a decline in the under-five mortality by 85% between 1967-2002 (15). However, targets have not been met. Improvements in antenatal care, neonatal intensive care, sanitation, and the development and implementation of immunisation programs have contributed to significant reductions in infant and child mortality in the last 40 years (16). Other key factors known to influence child mortality are maternal health and social determinants of health, including access to quality health care services and safe living conditions (10). The Australian Government recommends further research to understand how improvements to child health can be converted into greater reductions in child mortality rates (10).

Children living in rural and remote settings are particularly disadvantaged with regard to health outcomes. The Australian Institute of Health and Welfare (AIHW) reports higher rates of hospitalisations in rural (415 per 1000 population), remote (479 per 1000) and very remote (746 per 1000) settings compared to metropolitan areas (410 per 1000) (17). Death by drowning is nearly three times more common in children, particularly males, in a rural setting than metropolitan areas (18). Injury deaths across all age groups are also more common in very remote areas (87 per 100,000 population) compared to metropolitan areas (43 per 100,000) (17-19). These data reflect higher risk of injury in remote locations, a lack of preventative measures, poor living conditions, lack of transport to access services, and limited or poor-quality child health services (20).

1.2.3. Remote health service provision

Providing equitable access to high quality health care in remote regions can be challenging and is not readily achieved with traditional models of health care delivery, because of small population size, distance from major hospitals, and need for cultural and contextual awareness. The high cost of recruitment and retention of health professionals is a major prohibitive factor (21). Access to primary and preventative health care is thus an important factor for addressing health inequalities across Australia (22). Remoteness is often poorly defined as it can be considered in relation to population size, distance, or access to services. For this body of work, the ARIA Index of remoteness was used, by which The Fitzroy Valley communities are defined as very remote, which incorporates both variables (23).

1.2.4. The Fitzroy Valley: historical context

The Fitzroy Valley is located within the heart of Western Australia's Kimberley region and home to approximately 4500, predominantly Aboriginal, people. These Aboriginal people are from five distinct language groups: Bunuba, Walmajarri/Wangkatjungka, Nyikina and Gooniandi and they live across 40 communities. At the centre of the valley, approximately 400km east of Broome and 2500km north of Perth, is the main service town Fitzroy Crossing. Fitzroy Crossing and all the satellite communities are classified as very remote (23). Some of the smaller outlying communities have as few as 20-30 people and town is up to 190kms away along mostly pothole ridden, dirt roads, inaccessible in the wet season. Transport options are sparse – there is no public transport, and few people own a private vehicle or possess a driver's licence.

The people of the Fitzroy Valley have been subject to historic trauma arising from colonisation and currently live with significant disadvantage (24, 25). In the 1967 referendum, the Australian people voted overwhelmingly to remove the discriminatory law that prevented Aboriginal and Torres Strait Islander people from being recognised as human and counted in the census, marking the first shift towards ensuring equality for all Australians

(24). However, trauma continued to ensue after the passage of the 1967 referendum, as many Aboriginal people were removed from their traditional lands and forced to live together with different language groups in makeshift towns like Fitzroy Crossing (24). They had sub-standard housing and sanitation and were prevented from using traditional languages and engaging in cultural activities. Some became members of the stolen generation (involving forced removal of children from families by the Australian government under the policy of Assimilation); others were taken into local mission schools (24). With citizenship came access to government funding and to alcohol, which was used to deal with the stress from historic trauma and current stress. Alcohol abuse became widespread in the Fitzroy Valley as did alcohol-related accidents, injuries, ill-health and mental health problems (24).

In 2007, the Fitzroy Crossing Hospital had 30-40 admissions each day with alcohol-related injuries and intoxication. That year there were 55 tragic deaths (including 13 suicides), mostly of young Aboriginal people in the Valley. This high suicide rate, equivalent to 500 suicides per month in a city the size of Perth, prompted a Coronial Inquiry into death from self-harm in the Kimberley. State Coroner Alistair Hope concluded there was a very strong relationship between alcohol use and these suicides (26).

At the 2007 Annual Women's Bush Meeting, Aboriginal women decided that 'enough was enough' and immediate action was necessary. They consulted community members, then June Oscar and Emily Carter successfully lobbied the Director of Liquor Licensing in Western Australia and in September 2007 achieved a 6-month trial of restrictions on the sale of take-away alcohol in the Valley. The restrictions were extended and evaluated at 12 months and found to have significant benefits for health and wellbeing, including reduction in alcohol-related harms, violence and crime (27).

In October 2008, Aboriginal women became concerned about the effect that alcohol use in pregnancy might have on child health and the intergenerational transfer of culture including traditional art, stories and ceremonies. Led by Marninwarntikura Women's Resource Centre and Nindilingarri Cultural Health Services, they drafted a strategy to address Fetal Alcohol Spectrum Disorders and early life trauma called the Marulu strategy (27-29). Marulu is a word in the Bunuba language that means 'precious, worth nurturing' (28, 29).

1.2.5. The Lililwan Project

In 2009, Aboriginal women Maureen Carter (CEO Nindilingarri Cultural Health Services) and June Oscar (CEO Marninwarntikura Women's Resource Centre) initiated a research partnership with The George Institute for Global Health and The University of Sydney Medical School to conduct The Lililwan Project. The aim was to address the community priority of establishing the prevalence of alcohol use in pregnancy, fetal alcohol spectrum disorders (FASD) and early life trauma. Lililwan is a Kimberley Kriol word meaning 'all the little ones' (2).

Following best practice for research with Aboriginal communities, data collection began only after extensive community consultation and after obtaining community consent from Aboriginal leaders and Aboriginal-led organisations (30). Ethics approval was obtained for each stage of the Lililwan project from four ethics committees. Participants gave individual consent for each stage of the project. A memorandum of understanding was developed between research partners to articulate the potential risks and benefits of the project. The Aboriginal community has custodianship of all data and must approve any presentation, publication or reporting of data.

The prolonged and devastating impact of prenatal alcohol exposure (PAE) is increasingly recognised. PAE can injure the fetal brain and impact growth, development, learning and behaviour. It can cause birth defects and problems with vision and hearing. It may result in FASD with lifelong consequences. Worldwide, it is estimated that 10% of women drink during pregnancy and that FASD occurs in ~8/1000 pregnancies (31-33). However, rates of PAE and FASD are variable between and within countries and are significantly higher in at risk groups including children in Indigenous communities, foster care, juvenile justice, orphanages and mental health facilities (34).

FASD is characterised by severe neurodevelopmental impairments that affect educational and development trajectories and limit lifelong potential for employment and independent living. PAE during the first trimester is responsible for the three sentinel facial features of FASD (thin upper lip, flat philtrum, and small palpebral fissure) and for birth defects, however the ‘hidden’ damage to brain structure and function can be caused by PAE at any stage throughout pregnancy (35).

Data from the Lililwan Project indicate that more than half (55%) the mothers of our cohort consumed alcohol during pregnancy, of whom most (95%) drank at “risky” to “high risk” levels according to Alcohol Use Disorders Identification Test - Consumption (AUDIT-C) scores (36). Drinking through all three trimesters of pregnancy was reported by 53% of those who drank, with 88% drinking in the first trimester (36).

FASD was diagnosed in 21 of 108 (190 per 1000 or 19%) Lililwan children, which is one of the highest prevalence rates globally and the only population-based prevalence data available in Australia (37). It is important to note that these mothers did not have an understanding of the impact their drinking could have on their children.

Stage 1 of the Lililwan Project (2009-10) included the development and use of a medical history checklist to obtain information (such as demographics, antenatal exposures, early life trauma) by interview from parents and caregivers of children born in 2002 or 2003 and residing in the Fitzroy Valley. Stage 2 (2011-13) involved comprehensive multi-disciplinary neurodevelopmental and clinical assessments of children, including hearing and vision, and the development of management plans for families. Stage 3 (2014-19) involved evaluation of service utilisation in the Fitzroy Valley by mapping health services. Stage 4 (2014-21) addresses the needs of children living in the Fitzroy Valley through examination of medical records to document lifetime hospitalisations and emergency department presentations. My PhD project incorporates data from stage 2, stage 3 (**Chapters 2 and 3**) and stage 4 **(Chapters 4, 5 and 6);** (Figure 1.1).

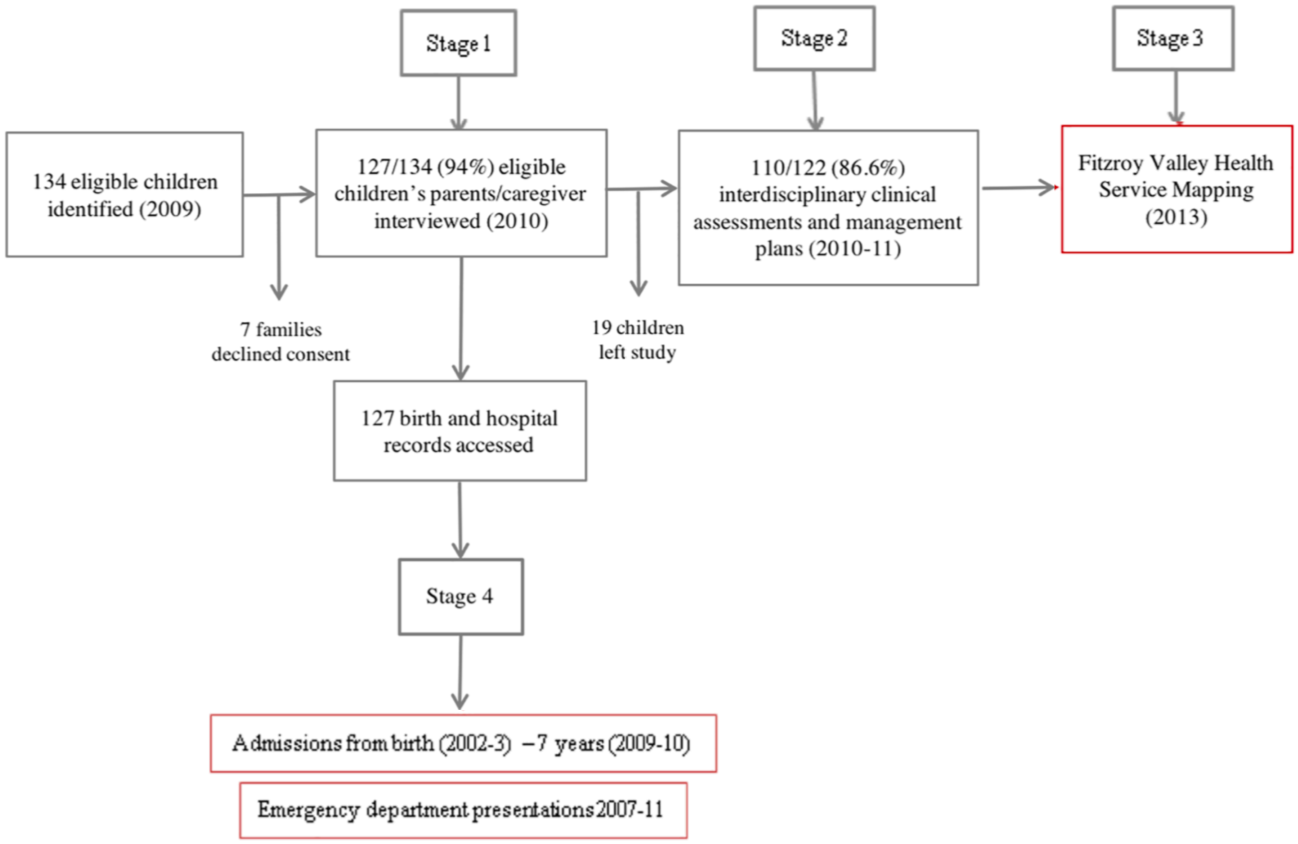

Figure 1.1. The Lililwan Project and how my PhD (red) interrelates.

1.3. Lililwan Health Services Project

Few people have documented existing health services, their use, and the challenges in accessing services for Indigenous children living in remote Australia. There are few population-based cohort studies that highlight and represent the interests and needs of an individual community. This PhD thesis provides the first population-based data on access to and utilisation of health services in the very remote Fitzroy Valley by predominantly Aboriginal, primary school aged children from the Lililwan cohort. I aimed to identify service use, gaps, and barriers to access, to inform future policy and planning for the Fitzroy Valley and similar remote Australian communities.

I hypothesised that the need for and use of health services would be high in very remote Australian Aboriginal communities; that services would be inadequate to serve children with acute and chronic complex disorders and disability; that many health conditions would be preventable; and that social disadvantage contributes to health service use.

This work was conducted in adherence to the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics and the National Health and Medical Research Council (NHMRC) guidelines for ethical research with Aboriginal and Torres Strait Islander populations (38, 39).

1.3.1. The research aims

The aims of this work, the way in which they were addressed, and the key outcomes are as follows:

> ***Aim 1.*** *To conduct a literature review to assess availability, access to, and use of health services by Aboriginal and Torres Strait Islander children in remote Australian settings; to compare available services with international best practice recommendations; and to identify service gaps to inform solutions* ***(Chapter 2).***

This encompassed a strategic literature search that identified 70 titles in electronic medical databases and 49 in the grey literature for review. Strict inclusion and exclusion criterion were applied. Data were extracted and summarised from 119 documents. This chapter highlights the paucity of information around remote dwelling children's access to and utilisation of health services across Australia. It highlights the difficulties of delivering services in these remote geographical locations, complete with environmental, workforce and cultural challenges. These findings provide a guide to the gaps in research and knowledge, and I have aimed to fill some of these gaps in subsequent chapters.

> ***Aim 2.*** *To document existing paediatric (medical, allied health and mental health services) in the Fitzroy Valley and to develop and utilise an illustrative case to show the full spectrum of burden of disease experienced by children in remote communities* ***(Chapter 3)****.*

We found no existing documents that provided a comprehensive overview of child health services in the Fitzroy Valley. The mapping of services was performed using information obtained through semi-structured interviews with clinicians and service managers from 17 key service providers in the Western Australian Country Health Service, Kimberley Population Health Unit, Nindilingarri Cultural Health Services and non-government agencies. Qualitative data were collected from answers to questions to guide our understanding of existing services. We identified that service delivery is impacted by inadequacies in staffing levels, facilities and accommodation for health professionals. There are challenges with staff recruitment, high staff turnover, funding complexities, duplication and lack of coordination of services, and the logistics of operating services in large geographic areas, extreme environments, and with a lack of transport options. In particular, there is a critical shortage of Aboriginal Health Workers. Services are currently under-resourced, necessitating they focus on acute illnesses, prohibiting provision of comprehensive preventative and primary health care and the management that is required for children with chronic, complex disorders associated with disability, such as FASD. This work will inform future health service planning and staffing attraction and retention strategies. This chapter incorporates an illustrative case to show the burden of disease experienced by children in remote communities and the number of services required to manage their complexities.

Aim 3.** To document and review lifetime (0-7 years) admissions to hospital for two complete birth cohorts of predominantly Aboriginal children in the Fitzroy Valley* ***(Chapter 4).

All children born in 2002-3 and living in the Fitzroy Valley in 2009-10 were eligible to participate. For most children (127/134 95%) interviews were completed with care givers, of whom 78% were birth mothers. Data from interviews were cleaned, coded and analysed. Medical case notes were reviewed in 2011. Lifetime hospitalisation data were available and included the dates and reasons for admission, together with comorbidities. Conditions were coded using the International Classification of Diseases (ICD-10). Most children were Aboriginal (95.3%) and half were male (52.8%). For children with at least one admission (89/127 or 70%) there were 314 admissions for 424 conditions (median five, range 1-12 admissions). Infants (N=56, aged < 12 months) accounted for 108 (38.6%) admissions (median 2.5, range 1-8). Twelve admissions were in neonates (aged 0-28 days). The primary reasons for admission (0-7 years) were infections, including of the: lower respiratory tract (27.4%); gastrointestinal system (22.7%); and upper respiratory tract (11.4%). Comorbidities were common. Many hospitalisations were feasibly preventable. The high rates likely reflect disadvantage and limited access to outpatient and preventative health services.

Aim 4. *To review emergency department (ED) presentations to the Fitzroy Crossing Hospital ED over a 5-year period (2007-11) for the Lililwan cohort* ***(Chapter 5).***

There were 1058 presentations during 2007-11 inclusive for our cohort. Most children (81%) had at least one presentation (median 9.0, range 1-50 for those with at least one presentation). Common presentations were for screening, follow-up and social reasons (16.0%), injury (15.1%), diseases of the ear (14.9%), skin (13.8%), respiratory tract (13.4%), and infectious and parasitic diseases (9.8%). Rates of presentation were higher for children with prenatal alcohol exposure (PAE). Socio-economic factors such as household over-crowding and financial and food insecurity were commonly associated with presentation to the ED. Many reasons for presentation were potentially preventable. There is a need for culturally appropriate, public health preventative strategies and improved access to primary health services in remote Australia.

Aim 5. *Consider public health preventative strategies and underlying reasons for high rates of presentation to emergency departments and admissions to hospital* ***(Chapters 3-5)*** *and develop recommendations for service provision and future research* ***(Chapter 6).***

In summary, the series of studies reported in this thesis provide unique data from the first population-based cohort study of predominantly Aboriginal children living in very remote Australia, including children with PAE and FASD. The findings provide new information on children's access to and utilisation of health services in remote communities. They demonstrate the significant challenges faced by children with complex chronic and acute health needs and disability in obtaining health services in this setting. The findings also highlight the impact of alcohol on health service needs and have significant implications for informing future health service and workforce planning in remote Australia. Work in disadvantaged remote communities is logistically difficult and emotionally challenging, however it is essential that we continue to work in partnership with Aboriginal people to address their priorities and ensure that the health and wellbeing of this particularly vulnerable group of children is addressed and standards established by the United Nations Convention for the Rights of the Child are met for all Australian children.

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Chapter 2: Health services for Indigenous children in remote Australia: a strategic literature review

Foreword for Chapter 2: Health services for Indigenous children in remote Australia: a strategic literature review

Chapter 2 provides an overview and analyses of all grey and peer-reviewed literature, published over twenty years (1990-2021), related to health service utilisation and needs of Indigenous children in Australia. The aim in performing this review was to identify existing gaps in knowledge as published in the literature, and to inform the future work comprising this thesis, and beyond.

This review (***Health services for Indigenous children in remote Australia: a strategic literature review***) will be submitted to *Rural and Remote Health* as a review for publication in June 2022.

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Australian
National
University

Statement of Contribution

This thesis is submitted as a Thesis by Compilation in accordance with https://policies.anu.edu.au/ppl/document/ANUP_003405

I declare that the research presented in this Thesis represents original work that I carried out during my candidature at the Australian National University, except for contributions to multi-author papers incorporated in the Thesis where my contributions are specified in this Statement of Contribution.

Title: Health services for Indigenous children in remote Australia: a strategic literature review

Authors: Philippa Dossetor, Kathryn Thorburn, Heather Jeffery, David Harley, Elizabeth Elliott & Alexandra Martiniuk

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2.1. Abstract

Introduction: In Australia, there is a significant gap between health outcomes in Indigenous and non-Indigenous children, which may relate to inequity in health service provision, particularly in remote areas. We aimed to review the literature to describe health services and their use by children living in remote Australia and compare services to best practice models to identify opportunities for improvements.

Methods: Electronic databases of medical literature were searched (Jan 1990 to May 2021). Grey literature was identified through investigation of websites, including of local, state and national health departments. Identified papers (n=1775) were screened and duplicates removed. Information was extracted and summarised.

Results: Electronic databases of medical literature were searched from Jan 1990 to March 2021. Essential information was extracted and summarised for papers meeting inclusion criteria for the review. A total of 70 titles was identified in a strategic search of electronic medical databases and 49 in the grey literature. Strict inclusion and exclusion criteria applied. Data were extracted from 119 documents.

Conclusions: Existing services struggle to meet demand. Barriers to effective child health service delivery in remote Australia include availability of trained staff, limited services and difficult access. Gold standard models for service delivery incorporating community engagement and collaboration should be explored. Increased resources with a focus on primary prevention and health promotion are essential.

2.2. Introduction

The estimated 727,500 Indigenous Australians comprise 3.3% of the total population. (1). One fifth of Indigenous Australians live in remote and very remote settings (1). Indigenous children living in remote Australia experience a greater burden of disease than children living in metropolitan settings (2-8).

Indicators of child health and life expectancy include low birth weight (< 2500g) and infant mortality rate (6, 9, 10). In 2010, Indigenous babies were twice as likely (12%) as non-Indigenous babies (6%) to have a low birth weight (LBW). The Indigenous infant mortality rate is 1.8 times higher for non-Indigenous infants (5.1 versus 2.9 infant deaths per 1000 live births, respectively) (11).

Indigenous Australians are hospitalised at 2.6 times the rate of non-Indigenous Australians (12). Rates of hospitalisation and emergency department presentation for Indigenous children living in remote areas are high, often for potentially preventable skin, respiratory and gastrointestinal infections (7, 13, 14).

Child health is a human right and Indigenous children living in remote areas need priority access to high quality health care (15) to decrease the risk of chronic disease and increase life expectancy. Social determinants contribute to Indigenous health inequality and include poor nutrition, housing shortage, limited primary health care access, low income and poor educational attainment (16).

Following the 2009 ‘Closing the Gap’ strategy each Australian State and Territory developed plans and policies to address gaps between Indigenous and mainstream health indicators and improve the effectiveness of health service delivery to children in remote settings (17, 18). For example, the Queensland State Government aimed to close the health gaps by 2033 by addressing risk factors, increasing primary prevention strategies and access to multidisciplinary health services, and nurturing safe environments for children (17).

The 2021 ‘Close the Gap’ report showed mixed success (19). There was a four-fold increase in health assessments for Indigenous Australians between 2010 and 2019 and a 17% reduction in avoidable deaths between 2006 and 2018 (19), however this rate of decline is slowing. Indigenous Australians currently die from avoidable causes at three times the rate of non-Indigenous Australians (19).

This review aims to identify relevant academic and grey literature to 1) describe existing health services and their use by Indigenous children in remote Australia; 2) compare these to best practice models; and 3) identify opportunities for improved service provision. All three project aims were fulfilled.

2.3. Methods

2.3.1. Search strategy

A comprehensive search strategy was developed with help from a medical librarian to find relevant articles from medical literature databases using MeSH Headings, key words, Boolean operators, and wildcard search techniques (e.g., a* to show derivatives. The search strategy was applied as consistently as possible across the varied databases and repositories.

2.3.2. Electronic databases of medical literature

Electronic databases of medical literature (Medline, Cumulative Index for Nursing and Allied Health Literature (CINAHL), Psychological Information Abstracts Services (PsycINFO), Web of Knowledge, Excerpta Medica Database (EMBASE), Educational Resources Information Centre (ERIC), and Scopus) were searched for relevant publications. Health department and other relevant websites were also searched (Figure 2.1).

2.3.3. MeSH headings and key words

The MeSH Headings used were health services; community health services; primary health care; family practice; child health services; adolescent medicine; health services, Indigenous; rural health; rural health services; rural population; rural; child; pediatrics; Oceanic ancestry group; and Australia. The key words searched were health services; community health services; primary health care; family practice; adolescent medicine; Indigenous health; Indigenous health services; rural; remote; rural health services; child; infant; paediatrics; paediatrics; Indigen*; Aborigin*; Oceanic ancestry group; allied health; Australia.

2.3.4. Grey literature search

A list of target websites was devised, including government agencies, research centres, Indigenous health portals, and non-government health-related or Indigenous advocacy organisations. Commonwealth and State/Territory websites were also searched, as were relevant university-based research centres, private research agencies, Non-government Organisations and international bodies. National databases focusing specifically on health or Indigenous people were also searched. Online searches were conducted using key words and terms similar to those used to search the academic literature.

2.3.5. Websites and databases for grey literature search

The following websites and databases were searched: Informit Indigenous Collection (IIC); Lowitja Institute, Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and Australian Aboriginal Health Info-net. Websites of the Federal and State Governments Health departments and associated agencies; parliamentary hearings and senate committees, Commonwealth and State; Aboriginal medical services; regional health services; Australian Human Rights Commission; National Health and Medical Research Council (NHMRC) of Australia; Royal Australasian College of Physicians; Royal College of Paediatrics and Child Health (UK); Australian Bureau of Statistics, Australian Institute of Health and Welfare (AIHW), Research Institutes focussing in Indigenous health e.g., Menzies, Centre for Aboriginal Economic Policy Research at Australian National University, Telethon Institute for Child Health Research (Western Australia), Centre for Remote Health, and Australian Primary Health Care Research Institute (APHCRI).

2.3.6. Inclusion criteria

All medical publications and grey literature published January 1990-May 2021 and describing existing rural and remote health services, health service use, or needs in relation to Indigenous Australian children (0-18 years) was included. Grey literature was not included unless it provided original data or insights on health service delivery to Indigenous children living in remote areas.

2.3.7. Exclusion criteria

Papers were excluded if they were not published in English, were outside the review time frame, or focused on: health services in foreign countries or large metropolitan areas; adult, dental, oral, or sexual health; education of children or health professionals; social or cultural issues; attraction and retention of health professionals; substance abuse and misuse; childcare centres; the judicial system; or health policy (Figure 2.1).

2.3.8. Article selection and review process

Two authors reviewed the title, abstract or summary and, when relevant, full text of all publications identified in the search for relevance and eligibility for inclusion. A third author resolved disagreements. Reference lists of publications were reviewed for additional relevant citations. Data from all included papers were extracted and summarised.

2.3.9. Definitions

Health services

We defined ‘health services’ as any primary, secondary or tertiary child health services, including paediatric specialists, remote nursing clinics, allied health professionals, hospital inpatient and emergency departments, patient retrieval through the Royal Flying Doctor

Service, fly-in-fly-out (FIFO) services, paediatric outreach services, multidisciplinary teams, tele-paediatrics and videoconferencing or ‘telehealth’ systems. Additionally, the public health approach to health services provides surveillance of the health service through the consideration of epidemiology, health, and ill-health.

Health systems

We used the World Health Organisation’s definition of ‘health systems’ or ‘healthcare systems’ to include all organisations, people, and actions whose primary intent is to promote health (20). A good health system incorporates the organisation of people, institutions, and resources to deliver health services which meet the needs of all people. This requires resilient and considered financial procedures, a qualified and well-paid workforce, reliable evidence-based information on which to base policies and treatments, adequate and well-maintained facilities, and logistics allowing the delivery of quality medicine and technologies.

Rural and remote locations

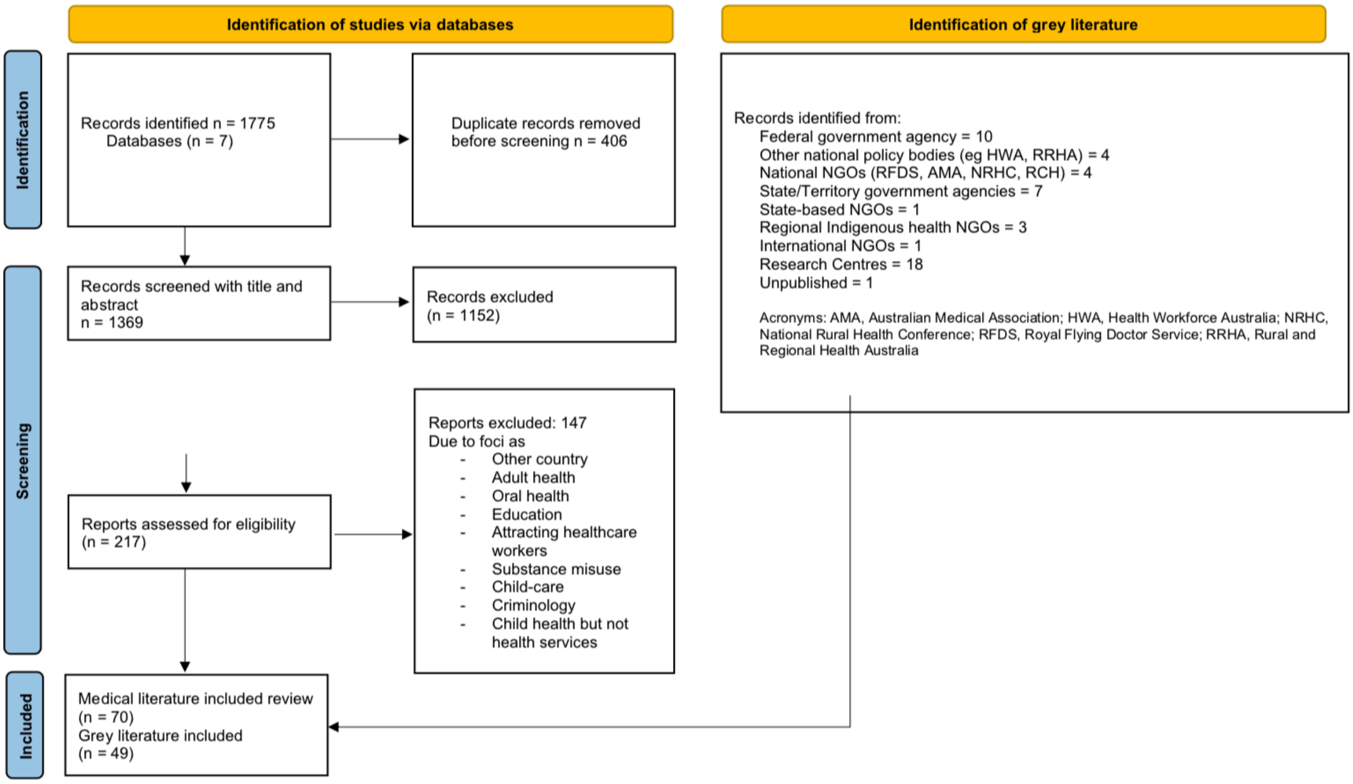
The classification scale used to define rural and remote varied between papers, however the Rural, Remote and Metropolitan Areas classification (RRMA) and the Accessibility Remoteness Index of Australia (ARIA) scales were most used (21, 22).

2.4. Results

We identified 1775 papers in the medical literature, removed 406 duplicates, and reviewed 1369 abstracts (Figure 2.1). Of these, 1152 (87.4%) were excluded. Following full text review of the remaining 217 (12.6%) papers, 70 were deemed eligible for inclusion. In addition, 49 reports from the grey literature satisfied inclusion criteria (Figure 2.1).

Publications exploring topics such as the physical or mental health of Indigenous neonates and children, infant mortality, disease prevention, and maternal or family health, were only included if they reported on health service utilisation. Additionally, papers that discussed child health services in Australia, health service utilisation and access, primary or other health care in rural/remote settings, ambulatory services, emergency department presentation patterns, and barriers to effective primary health care for children were included (Table 2.1).

The findings of this review are presented under the following subheadings to address the outlined aims: 1) existing health services and service use for Indigenous children in remote Australia, 2) workforce challenges in remote settings, 3) characteristics for an effective service, and 4) models of care and solutions.



Adapted from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Figure 2.1. Search results from electronic databases of medical literature

Table 2.1. Grey literature search summary

Website type	**Number of websites that yielded results**	**Number of documents found**
Federal government agency	6	10
Other national policy bodies (e.g., HWA)	2	4
National NGOs (e.g., RFDS, AMA, NRHC)	6	3
State/Territory government agencies	5	6
State-based NGOs	5	1
Indigenous health NGOs – regional	4	3
International NGOs	1	1
Research Centres	15	18
Unpublished	N/A	1
Total		**47**

AMA, Australian Medical Association; HWA, Health Workforce Australia; NRHC, National Rural Health Conference; RFDS, Royal Flying Doctor Service

2.4.3. Existing health services for Indigenous children in remote Australia

2.4.3.1. Children's use of services

Indigenous adults are more likely to use health services than non-Indigenous adults (23). In contrast, Indigenous children are less likely than non-Indigenous children to have visited a health service in the last 12 months (mean 2.5 v 3.1, $p<0.001$), used maternal and child health services (OR=0.35, 95%CI: 0.24-0.49), general practitioners (OR=0.45, 95%CI: 0.35-0.64) or paediatricians (OR=0.52, 95%CI: 0.35-0.77) (24). However, Indigenous children are more likely to be hospitalised (17% versus 9.9%, $p=0.01$) (24).

There is interplay between social structures and health outcomes (13.0% versus 3.7%, $p<0.001$) (24). Proportionally, more Indigenous than non-Indigenous infants live remotely or very remotely but it is not known whether outcomes are worse for Indigenous infants because of lack of access to services or the impact of lower levels of parent education, employment and private health insurance, younger maternal age, and increased rates of single parenting (24). The causal relationship between health services and outcomes cannot be assessed using cross-sectional data and some datasets do not incorporate Aboriginal-specific health services (24). No theoretical framework (such as the Anderson behavioural model) was used for modelling the risk factors for health service use and health outcomes (24).

A retrospective cohort study of 756 mothers and their 1494 children over 14-years (1984-1997) at three metropolitan Western Australian general practices demonstrated that children's use of health services was positively correlated with their mothers' use of services, mothers' stress level, psychosocial problems in the child, and poor-quality mother-child relationships (25, 26). Additionally, the rate of primary health service use by children is influenced by their health status, birth order and socioeconomic status. Children with poorer health, younger age, higher birth order and more socioeconomic disadvantage attend more frequently) and whether the appointment is physician initiated (if so, children are more likely to attend), and bulk billed (increased attendance) (25, 26). There is also a positive correlation between a child's use of a GP or attendance at hospital and that of their sibling (25). Integration of maternal and child health services increases children's use of health services (25, 27).

A clinical audit of monitoring of developmental outcomes in Aboriginal healthcare services found that children who attended infrequently were less likely to be monitored (28). The study found that training of remote Aboriginal health workers and remote area nurses in developmental monitoring could increase consistency.

2.4.3.2. Access to effective health services and challenges and barriers to their provision

Health professionals who work in or visit remote communities understand the barriers to accessing health services, but limited evidence is published (29, 30). Identified challenges to delivering effective and equitable health services to Indigenous children in remote areas include:

- poor access (distance between services and communities, dirt roads, lack of private transport, limited patient accommodation, lack of outreach services);
- poor communication and infrastructure (lack of internet/telephone access, public transport, sewerage, water supply, electricity);
- lack of skilled health professionals (difficulty in recruitment and retention and high staff turnover, limited accommodation);
- limited Aboriginal and Torres Strait Islander health workforce;
- environmental factors (high temperatures, flooding, risks associated with travelling long distances in remote Australia);

- health service factors (inflexible health service structures, poor communication and coordination between services, resource constraints e.g., inadequate staff/equipment);
- economic factors (increased cost of transport, food, accommodation);
- issues of cultural safety (lack of interpreters, poor doctor-patient communication; lack of cultural competency; different perceptions of health, illness and medicine; historical association of hospitals with death and mistreatment of Indigenous people);
- lack of engagement with and input from consumers including young people.

The *Kimberley Regional Aboriginal Health Plan*, developed with representatives from Aboriginal, state and commonwealth government-controlled organisations provides recommendations to improve Aboriginal health in the very remote Kimberley region of Australia (29). It recommends coordination of planning and service delivery for primary health services, growing the Aboriginal health workforce, increasing health prevention and promotion, and ensuring culturally sensitive collaboration and communication (29). The collaborative nature of this report gives credence to the concerns raised and the recommendations and provides goals for improving access to gold standard health services for remote dwelling children in the Kimberley, Western Australia (29).

Interviews with health practitioners, outreach specialists, regional health administrators and patients in remote Northern Territory (NT) communities provided opinion on the challenges and barriers to accessing health services in remote settings (30). Informed by this information, a specialist outreach service was developed and implemented, which increased gynaecological consultations four-fold over 3-years (1996-1999) (31). Equivalent increases have not been seen for specialties without outreach services (30). Another study showed that specialist outreach services increased access to elective and urgent surgery (32).

Access depends on service availability (including out of hours), travel/transportation, costs, and language and cultural barriers (29, 30). There is no standard measurement for access to health care for children in remote Australia and the validity of the hospitalisation for Ambulatory Care Sensitive Conditions (ACSH) measurement of access to health services and avoidable morbidity is debated for communities with limited health services (33). Nevertheless, the ACSH provides a measure that is independent of tendency to seek care, disease burden or prevalence, and workforce supply (34). A higher ACSH score correlates with poorer access (33). The ACSH has been used to measure access to services based on physician supply and potentially preventable hospitalisations, however increased physician supply is not the sole determinant of health care quality (33). Increased residential remoteness, lower income, lower educational level and current smoking status are also associated with a higher ACSH score, reflecting the impact of social determinants on access to health care (33). Measuring access requires incorporation of many factors, including the features of a health care system and characteristics of individual patients or target populations.

An alternative measure of health service availability is the population-based distribution of health facilities (35). The distribution of intensive care units (ICU) correlates with population distribution, but accessibility varies geographically. For example, the median distance to the nearest ICU is 161.7km in Western Australia and 7.6km in the ACT (35). However, there are few data on the availability of other health services by population and the relationship between access to primary health care services and health outcomes in rural and regional Australia has not been evaluated (3, 36). It is important that researchers partner with service providers to ensure that new remote services are adequately evaluated.

It is difficult to compare services across Australian States and Territories because each jurisdiction manages its own health budget and policies. It is also difficult to compare health system performance at a jurisdictional level, apart from reviewing CoAG-monitored health indicators (e.g., Close the Gap targets). Life expectancy, mortality rates, morbidity from chronic diseases and lifestyle factors (obesity, smoking, poor nutrition, physical activity) are used as measures of population health but are less relevant to children (37). Indigenous child health outcomes do not solely reflect health system functioning, but are impacted by social and environmental factors, case-mix, and public health campaigns (38-40).

Families must travel long distances to access allied health services for children in remote settings, notably paediatric speech pathologists (41). Most (98.6%) allied health treatments are not delivered at the ideal rate of at least once per week in rural NSW and Victoria (41). There, over 30% of residents live beyond the ‘critical maximum distance’ of 50km from the therapist, beyond which patients are less likely to travel. Access to speech therapy is particularly important because of high rates of otitis media, hearing problems and poor language skills in remote Indigenous children (42), which impact development, education and intergenerational transfer of cultural knowledge.

Extremely isolated communities often depend on the Royal Flying Doctor Service (RFDS) for basic primary health care services and to coordinate emergency responses (43). Remote communities rely on aeromedical transport both to bring in health professionals and evacuate children for emergent and non-emergent care (44). Between 2003-2005, 6.5% of people in a very remote east Arnhem Land community were evacuated by air, with one evacuation every 2.2 days. Evacuation rates were higher during the monsoon; 47% occurred after hours; and the median wait time for the plane to arrive was 3 hours (1-21 hours). Children (37.7%) were over-represented (44). Four conditions accounted for 61% of all aeromedical evacuations: respiratory disease (21%), obstetric conditions (15%), gastroenteritis (14%) and injury or poisoning (11%) (44). This highlights the need for support and funding for local staff and services to meet prevention and primary health care (PHC) demands (44). Many people transported by the RFDS would benefit from access to multidisciplinary care (53/78, 68%) or shared specialist care (41/78, 53%) provided locally (45).

2.4.3.3. Social and cultural factors impact service use

Social and cultural factors influence service use by Aboriginal people. Some health professionals have ethnocentric attitudes and lack understanding of Aboriginal culture (29). Lack of cultural competence among health professionals deters service use by Aboriginal people (29). Disrespectful or inappropriate communication and racism also impact engagement (29). Employment of Indigenous people in health-related occupations increased from 96 to 173 per 10,000 between 1996 to 2016 (46). Although 54% of the full-time equivalent workforce in Commonwealth-funded Indigenous primary healthcare are Indigenous people, they are 3 times less likely than non-Indigenous people to be part of the national health workforce (46). Appropriate training in cultural competence of non-Indigenous staff and employment of more Indigenous staff would increase access to culturally appropriate health services (29).

2.4.3.4. Funding complexity

Local, state, and national governments, privately funded organisations and NGOs all provide funding for remote health services. The Medical Specialist Outreach Assistance Program (MSOAP) was funded to improve delivery of specialist health services in remote Australian (47). In jurisdictions including the NT this funding is accessed directly from the Department of Health. In others, such as Queensland (***Check-up***) and WA (***Rural Health West***), non-government entities receive the MSOAP funding and report back to the Australian Government (47). Part of MSOAPs responsibility is to ensure that the services they fund are linked with existing services. Access to the funding requires lobbying by medical professionals and a competitive application process (47).

Overall expenditure for Indigenous health services and per capita expenditure on public hospital services is higher for Indigenous than non-Indigenous Australians (48). During 2008-09, a total of $3,700 million was spent on Indigenous health services. Per capita expenditure for Indigenous Australians was 155% of the expenditure for other Australians, being even higher for Indigenous people in remote (241%) and regional (144%) settings (48). In 2015-16 the average expenditure per Indigenous Australian was approximately $8,494 (130% the amount for non-Indigenous Australians $6,657), with almost half ($4,436) of this expenditure on hospital services (46).

2.4.4. What do we know about the workforce in remote locations?

2.4.4.1. High pressures on workforce

Aboriginal Medical Services (AMS) and specialist services in rural and remote Australia report increased workforce stress, compared with metropolitan services (42, 49). In rural and remote settings there is a high demand for local services but physicians report fewer child health services in rural/remote compared with urban settings for audiology (11.1% versus 0%), ENT (33.3% versus 3.9%) and hearing aid provision (37.7% versus 1.9%)(42). Children in rural and remote settings experience longer wait times for audiologists than urban children (18.3% versus 1.9% waited over the recommended 3 months) (42). Between 1996-2001, the Australian health workforce increased by 14.7%, yet the number of health workers/100,000 population remains low in remote (1498/100,000) versus metropolitan (3005/100,000) locations. (50, 51). The number of specialists is increasing in Australia, however they are unequally distributed with an oversupply in urban locations (51). In 2001 there were only 75 specialists in the "Top End" region of the NT to care for a population of 148,641 people spread across an area of over 500,000 km^2, with 30% living in rural and remote areas. Of these 75 medical specialists only 12% reside in rural and remote areas, compared to 28% of the general Australian population.

There are many workforce initiatives to help alleviate rural GP service pressures, many of which rely on encouraging doctors to work in rural settings (52-55). Up-skilling of paediatric nurses and Aboriginal Health Workers aims to alleviate some workforce shortages (56).

Multidisciplinary assessment (incorporating medical, nutritional, psychosocial, and allied health) of children living in remote communities has demonstrable benefits. These include: recognition of ill-health and risk factors across multiple functional domains; providing data to inform development of individualised management strategies; and enabling coordinated collaboration and communication between teams to avoid service delivery gaps (52-55). Regular meetings that facilitate communication between health professionals, disciplines and organisations are beneficial in establishing clear roles and responsibilities (57, 58). Employment of administrative staff for coordination and communication with and on behalf of communities would alleviate some time pressures experienced by health personnel and improve organisation (54). Additionally, improved infrastructure (e.g. telehealth, internet and IT services) would support workforce in remote locations (55).

Improving access to primary, secondary and tertiary health services is crucial to improve child health (30). In remote communities, patient access is limited by lack of transport and accommodation options (54). Increasing public transport to isolated communities or implementing other service delivery models (e.g. outreach or telemedicine) may increase equity of access and service use (27). Paediatric outreach services to rural and remote areas benefit children and their families in part by reducing their need to travel to services. Such services also increase health professionals' cultural understanding and engage communities (32, 59-61).

Mobile services may be a valuable tool to address rural-urban healthcare differences. The cost-effectiveness of outreach ear-health service was compared to a mobile ear screening and surveillance service (62). The mobile service was cost-effective but was based on nascent modelling of ear disease in Indigenous children.

2.4.4.2. Optimal staffing for remote health services

Optimal health professional staffing levels for Australia were not found during our search, other than for nurses (8). However, some regional planning documents prescribe optimal ratios for their region (29, 63). Based on recommended population ratios for Central Australia, there should be 1 Aboriginal Health Worker per 100 Aboriginal people, 1 community nurse per 250 people and 1 doctor per 600 people (64). It is suggested that communities with a stable population of 250 should have a health service located within the community as well as access to on-call services. Communities of between 100-250 people should have a clinic staffed by two health professionals, either senior Aboriginal Health Workers or registered nurses (8). These targets were established in 1997 and meeting them continues to be a challenge due to difficulties with workforce retention and resources (8).

2.4.5. What constitutes an effective service?

2.4.5.1. Measuring the effectiveness of a health service

The effectiveness of a health service can be indicated by its use (the number of presentations); the system performance; or community health outcomes (65). However, effectiveness frameworks are difficult to apply in remote health settings that are not designed to capture these metrics. The Australian Institute of Health and Welfare compared health system performance across all jurisdictions (2012). They reviewed health service efficiency and appropriateness; responsiveness to the needs of Indigenous people; accessibility; continuity of quality health care; and the capability and sustainability of health care systems (48).

Immunisation rates reflect the reach of prevention programs. In 2018, Immunisation rates in 5-year-olds were higher for Indigenous (97%) than non-indigenous (95%) children (46). In

Western Australia from mid-2015 to mid-2017 preventable hospitalisations were 3.8 times higher in Indigenous Australians (91 per 1,000 compared to 24 per 1,000 non-Indigenous people, in age-standardised groups) (46).

A comprehensive review of the underlying features of effective primary health care models in rural and remote Australia highlighted the importance of supportive policy, positive State and Territory relationships, and community commitment (66). Fundamental requirements for effective and sustainable health services include good governance and management, community involvement and leadership, adequate financing, infrastructure, and ample workforce supply (66). The effectiveness of a service can be measured using a Primary Health Care (PHC) framework which assesses health service process and outcomes (e.g., increased recruitment, decreased wait times, decreased suicide rates and GP feelings of isolation, increased community participation, increased workforce retention, improved cost effectiveness, increased referrals, and improved access to records) (66).

Many authors highlight the importance of evaluating health services to underpin best practice, ensure improvements are maintained, and inform establishment of future health services (2, 56, 61, 65-70). Evaluation highlights the key features of optimal health services (57) however the evaluation method needs to be carefully considered. For example, Key Performance Indicators (KPI) can be used to quantitatively assess Indigenous PHC services. However, KPIs have been discredited because their narrow focus overlooks programs underpinned by social theories and Indigenous concepts of health, and thus they fail to accurately reflect the contribution of a service to health (71). Several studies discussed assessment of the sustainability and effectiveness of remote health services through continuous quality improvement (CQI, Figure 2.2) (68-70). CQI involves ongoing collection, through community-based research, of data which aligns with Indigenous concepts of health and service delivery principals, to determine the functionality of an organisational system and enable implementation of improvements (68, 69). CQI has proved very effective for assessing PHC of chronic conditions in remote Australia (58, 68, 69). When applied to regional services, CQI has resulted in large increases in the number of patients accessing PHC services (from 12 to 4000 patients from 1995-2009) (70). Thus, qualitative assessment of programs is also important.

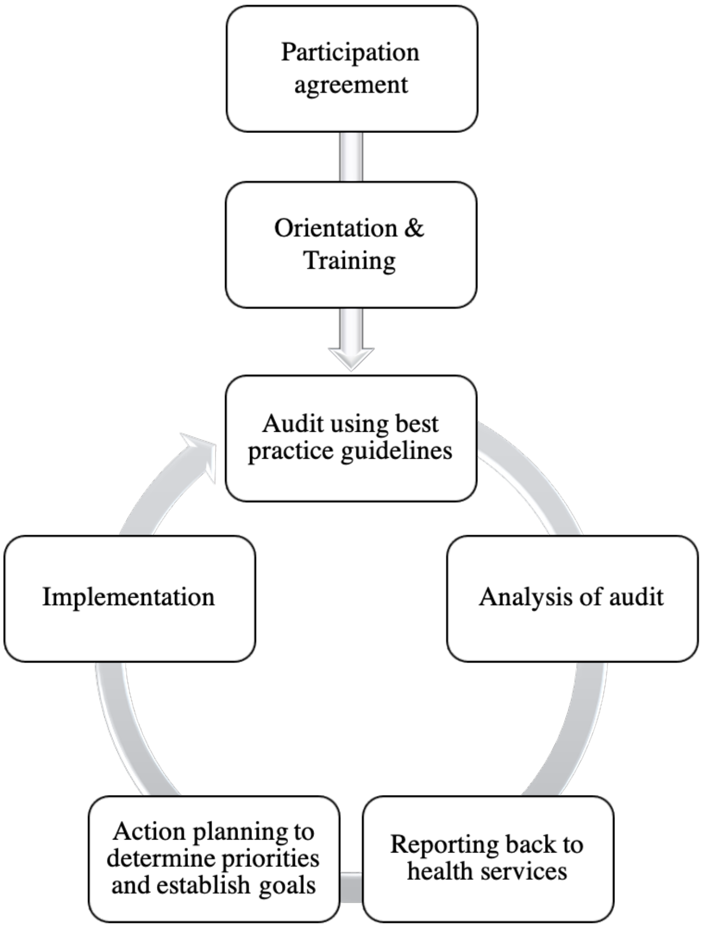


Figure 2.2: A CQI approach with the continuous cycle ensuring quality improvement and service delivery.

2.4.5.2. Limitations to the effectiveness of health services

Remoteness, inadequate medical workforce, and poor coordination negatively impact health service effectiveness (8, 72). In some very remote settings (including the Fitzroy Valley, WA) Community Health staff, whose primary role is in preventative health care, are forced to deliver acute medical care (43). There is an increase in the proportion of children receiving nursing (rather than doctor) consultations as remoteness increases (43). The total number of midwives and child health nurses in very remote Australia has decreased in the last decade, aligned with a decrease in the number of nurses obtaining midwifery qualifications (65% in 1999 to 29% in 2008) (73). Efforts to address this issue were made by the NT Department of Health and Families by supporting remote area nurses through midwifery training (73).

Aboriginal Medical Services (AMS) are an important means of delivering culturally appropriate services for remote Indigenous children. In WA (2004), fewer than 5% of doctors, including specialists, practice in remote and very remote areas and only 5.8 full time equivalent (FTE) doctors worked in culturally tailored organisations such as AMS (43). Health systems in remote Western Australia (WA) suffer from high staff turnover and lack of specialised knowledge (74). A review of services in a remote Western Australia town of approximately 3500 population found they received monthly general paediatrician visits, and had three medical officers at the hospital, only one of whom was residing in the town permanently (74).

There are challenges in attracting and retaining clinicians, and many programs do not address the cultural, locational, and financial barriers that prevent Indigenous children from gaining access to physicians (43, 74, 75).

Individual health professionals in the remote health workforce are often forced to manage extremely complex, chronic disorders with a lack of resources and limited options for specialist referral (52) and this is rendered more difficult by professional isolation. Paediatricians are required to meet a greater demand than their capacity and resources allow, due to limited PHC services. As a result, time is allocated to children with the greatest urgency and acuity, thereby restricting the time available for primary and preventive health care services (76).

Research examining health system changes for maternal and infant health in remote parts of Australia's 'Top End' found little relationship between staff numbers and skills and the acuity and volume of patients using a service (72). Key concerns included insufficient or absent Aboriginal leadership and inadequate coordination between remote and tertiary services (72).

Qualitative research in a northern Australian health system identified six themes that contributed to a 'very chaotic system': very adhoc', 'swallowed by acute', 'going under', 'a flux', 'a huge barrier' and 'them and us' (77). A limitation of this study is that researchers observed the service in community for only a few hours.

2.4.5.3. Difficulties with communication, coordination, collaboration

Many services have difficulty communicating with patients and other health professionals, due to cultural incompetence and technological barriers and struggle to ensure cooperation, collaboration, and coordination between different organisations (29, 52) and remote communities. This is aggravated by challenges in case planning and organising referrals (52). It has been recommended that there should be community paediatricians who commits solely to advocating for and co-ordinating outreach services to alleviate this burden from organisations and other health professionals (76). Currently, it is estimated that for each day of clinical work one day of administration and liaison is required (52, 74, 76).

Few online sources are designed to assist in the co-ordination of health services. In the NT, the Department of Health's online Remote Atlas has a section specifically for SONT (Specialist Outreach NT). Protocols to facilitate efficient and co-ordinated health service delivery to remote communities, including SharePoint access and an online calendar with schedules of all specialist and other health services, would improve services (78).

2.4.5.4. Core health services that should be available

Using a survey and Delphi process, core primary healthcare (PHC) services for rural and remote communities were identified with key stakeholders, only 4 (10%) of whom were Aboriginal community members or consumers (79). They identified eight essential PHC services: care of the sick and injured, mental health, maternal/child health, allied health, sexual/reproductive health, rehabilitation, oral/dental health, and public health/illness prevention. They also identified seven functions required for PHC support: good management/governance/leadership, coordination, health infrastructure, quality systems, data systems, professional development, and community participation. Qualitative research found that equity in rural and remote areas was improved by prioritising service coordination, having diverse strategies, and addressing the difficulty in attaining clinicians (79).

2.4.6. Models of care/solutions

2.4.6.1. Recommendations

Numerous recommendations have been made for models of care to improve Indigenous health services, but the challenge remains to implement these (8, 65).

One recommendation is that State and Territory Health Departments engage more with other relevant health organisations to develop Aboriginal child health care policies (27). Health care delivery may improve with a national policy framework for maternal and child health (80), child and adolescent mental health services, and child nutritional supplementation (57, 81). Implementation of supportive programs to augment Aboriginal Community Controlled Health Services, particularly services with a focus on health promotion and early intervention, would improve child health outcomes (54, 55, 82).

One example of an all-encompassing model of care for remote Australia is provided by the *Kimberley Aboriginal Health Performance Framework* (KAHPF in which key recommendations address social determinants (8). Measures to improve services include better coordination and inter-agency collaboration; use of innovative programmes of health promotion targeting specific groups and using culturally appropriate, locally relevant resources; allied health support for children in classrooms; a School Entry Check for early identification of health and developmental problems; screening for common childhood problems including anaemia and growth faltering; better access to specialists; use of diagnostic protocols; clear referral pathways; long term funding for successful programs; and ongoing training of health professionals (8). This model, which is not yet fully implemented, provides a gold standard for future remote health services, and highlights the complexity of providing a thorough, effective service.

2.4.6.2. Best Practice: moving towards health equity for Aboriginal children - models of care

Another best practice public health model for child and adolescent health entails prevention programs, with individual child multidisciplinary assessments and early and secondary intervention (81). This approach maintains a reactive health system, meeting individual needs, whilst instilling preventative strategies within community. An holistic approach to health engages families and ensures Indigenous involvement in identifying problems and informing solutions for child health, growth and development (52).

Ensuring continuity of care in rural and remote settings is difficult but essential, including transition from child to adult health services and supports (52). A review of transition to adult care for children with chronic conditions stressed the importance of 'local navigators' who aid adolescent patients and families with cultural and language barriers to access care (83). Investment in local, trusted, and Indigenous people as navigators may improve care without additional financial burden (83).

Meeting optimal child health service requirements and providing access for remote communities underpins best practice service models (52). Adjustments required to improve the current service provision include increasing Indigenous involvement in service delivery and prevention programs, improving access to services, dismantling cultural barriers to increase use of existing services, using a multidisciplinary approach for diagnosis and management, increasing IT capabilities, workforce initiatives, and integrating mother and child health services. A national framework for child health services in remote health settings would be useful (8).

2.4.6.3. Community engagement

It is essential that in planning and delivering remote services there is Indigenous community leadership and involvement (29, 54) via collaborative partnerships with external organisations (54, 70, 84, 85). Ongoing program evaluation would ensure the opinions of Indigenous families using services are recognised and highlight priorities for child health (27). If possible, community-based child health services and organisations should be controlled and managed by Indigenous community members (54). Enhancing access to Aboriginal Health Worker training and increasing numbers of graduates would help dismantle cultural and language barriers that limit service use and effectiveness (82). Protocols should be generated for individual agencies, outlining best practice policies for child health and providing guidance to ensure culturally appropriate services are delivered (27, 80).

Improved youth engagement is integral to use of adolescent services. The Derby Aboriginal Health Service talked to young Aboriginal people about barriers and enablers to healthcare (86). They found that engagement was key, and best fostered by trained staff members skilled in caring for young people and continuity of staff.

2.4.6.4. Improving communication

Communication challenges between health professionals, inter-agency, communities and health departments could be improved with better infrastructure, increased use of videoconferencing, and shared electronic medical information systems (27, 54). Videoconferencing (Telehealth) is a valuable tool for specialist consultations in remote settings and supports local health professionals (87-89). In isolated areas videoconferencing saves patients time and money and alleviates stress by improving their access to better services. Videoconferencing enables education and career development for medical professionals but is dependent on technology, including secure internet coverage, which is inadequate in many remote settings (87-90).

Allied healthcare has been delivered with telehealth in rural areas and may help fill service gaps in remote locations and improve Indigenous child health (91). Children receiving therapy engage more with school and benefits could be maximised by targeting therapy to certain year levels. Because of limited funding telecare was not compared with in-person delivery of allied health services (91). Increasing health personnel's' knowledge of, access to, and skills in information technology (IT) and their capacity to deal with IT failures provides additional challenges in remote settings.

2.4.6.5. Access to services

Provision of social support and accommodation for patients and families travelling to access health services may increase the likelihood of subsequent visits, in turn improving health outcomes (54). Increasing the availability of accommodation for health professionals in remote communities would increase face-to-face clinical time, facilitate multidisciplinary care, and reduce wait times (27). Improving public and private transport options would improve access to services (27).

2.4.6.6. New services

When new health services are developed, they require adequate infrastructure and staffing to avoid being overloaded. Collaboration with Indigenous-controlled health organisations to improve public and environmental health (including preventative health strategies) and address the social determinants of health is imperative (48, 54, 80). Ensuring that new services undergo intrinsic evaluation of their processes and outcomes and undertake continuous quality improvement (CQI) is crucial.

2.5. Discussion

In this review we identified relevant academic and grey literature and have described existing health services, their use by remote dwelling Indigenous Australian children. This strength of this review is within its incorporation of a vast body of both academic and grey literature spanning over 30 years (1990-2021). It involved a comprehensive search of available literature and rigorous inclusion and exclusion criteria. As such, we were unable to cover all related topics as outlined in the methodology. We documented a high burden of child health needs in remote communities, limitations to the delivery of existing health services, and barriers to effective service delivery including distance, workforce, and cost. Models for better service delivery have been proposed and require co-ordination of and collaboration between existing services and involvement of local Indigenous communities in their planning and implementation. Attracting and retaining medical professionals to service remote locations is a challenge and additional financial, emotional, educational, and collegiate support must be considered to support their well-being and enable them to provide optimal patient care. Support could include new technologies such as telehealth and practical strategies for attracting and maintaining staff, including appropriate housing in remote settings. Gold standard recommendations for staffing numbers in remote Australia need to be established and supported by a national policy framework.

If early onset chronic diseases are to be prevented, then investment could be made to enable schools to provide adequate child nutrition and preventative programs such as vaccination. Promoting maternal health literacy, pre-conception, and pregnancy care, parenting programs and early infancy and childhood programs is paramount. The importance of the Developmental Origins of Health and Disease (DOHaD) needs to be embodied in the health promotion message of the first 1000 days of a child's life (92). These are windows of opportunity for prevention and unless incorporated into policy and programs will precipitate late intervention in adulthood – which demands a reactive health system. Many acute childhood illnesses and accidents are also preventable. Implementation of a holistic public health approach or development of a national framework that integrates maternal and child health could be considered to address the determinants of health and ensure that infants receive the best start in life.

The cost to deliver health services to Indigenous people is often quoted as higher than that allocated to non-Indigenous services (e.g., \$8,494 vs \$6,657 respectively), but there is little consideration of the causes of poor health, chronicity and complexity of service delivery required in remote settings (46). The higher costs reflect the increased morbidity among Indigenous populations, expenses incurred by remote service delivery, and incentives for health professionals (54). Indigenous people may be sicker, services less efficient or conversely more effective than urban and city services, and any or all these factors could contribute to greater costs.

Furthermore, there is a lag between funding and implementation of preventive healthcare measures, particularly those related to social determinants of health, improved service delivery, and resulting improved health outcomes, particularly for child populations (54). Funding for Indigenous child health services has increased over time, however implementation costs have also increased in keeping with inflation and demand (93). The case-mix method for allocating hospital funding uses benchmarks including national averages, cost weights and length of stay (39). This has been criticised as further disadvantaging Indigenous children who present more frequently to health services, have complex illnesses and comorbidities, and prolonged hospital stays (22.6% v 1.5% non-Indigenous children) (39). They receive inadequate funding for their disease progression, and an unfair funding distribution which may further impair service delivery (39). We did not aim, and are not able, to discuss how investment to support social determinants of health would alter patient outcome but instead our findings underscore the importance of responsive, high quality, well-resourced and funded reactive and preventative health models. Savings could result from better primary health care and prevention models for children in remote communities, resulting in disease prevention and improved disease management (27). Implementation of continuous quality assurance assessments of existing programs is crucial to assess these factors and indicate areas of need, inefficiencies and where funding may be best allocated.

Implementation of supportive and collaborative programs that augment Aboriginal and Torres Strait Islander Community controlled health services and increased funding towards expansion of training opportunities and positions for Aboriginal Health Workers is pivotal to improving engagement with and cultural safety within health services. Expenditure on appropriate, well-resourced services across areas of greatest need (e.g., maternal and child health programs) in remote Australia would have a strong impact on child well-being (27, 94).

2.6. Declarations, abbreviations, and acknowledgements

2.6.1. Abbreviations: AMS – Aboriginal Medical Services; CQI – Continuous Quality Improvement; DOHaD - Developmental Origins of Health and Disease; ENT – Ears, Nose Throat (Otorhinolaryngology) Surgeon; FIFO – Fly-in Fly-out; KPI – Key Performance Indicators; NSW – New South Wales; NT – Northern Territory; PHC – Primary Health Care; RFDS – Royal Flying Doctors Service; SA – South Australia; WA – Western Australia.

2.6.2. Declarations

2.6.3. Ethics approval and consent to participate

Not applicable

2.6.4. Consent for publication

Not applicable

2.6.5. Availability of data and materials

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study. Protocol for search strategy as outlined in methodology.

2.6.6. Competing interests

The authors declare that they have no competing interests.

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2.6.8. Author's contribution

The authors declare that they have no competing interests. PJD performed the research, analysed the data, interpreted the results, drafted the manuscript, wrote the final manuscript. KT performed the research, collecting and interpreting the data, proofed and approved the manuscript. HEJ interpreted the results, drafted the manuscript, and read and approved the final manuscript. DH interpreted the results, drafted the manuscript, and read and approved the final manuscript. EJE conceived the study, designed the study, performed the research, read and approved the final manuscript. ALCM conceived the study, designed the study, and performed the research, read, reviewed, edited and approved the final manuscript. All authors contributed to and approved the final manuscript.

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Chapter 3: Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions

Foreword for Chapter 3: Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions.

Analysis of the literature presented in **Chapter 2** highlighted the lack of information about existing remote child health services in Australia, their limitations, utilisation, and barriers to access. It identified that challenges in service delivery are compounded by remote geographical locations, demanding environments, attraction and retention of a workforce and cultural and language differences.

Following the literature review we audited existing child health services in the Fitzroy Valley (**Chapter 3**) to address the knowledge gap. Assessments of the Lililwan cohort in 2012 resulted in over 400 referrals to local health services. There was concern that existing services would be overwhelmed by the unprecedented demand. We found no prior documentation that summarised services and their availability. The process for accessing services seemed complex and begged the question – how does a remote-dwelling child with complex health needs (e.g., with FASD) access the services they require? The aim was to establish what services existed, who funded them, how they interrelated, what they provided, and barriers to service delivery in this challenging remote setting. A case illustrating the health burden of a child living with FASD in remote Australia was created to illustrate the complexities and challenges for access to and provision of services. We hypothesised that child health services provided in the Fitzroy Valley would be fragmented and complex, with many barriers to both access and provision of services. **Chapter 3** was published as ***Dossetor, P. J., et al. (2019). "Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions." BMC Health Services Research 19 (758)***. *Word count: 7195, Citations: 4*

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Statement of Contribution

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I declare that the research presented in this Thesis represents original work that I carried out during my candidature at the Australian National University, except for contributions to multi-author papers incorporated in the Thesis where my contributions are specified in this Statement of Contribution.

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Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions

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Abstract

Background: Despite a national focus on closing the gap between Aboriginal and non-Aboriginal child health outcomes in Australia, there remain significant challenges, including provision of health services in very remote communities. We aimed to identify and map child health services in the very remote Fitzroy Valley, West Kimberley, and document barriers to effective service delivery.

Methods: Identification and review of all regional child health services and staffing in 2013. Verification of data by interview with senior managers and staff of key providers in the Western Australian Country Health Service, Kimberley Population Health Unit, Nindilingarri Cultural Health Services and non-government providers.

Results: We identified no document providing a comprehensive overview of child health services in the Fitzroy Valley. There were inadequate numbers of health professionals, facilities and accommodation; high staff turnover; and limited capacity and experience of local health professionals. Funding and administrative arrangements were complex and services poorly coordinated and sometimes duplicated. The large geographic area, distances, extreme climate and lack of public and private transport challenge service delivery. The need to attend to acute illness acts to deprioritise crucial primary and preventative health care and capacity for dealing with chronic, complex disorders. Some services lack cultural safety and there is a critical shortage of Aboriginal Health Workers (AHW).

Conclusions: Services are fragmented and variable and would benefit from a coordinated approach between government, community-controlled agencies, health and education sectors. A unifying model of care with emphasis on capacity-building in Aboriginal community members and training and support for AHW and other health professionals is required but must be developed in consultation with communities. Innovative diagnostic and care models are needed to address these challenges, which are applicable to many remote Australian settings outside the Fitzroy Valley, as well as other countries globally. Our results will inform future health service planning and strategies to attract and retain health professionals to work in these demanding settings. A prospective audit of child health services is now needed to inform improved planning of child health services with a focus on identifying service gaps and training needs and better coordinating existing services to improve efficiency and potentially also efficacy.

Keywords: Indigenous, Remote Australia, Child health, Health services, Coordination, Integration, Fetal alcohol Spectrum disorders

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Background

An 8-year old child living 150 km from the very remote service town is seen in the paediatric clinic in Fitzroy Crossing and suspected to have fetal alcohol spectrum disorder (FASD). Problems with learning and academic achievement, oppositional behaviour, attention and hyperactivity, writing and growth are identified. Current skin infections (scabies and impetigo), suppurative otitis media, severe dental caries and asthma are also diagnosed. The child requires assessment by the school psychologist and ongoing management by paediatric, allied health, community health, dental, and child and adolescent mental health (CAMH) services.

The disparity in child health and developmental outcomes between Aboriginal and non-Aboriginal children living in remote Australian communities is well described [1, 2]. Although few population-based studies are available [1, 3] data consistently demonstrate a high burden of health needs and demand for services for Aboriginal children. One retrospective cohort study of Aboriginal infants in remote Northern Territory communities reports high rates of hospital admission and visits to remote primary health centres beginning in early childhood and notes the inadequacy of services to meet demand [3].

Population-based data from the Lililwan Project in the Kimberley's Fitzroy Valley in Western Australia suggest a similar scenario [4]. The Lililwan Project was initiated by Aboriginal communities to determine the prevalence of Fetal Alcohol Spectrum Disorder (FASD) and health and developmental problems [4–6]. The Fitzroy Valley (Fig. 1) incorporates 45 communities serviced by the town of Fitzroy Crossing, all of which are classified as very remote by the Accessibility/Remoteness Index of Australia [4, 7]. Fitzroy Crossing has a population of approximately 1600, including about 1000 Aboriginal people. Surrounding communities account for another 1500, mainly Aboriginal, people [8, 9]. According to Communicare™, a patient database used in the Kimberley, there were approximately 1400 children under the age of 16 living in the Fitzroy Valley in 2013 [9, 10].

Since 2009, assessment data on Australia's five-year-olds in the Australian Early Development Census (AEDC) have consistently demonstrated that children from rural and remote Australia, particularly Aboriginal children, have high levels of developmental vulnerability across all five domains: physical, social, emotional, language and culture. In 2018, 54.5% of children in the Fitzroy Valley had developmental vulnerability in 1 domain and 27.3% in 2 domains according to the AEDC. This provides a stark contrast to Australia-wide data, with rates of 21.7 and 11.0% respectively, and indicates the disparity in need of remotely-dwelling Australian children [11]. Wait times for developmental services are long with improvements over recent years (18 months in 2010 to 4 months in 2013) [12]. In 2012, there were 3.6 doctors per 100,000 population in Australia, which trumped the Organisation for Economic Co-operation and Development (OECD) average of 3.3. Unfortunately, the report on Australia's Future Health Workforce clearly stipulates this does not account for the geographical distribution of doctors, and rural and remote Australia is poorly serviced [13]. Isolation, a measure of remoteness, has a demonstrated detrimental impact on the number of contacts children living in those locations have with doctors [14]. In addition, if their primary carer

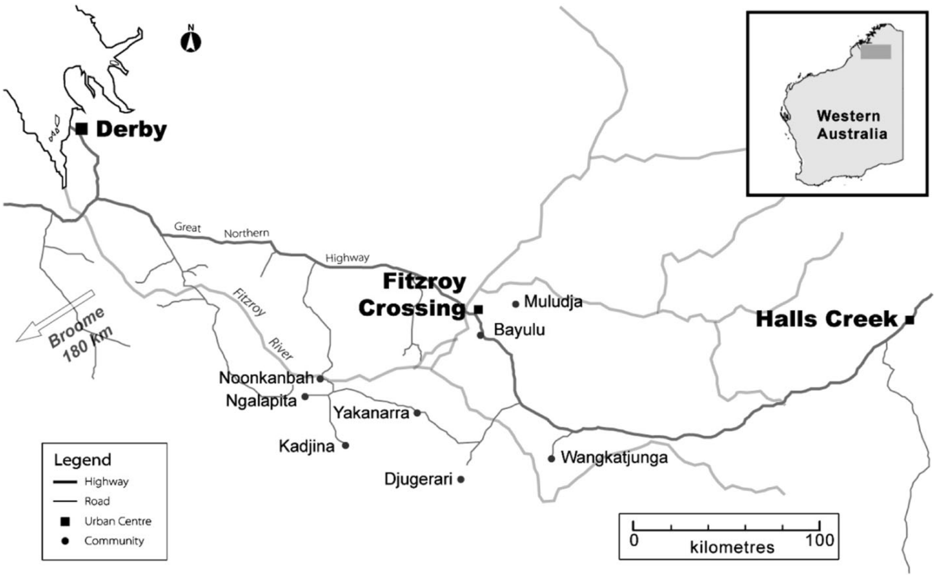


Fig. 1 Fitzroy Crossing and surrounding communities

is Aboriginal they are more likely to be seen by a nurse or Aboriginal Health Worker (AHW) than a doctor [14].

Approximately 20% of the children in the Lililwan cohort (born in 2002 or 2003) were diagnosed with FASD by a multidisciplinary clinical team assessment by 2012 [5, 6, 15]. Many demonstrated chronic and complex needs. Hospital admissions with infections, dental, ear and skin disease, injury and growth faltering were common [4]. Our preliminary data (unpublished) also indicate high rates of emergency department presentations and frequent problems with learning and development [16–18]. Following the Lililwan study, over 400 referrals were made to local health services for 108 children, representing nearly four referrals per child. Nearly half of the children required referral to ear, nose and throat or audiology services; one third had severe dental caries, one third were referred to paediatric or allied health services and 40% to child mental health services (E Elliott personal communication). The burden of complex and chronic health needs documented in the Lililwan Project raised community concerns that child health services were inadequate the very remote Fitzroy Valley. This study was requested by Aboriginal leaders in response to the health service needs identified in the Lililwan Project (2010–2012).

According to the World Health Organisation, the functionality of a health system can be measured by six key factors: health service delivery, health workforce, health information systems, access to essential medicines, health systems financing, and leadership and governance [19]. We utilised the WHO definition of health system functionality as a conceptual framework to examine health service delivery. Other theoretical frameworks informed our study, such as the Penchansky and Thomas theory of access, which describes how the effectiveness of a service depends on optimisation of accessibility; availability; acceptability; affordability; and adequacy in service design, implementation and evaluation [20]. Subsequent modifications by other authors, to the Penchansky and Thomas Theory of Access also incorporate awareness of services as a core domain [21]. Although the core components of this theoretical framework were considered throughout our data collection and analyses, we were unable to address all aspects of their theory because of the limited available data. Specifically, we found no comprehensive overview of all the child health services operating in the Fitzroy Valley in either the published or grey literature and this remains the case.

Our primary objective was to identify and map child health services in the Fitzroy Valley in 2013 to provide a snapshot of the services available to respond to the health needs identified in the Lililwan project (2010–2012) and identify their limitations and barriers to service delivery and access. Data collected included from services involving paediatric specialist, medical officer, allied health, child and adolescent mental health, hospital-based, and emergency services. We also aimed to identify barriers to effective services in this very remote community context.

Methods

Identification and description of child health services

In 2014, we approached the regional department of health, child health workers, and searched health department websites to identify child health services operating in the Fitzroy Valley in 2013. We used a semi-structured interview with service providers to confirm the role of services, staffing levels and clinic schedules for 2013. Providers were asked how the referral system worked, what barriers were perceived to affect service provision in remote locations, and how child health services might be made more effective and client-focused. They were asked to clarify the number of full-time equivalent (FTE) staff and the proportion of patient contact time versus travel time, which was not always apparent in schedules. Interviews were conducted with four service managers and 13 practitioners from 17 services including: six from the Western Australian Country Health Services (WACHS); six from the Kimberley Population Health Unit (KPHU); two from Boab Health; two from the Department of Education; and one from the Royal Flying Doctor Service (RFDS). Interviewees included nurses, allied health professionals, specialists, midwives, psychologists, health service administrators and their managers.

We employed qualitative data analysis to gain understanding of the health services available to meet the needs of children in the Lililwan cohort in the region at the time. For this study, we analysed the qualitative data as we engaged in data collection [22]. What we ascertained informed our future interviews and questions.

A content analytic approach was applied to our interview data [22]. We also utilised a narrative analytic approach for data which we obtained from a variety of sources including field notes and documents provided to us during interviews or found on the internet. For this research, our approach was more focused than some qualitative research projects. We were seeking to understand health services, as well as seeking answers to particular questions which we had developed a priorie.

During analysis we categorised the data, indexing the data by our a priorie research questions. The analysis was explanatory and was guided by the research questions. Through our analyses we identified patterns and made connections. We then summarised key themes/ideas from our qualitative findings regarding health services available in the Fitzroy Valley for children with

FASD and other developmental, behavioural and mental health needs.

Ethics

This project was approved by the Western Australian Aboriginal Health Ethics Committee (Approval number 344–04.2011) and the Western Australian Country Health Service Research and Ethics Committee (Approval number 2013:18).

Results

We could not identify any existing document that provides a comprehensive overview of available services in this region.

Service providers

Using information from multiple sources we identified the following services (Fig. 2):

1. Services provided by WACHS included: paediatric and other specialist services, a paediatric nurse practitioner, acute hospital-based care, emergency evacuations, the Child and Adolescent Mental Health service (CAMH), and a dental service based in Fitzroy Crossing.
2. Services provided by the KPHU included: primary health care, child and maternal health and Allied Health clinics. KPHU is part of WACHS but in many ways, is functionally separate.
3. Services provided by the Aboriginal Medical Service. In the case of the Fitzroy Valley Nindilingarri Cultural Health Services (NCHS) [23] oversees, advises and co-ordinates all government-run health services operating in the Fitzroy Valley via a Memorandum of Understanding with the WACHS and KPHU, effective since 2000. NCHS is the only Aboriginal Medical Service in the Kimberley that does *not* offer a clinical service. Rather, by collaborating with government agencies, it aims to ensure that services are culturally relevant and safe. NCHS does deliver a wide variety of health promotion and disease prevention programs.
4. Services delivered by independent non-government (NGOs) organisations. The RFDS provides emergency evacuations and runs general practitioner (GP) and nursing clinics in certain communities. Boab Health Care [24] is a not-for-profit primary health care organisation that provides services across the Kimberley in mental health, allied health and a range of health promotion programs. Apart from dietetic services, their client base is adults. The Kimberley Aboriginal Medical Services Council (KAMSC) employs an Ear Health Co-coordinator.

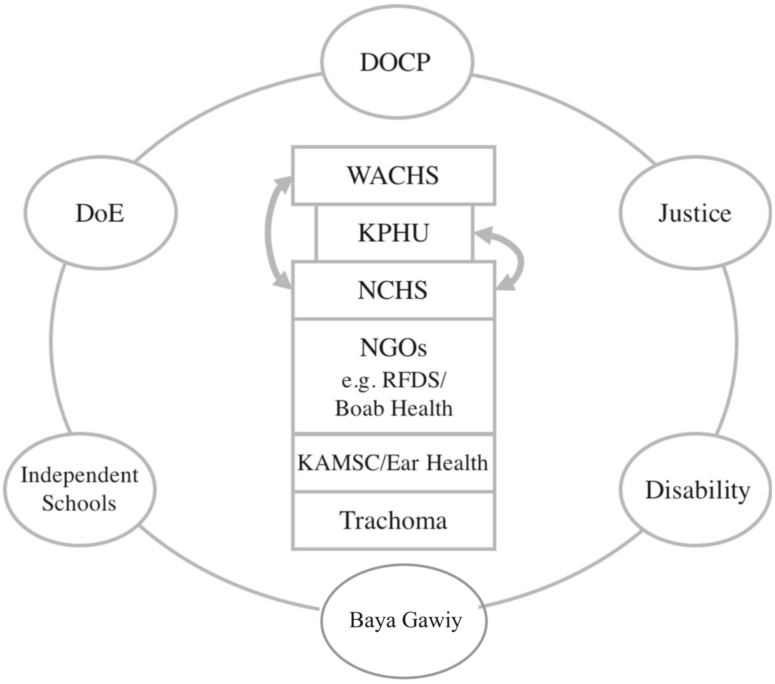


Fig. 2 Illustration of the health, education and support services in the Fitzroy Valley and their inter-relationships. Abbreviations: DOCP: Department of Child Protection; DoE: Department of Education; WACHS: WA Country Health Service; KPHU: Kimberly Public Health Unit; NCHS: Nidilingarri Cultural Health Service; NGOs: Non-government organisations; RFDS: Royal Flying Doctors Service; KAMSC: Kimberley Aboriginal Medical Service Council

5. Other services - An annual trachoma screening and treatment program funded by the Federal Government operates in schools throughout the Kimberley. A program coordinator manages the program and trains local community health nurses in diagnosis and treatment [25].

Schedules of visiting specialists, the paediatric nurse practitioner, Allied Health and Child and Adolescent Mental Health Service teams and others to the Fitzroy Valley are shown in Table 1.

Other agencies act collaboratively at a local level to address child health and wellbeing in the Fitzroy Valley (Fig. 2). These include the Department of Child Protection, the Department of Education (a nurse and a psychologist are employed at the Fitzroy Crossing District High School for example, and another psychologist oversees all four Independent Community Schools in the Kimberley) and Baya Gawiy, the Children and Family Centre in Fitzroy Crossing, established in 2013. Marninwarntikura Women's Resource Centre [26] manages Baya Gawiy, a domestic violence shelter, and the Marulu Unit. This unit was established with a full-time youth worker to respond to findings of the Lililwan project, to support children and families living with FASD and coordinate involvement by agencies in the interests of families and children. The Department of Justice, in its support of juvenile offenders is also part of this picture. The Disability Services Commission WA has an office in Fitzroy Crossing and provides support to eligible children and families. Figure 2 illustrates the health services in the Fitzroy Valley.

Fitzroy crossing hospital

Fitzroy Crossing hospital, run by WACHS, is the hub of the health system in the Fitzroy Valley. On average the hospital is staffed by eight nurses (from a pool of 19) and three medical officers. It has a Level 3 paediatric facility [27] with an emergency department and 12 inpatient beds (2 designated for children) staffed by a Medical Officer. Two inpatient beds are designated for outpatients requiring dialysis. Doctors usually have limited post-graduate training in paediatrics. On most days one of the three doctors will be away working in a community clinic. The medical positions are funded but not always filled. In 2013 only one of the doctors resided permanently in Fitzroy Crossing and the others travelled from Derby or Broome. The hospital employs three Aboriginal Liaison Officers whose primary role is to locate, and provide a transport service for, patients to attend medical appointments.

According to the nature and severity of their illness and the availability of beds and staff, children may be transferred to the regional hospital in Broome for Level 5 paediatric care (400 km) [27], where there is an 8 bed paediatric ward staffed by a resident medical officer, a paediatric registrar, and an on-site consultant paediatrician. Two paediatric registrars undertake 6 or 12-month rotations to Broome from the Princess Margaret Hospital for Children in Perth. Acutely ill children may also be transferred from Fitzroy Crossing to the Level 3 paediatric care hospital in Derby (260 km) [27], which does not have a paediatrician on-site, or to the Level 6 tertiary hospital (Princess Margaret Hospital for Children) in Perth (2500 km) [28] .

Few people in the Fitzroy Valley own cars and there is no public transport. The mode of patient transfer is dictated by the severity of the patient's condition and the destination and includes evacuation by the RDFS and road ambulance to Derby or Broome. There are two road ambulances at the Fitzroy Crossing Hospital, however patients from remote communities often drive to meet the ambulance half-way, to halve the time the ambulance is out of reach. Patients may also take the

Table 1 Paediatric Outreach services to Fitzroy Valley and staffing

Service	Agency	Service base	Regularity of service	FTE staff
Paediatrics	WACHS	Broome	Monthly visit	.2
Allied Health	KPHU	Derby	Weekly visit of 1–3 days	3
Community Health child health nurse	KPHU	Fitzroy Crossing	Full time	1
School health nurse	KPHU	Fitzroy Crossing	Full time	1
Community Health remote area nurses – clinicsat Bayulu, Wangkatjungka and Noonkanbah	KPHU	Fitzroy Crossing	Full time	6
RFDS – 2 x Primary Health Care Nurseand GP Remote clinics	RFDS	Derby	Fixed schedule between weekly andtri-monthly depending on size ofcommunity	2 x .5
CAMHS	WACHS	Broome	One week per fortnight	1
School Psychologists × 2	Department of Education	Fitzroy Crossing and Derby	Full time	2

CAMHS: Child and Adolescent Mental Health Service; KPHU: Kimberley Population Health Unit; RFDS: Royal Flying Doctor Service; WACHS: Western Australian Country Health Services

Table 2 Paediatric and child health services in the Fitzroy Valley 2013: by location

Health professional	*Visiting schedule*
Fitzroy Crossing (total population approx. 3500)	
Specialist – Paediatrician	Monthly (Mon/Tues/Wed of the week)
Specialist – Paediatric cardiologist	6 monthly
Specialist – Ear/Nose/Throat (not child specific)	4 times yearly
Paediatric nurse practitioner	1 week per month (with paediatrician)
Allied Health team (OT/ST/PT)	Twice monthly (6 days per month)
WA Country Health Service dietician	1 day per month
Child and Adolescent Mental Health Service	Week on/week off (no specific days for visiting remotes)
Department of Education psychologist (4 schools in the Valley including Fitzroy Crossing)	Full time
Department of Education psychologist (4 Independent community schools, outside of Fitzroy Crossing)	Full time
Community health nurse	Full time
School nurse	Full time
Large Remote Communities (total population > 150)	
Noonkanbah (pop.315; 135 km)*	
Specialist – Paediatrician	12 times/ year (Tuesdays)
ENT	Will visit but only if sufficient patients
Allied Health team	1 day/month (Mondays)
Boab Health dietician	1 day/month
Remote clinic	4 × 5 h days per week
VRFDS clinic – GP plus RFDS primary health care nurse CAMHS worker	Every second Wednesday Monthly
Bayulu (pop. 271; 20 km)*	
Specialist – Paediatrician	6 times/year (Thursdays)
Allied Health team	Visit from Fitzroy Crossing – on demand
Remote clinic	4 × 6 h days per month
Boab Health dietician	1 day per month
Wankgatjungka (pop. 169; 140 km)*	
Specialist- Paediatrician	6 times/year (Thursdays – alternatemonths with Bayulu)
Allied Health team	12 times/year (Wednesdays)
Remote clinic	4 × 5 h days per week
Boab Health dietician	1 day per month
CAMHS worker	Monthly
Small Remote Communities (total population < 100)	
Yakanarra (pop. 100; 150 km)*	
Allied Health team	3 times/year
RFDS clinic – GP plus RFDS nurse	Weekly
Boab Health dietician	1 day/month if seat available on RFDS plane
Koorabye (pop. 64; 100 km)*	
RFDS clinic – GP plus RFDS nurse	Twice monthly
Boab Health dietician	1 day/month if seat available on RFDS plane
*Djugerari (pop. 59; 125 km**	
Allied Health team	3 times/ year

Table 2 Paediatric and child health services in the Fitzroy Valley 2013: by location *(Continued)*

Health professional	*Visiting schedule*
RFDS clinic – GP plus RFDS nurse	Weekly
Boab Health dietician	1 day/month if seat available on RFDS plane
Kadjina (pop. 39; 210 km)*	
Allied Health team	3 times/ year
RFDS clinic – GP plus RFDS nurse	1 day/month
Boab Health dietician	1 day/month if seat available on RFDS plane

Population derived from Morphy F [9]
*Approximate distance from Fitzroy Crossing

daily (except for Saturday) Greyhound bus from Fitzroy Crossing to Derby or Broome if their condition allows, or use the 'linen run', which transports hospital laundry to Derby. During our audit the Greyhound bus departed Fitzroy Crossing at 1:00 am, arrived into Derby at 4:00 am ($62 AUD) and into Broome ($92 AUD) at 6:40 am.

Services in Fitzroy Crossing

The visiting schedule for all services for Fitzroy Crossing in 2013 is shown in Table 1. In 2013 there were 6 individual paediatricians comprising three FTE consultant positions. These consultants serviced the entire Kimberley, a vast geographical area incorporating hundreds of remote communities, and provide outreach services from Broome to Derby, Fitzroy Crossing, Kununurra, Halls Creek and communities on the Gibb River Road and around Balgo (Fig. 1). When possible, individual paediatricians provide a service to specific communities on a regular basis to increase continuity of care. One paediatrician, the only one with a full time equivalent position, resided 'locally' in Broome, which is approximately 400 km from Fitzroy Crossing. All the others flew in from Perth (1) or interstate: NSW (1), Victoria (2) and NT (1) and work between 0.1 and 0.5 FTE. In 2013, two of the paediatricians attended clinics in Fitzroy Crossing and surrounding communities, accompanied by one of the two paediatric registrars. Locums are sometimes employed to cover consultant and registrar leave and illness.

Services in outlying communities

Outside Fitzroy Crossing, the three largest communities in the Fitzroy Valley are Noonkanbah, Bayulu and Wangkatjungka (Table 2). Bayulu is closest to Fitzroy Crossing (10 km south). Wangkatjungka (130 km south east; 100 km bitumen, 30 km unsealed) and Noonkanbah (165 km west; 100 km bitumen) can only be accessed via significant sections of unsealed road, which can become impassable in the wet season (December to April). Each community has its own remote health clinic, serviced by remote area nurses and nurse generalists employed by the Community Health service, administered by the KPHU. They operate in isolated and demanding environments. Their portfolio, according to the remote clinic manager based in Fitzroy Crossing, includes:

> *"… sexual health, antenatal and postnatal child health, immunization, rheumatic heart disease, adult health, aged care, chronic disease pathways including for diabetes, cardiac and respiratory conditions, communicable disease, wound care, primary health care and all acute presentations to remote clinics".*

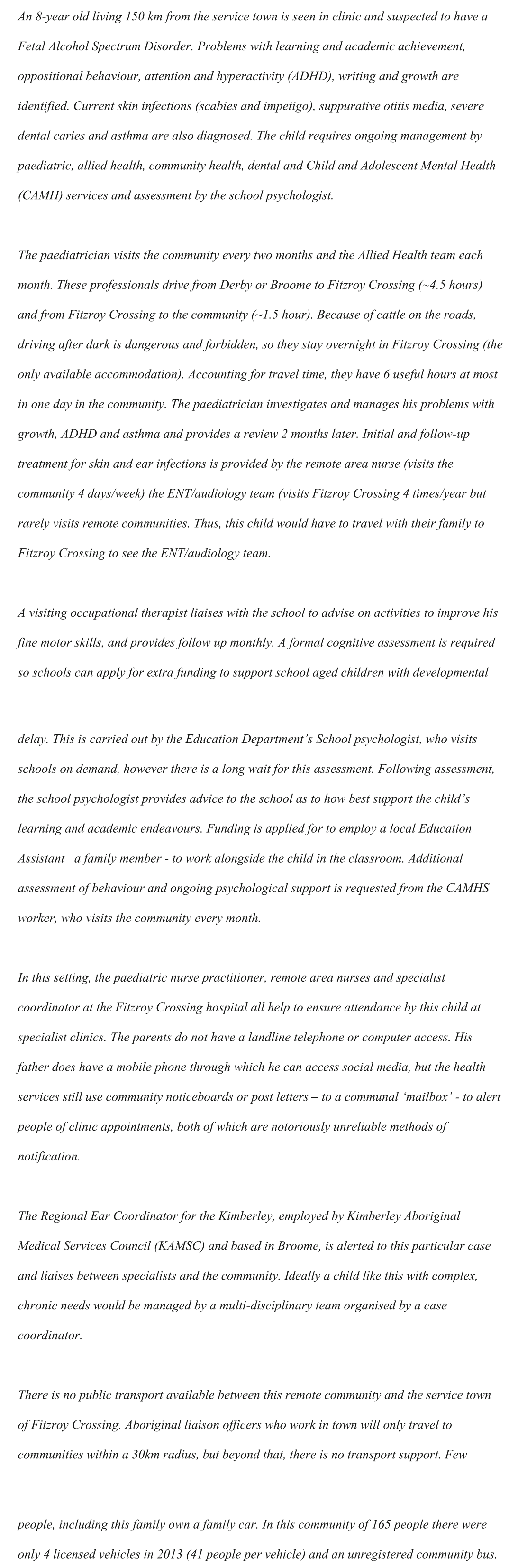
Paediatricians and allied health professionals visit the three remote clinics every 8 weeks and the RFDS runs a fortnightly GP clinic in Noonkanbah with a district medical officer from Fitzroy Crossing (Table 1). To demonstrate the difficulties in accessing services in outlying communities, a fictitious, but representative, case with chronic and complex health and developmental needs is illustrated in Fig. 3.

Services in smaller, more remote communities

People in the 42 remaining smaller communities (which range from approximately 40 to 300 people) [10] receive health care from clinics at the three larger communities or hospital-based clinics in Fitzroy Crossing. The Allied Health team and RFDS visit four of these communities (Yakanarra, Kadjina, Djugerari and Koorabye) periodically, ranging from weekly to monthly (Table 1).

Paediatric services

A paediatrician visited the Fitzroy Valley every two months and the Allied Health team visits each month. These professionals drive from Derby or Broome to Fitzroy Crossing (~ 4.5 h) and from Fitzroy Crossing to the outlying, smaller communities, on average about 1 h from Fitzroy Crossing. Due to unfenced cattle on the roads, driving after dark is dangerous and not recommended, so staff stay overnight in Fitzroy Crossing (the only available accommodation). Accounting for travel time, they have 6 h available to spend in the community. The paediatrician investigates and manages health problems, for example: growth, attention deficit hyperactivity disorder, and asthma and provides a review 2 months later. Initial treatment for skin and ear infections is provided with follow-up by the remote area nurse (visits the community 4 days/week) and the ENT/audiology team (visits Fitzroy Crossing 4 times/year but does not visit remote communities with the occasional exception of Noonkanbah via RFDS if there are sufficient referrals). A child who needs ENT/Audiology review must travel with their family to Fitzroy Crossing to see the ENT/ audiology team.



An 8-year old living 150 km from the service town is seen in clinic and suspected to have a Fetal Alcohol Spectrum Disorder. Problems with learning and academic achievement, oppositional behaviour, attention and hyperactivity (ADHD), writing and growth are identified. Current skin infections (scabies and impetigo), suppurative otitis media, severe dental caries and asthma are also diagnosed. The child requires ongoing management by paediatric, allied health, community health, dental and Child and Adolescent Mental Health (CAMH) services and assessment by the school psychologist.

The paediatrician visits the community every two months and the Allied Health team each month. These professionals drive from Derby or Broome to Fitzroy Crossing (~4.5 hours) and from Fitzroy Crossing to the community (~1.5 hour). Because of cattle on the roads, driving after dark is dangerous and forbidden, so they stay overnight in Fitzroy Crossing (the only available accommodation). Accounting for travel time, they have 6 useful hours at most in one day in the community. The paediatrician investigates and manages his problems with growth, ADHD and asthma and provides a review 2 months later. Initial and follow-up treatment for skin and ear infections is provided by the remote area nurse (visits the community 4 days/week) the ENT/audiology team (visits Fitzroy Crossing 4 times/year but rarely visits remote communities. Thus, this child would have to travel with their family to Fitzroy Crossing to see the ENT/audiology team.

A visiting occupational therapist liaises with the school to advise on activities to improve his fine motor skills, and provides follow up monthly. A formal cognitive assessment is required so schools can apply for extra funding to support school aged children with developmental delay. This is carried out by the Education Department's School psychologist, who visits schools on demand, however there is a long wait for this assessment. Following assessment, the school psychologist provides advice to the school as to how best support the child's learning and academic endeavours. Funding is applied for to employ a local Education Assistant –a family member - to work alongside the child in the classroom. Additional assessment of behaviour and ongoing psychological support is requested from the CAMHS worker, who visits the community every month.

In this setting, the paediatric nurse practitioner, remote area nurses and specialist coordinator at the Fitzroy Crossing hospital all help to ensure attendance by this child at specialist clinics. The parents do not have a landline telephone or computer access. His father does have a mobile phone through which he can access social media, but the health services still use community noticeboards or post letters – to a communal 'mailbox' - to alert people of clinic appointments, both of which are notoriously unreliable methods of notification.

The Regional Ear Coordinator for the Kimberley, employed by Kimberley Aboriginal Medical Services Council (KAMSC) and based in Broome, is alerted to this particular case and liaises between specialists and the community. Ideally a child like this with complex, chronic needs would be managed by a multi-disciplinary team organised by a case coordinator.

There is no public transport available between this remote community and the service town of Fitzroy Crossing. Aboriginal liaison officers who work in town will only travel to communities within a 30km radius, but beyond that, there is no transport support. Few people, including this family own a family car. In this community of 165 people there were only 4 licensed vehicles in 2013 (41 people per vehicle) and an unregistered community bus.

Fig. 3 Fictitious case illustrating challenges in accessing services

One clinician reported to us

> *" … physically getting the kids to the clinic to see me is the greatest influence on how many kids I have seen so far, school age kids in particular. Very tricky to work around school hours, I am typically gone by 2-2.30 [to complete the return drive back to Broome] so often miss the afterschool window and have rung schools before but cannot see kids without parental consent/ presence and mum might be at work or uncontactable. Availability of Aboriginal health workers is crucial – and I notice a significant reduction in numbers."*

A visiting occupational therapist liaises with the school to advise on activities, such as those to improve fine motor skills and provides monthly follow-up. A formal cognitive assessment is required before schools can apply for extra funding to support school aged children with developmental delay. This may be carried out by the Education Department's School psychologist, who visits remote schools upon request. However, there is often a long wait for these assessments. Following assessment, the school psychologist provides advice to the school as to how best support the child's learning. Funding may be justified for employing a local Education Assistant – often a family member - to work alongside the child in the classroom. Additional assessment of behaviours and ongoing psychological support can be provided by the Child and Adolescent Mental Health Service (CAMHS) worker, who visits the community every month.

Based on Lililwan data up to 20% of children in the Fitzroy Valley have FASD with complex, chronic needs as in the child described in Fig. 3. These children would optimally be managed by a multi-disciplinary team with a case coordinator, but such services are lacking. In the Fitzroy Valley, the paediatric nurse practitioner, remote area nurses and the specialist coordinator at the Fitzroy Crossing hospital all help to ensure attendance by children with complex, chronic needs at specialist paediatric clinics in Fitzroy Crossing. There is a Regional Ear Coordinator for the Kimberley, employed by KAMSC and based in Broome, who can be alerted to particular children's needs and liaise between specialists and communities.

There is no public transport available between remote communities and the service town of Fitzroy Crossing. Aboriginal liaison officers work in town and travel to communities within a 30 km radius to provide transport, but beyond that, there is no transport support. Few people own a family car. In 2013, in one community of 165 people there were 4 licensed vehicles (41 people per vehicle) and an unregistered community bus. Few houses have landline telephones or computers. Many people now have mobile phones through which they access the internet and social media, but health services still use community noticeboards and post letters – to a communal 'mailbox' - to alert people of clinic appointments, notoriously unreliable methods of notification.

Allied health

All allied health workers in 2013 were based in Derby, and travelled from there (260 km, 40 min by air) to Fitzroy Crossing. Two allied health teams operated in the Fitzroy Valley. These teams consist of an occupational therapist, a physiotherapist, a speech therapist and an Indigenous therapy assistant. Their visiting schedule for the Valley over four weeks is 3 days/2 days/4 days/2 days, or 11 days per month. In the weeks when they visit for three or four days, the team drives out from Derby. On the 2-day weeks - every fortnight - they fly with the RFDS to remote communities or charter a flight. When in town for three or four days, they drive out to remote communities from Fitzroy Crossing (see Table 1). This team also services the town and communities of Derby and the communities of the Gibb River Road and Looma.

Most of the occupational and speech therapist caseload is children, and the team liaises closely with all schools in the Fitzroy Valley and with Baya Gawiy, the Children and Family Centre in Fitzroy Crossing. In late 2012, funding was secured for a 1.0 FTE occupational therapist to work exclusively with children in the Fitzroy Valley. Referrals to Allied Health can be made by paediatricians, remote clinic nurses, teachers and school nurses. Visiting therapists must prioritise the most acute problems, at times displacing children with less urgent problems who are on their waiting list. A monthly meeting is held between the allied health team and the paediatrician in Fitzroy Crossing, with a focus on children with developmental delays and other complex needs.

Child and adolescent mental health service (CAMHS) and school psychologists

There was one FTE child and adolescent mental health worker (a clinical psychologist, nurse or social worker can hold the position) based in Fitzroy Crossing in 2013. Due to a lack of accommodation, this person spent every second week in Broome dealing with administration and referrals from the week spent in Fitzroy Crossing. There was also one FTE Indigenous mental health worker who works with families (adults and children together), and acts in an advisory role to the other worker. Most referrals to CAMHS come from health services and government agencies, including the Department of Child Protection, Department of Education (school psychologists) and Department of Justice (Youth Justice worker). One day each fortnight is allocated to providing services to more remote communities if there is a child requiring services. Thus, the three larger communities may see this worker every two to 3 months if there is a child in ongoing care. Only in extreme cases do mental health patients get evacuated out of Fitzroy Crossing (to Perth), because the experience of being removed from familiar surroundings can be extremely traumatic. Although available for consultations via teleconference, the child psychiatrist visits the Kimberley for only 1 week per year, leaving mental health workers to take considerable clinical responsibility.

There are two school psychologists in the Fitzroy Valley. One is based at the Fitzroy Crossing High School and covers the Department of Education's other four remote community schools. The other is based in Derby and covers the four Independent (non-government) community schools in Fitzroy Valley. Their predominant role is to guide teachers and families in managing challenging behaviour and academic difficulties in the school setting. They also conduct cognitive assessments, which may be used by the school to apply for extra funding to support students with cognitive deficits and learning problems. Historically, these assessments have not been shared with service providers outside of the Education Department including the Health Department.

Paediatric nurse practitioner

A paediatric nurse practitioner (PNP) position was initiated in April 2013 in response to concerns that there was inadequate coordination of paediatric clinic lists, resulting in few referrals and a limited focus on children most in need of specialist care. The number of children on the paediatric list almost trebled with this appointment, suggesting that there was underservicing of children previously.

The PNP's role is to coordinate services for children with referrals to paediatric practitioners, numbering over 300 in 2013. This requires liaison with remote area nurses (RANs) in the three remote clinics, and with primary health care nurses for the RFDS clinics to organise referral lists prior to the paediatricians' visits to outlying communities. Children with complex medical conditions, including growth faltering, are seen by the PNP in the week prior to clinics. The PNP manages a case-load of children with chronic illness in partnership with the district medical officer and paediatrician, and liaises with Aboriginal health workers, where available, who communicate with families to inform them of impending visits. When Aboriginal health workers are not available, families are notified by whatever means available (e.g. door knocking, Facebook, or telephone if available). Ongoing referrals are also managed by the PNP, including those to the Princess Margaret Hospital's ambulatory care service in Perth. In 2013, the PNP began to develop 'chronic disease plans' for specific children, which were made available to all practitioners via the Communicare™ patient database. The PNP plays a crucial role in communicating with families about details of their medications, identifying the best family members to take on supervisory responsibilities relating to medication and diet, and liaising with other agencies where necessary.

There is a 'Specialist Booking Co-ordinator' responsible for generating patient lists and visit dates for all visiting specialists, excluding paediatricians. Paediatrician visits are organised by the Population Health Child Health Nurse. This role has previously had more staff turnover than the specialist booking co-ordinator. With each change of staff, time to fully grasp the context and requirements of the job is required, as well as re-establishment of systematic approaches to the role. This disjunction could have contributed to issues related to capturing the children that needed to be seen. Providing administration assistants or centralisation of this role within the hospital could improve outreach capacity of Child Health Nurses, along with AHW, by allowing them to redirect their time expenditure towards seeing children rather than grappling with technology and databases, ultimately improving functionality of this role and capitalising on the systems already in place, making a more robust and consistent system to capture the children who needed to be seen (personal communication, Ruth Kinninburgh-White).

Community health services

The Community Health service, which is part of the KPHU, employs one child health nurse based in Fitzroy Crossing. There is no requirement for training in child health or Aboriginal health, however the nurse oversees the immunisation program throughout the Valley and runs the Under-5 s program, which aims to review all children on a regular basis. This nurse is also responsible for monitoring babies deemed 'at risk', that is, pre-term, underweight or suffering from congenital anomalies. The Community Health midwife estimates that of the 76 babies born in 2012–13, ten (13.2%) were in this category. The child health nurse also assists with coordinating paediatric clinics in Fitzroy Crossing, managing referrals from Fitzroy Crossing-based medical officers and the School health nurse. The School Health nurse, also employed by KPHU, is responsible for developmental and general health checks for all school aged children and the child health nurse is responsible for these same checks in children aged five and under.

Dietician services

WACHS and Boab Health Service both provide paediatric dietician services to the Fitzroy Valley. WACHS serves residents of Fitzroy Crossing town and communities of Kadjina and Yakanarra, provided a referral has been made and there is a seat available on the RFDS flight. The WACHs dietician visits Fitzroy Crossing, using the RFDS flight from Derby, once per month, holds her clinic at the hospital and is assisted by the Aboriginal Liaison Officers in finding her clients. The Boab Health dietician, who has both paediatric and adult clients, visits outlying communities only, namely Bayulu, Wangkatjungka and Noonkanbah. She spends 1 week per month in the Fitzroy Valley (10 visits per year) and also visits the smaller communities of Koorabye and Djugerari if there is a seat available on the RFDS flight.

Cultural brokers: aboriginal health workers

All health service providers interviewed emphasized the importance of Aboriginal Health Workers (AHW) or liaison officers/cultural brokers and noted that the effectiveness of services was diminished by the absence of AHWs. Currently, there are only two AHW in the entire Fitzroy Valley, three Aboriginal liaison officers employed by the hospital, and one Aboriginal therapy assistant who travels with the Allied Health team from Derby.

Discussion

The delivery of health services in remote settings is complex. This study highlights health workforce shortages in the Fitzroy Valley, in particular for medical staff and community nurses, with a severe shortage (only 1/3 of the required number) of AHW [29]. Barriers to delivering an effective service, identified in interviews with staff across agencies, were consistent with those documented in the literature. Unsealed roads and climatic factors such as the tropical wet season limit access to health service facilities for people living in remote communities and by nurses and doctors to those communities. Limited accommodation is an invisible barrier to health care delivery and often means that health staff must fly or drive in/out. This is expensive, time-consuming and may result in inconsistent health care from a workforce not well known to or culturally informed about the community.

The challenges we identified in health service delivery in remote settings is reflected in the few reports available that describe the institutional landscape of health services in the Kimberley [30, 31]. Lewis (2013) detailed challenges including: population growth of 2% per year with a predominance of young people (25% of the population is aged 0–9 years) in the Kimberley Aboriginal community; high rates and burden of ill-health experienced by the community compared to both Indigenous and non-Indigenous populations elsewhere in Western Australian (e.g. infant mortality rates 1.2 times higher than WA Indigenous populations and 4 times higher than in the total state population from 1998 to 2007); high costs of service delivery in the Kimberley compared to metropolitan areas; difficulties with recruitment and retention of staff due to national shortages of those with appropriate skill sets; and fundamental obstacles due to structural issues such as lack of housing for staff in remote areas [32]. Atkinson et al. (1999) described deficiencies in funding for Aboriginal health care services across Australia and the skewed distribution of expenditure on hospital services for Aboriginal compared to non-Aboriginal people, indicating poor use of primary health care services and resultant late presentations [29].

The role of child health nurses, Aboriginal liaison officers and others in assisting families to navigate the health system is crucial. While health practitioners 'on the ground' strive to work together to achieve the best possible outcomes for their paediatric patients, the institutional landscape in which they operate is a hindrance. This includes the lack of consistent and up-to-date documentation or a 'one-stop-shop' source of information regarding health service provision in the region. Difficulty recruiting and retaining health professionals is a significant and well-documented issue [3, 29, 32, 33]. The dearth of Aboriginal health workers (AHWs) documented in our study (two per 3100 population) is not a new observation in the Kimberley, recruitment of AHW having been identified as a top priority 20 years ago in the 1999 Kimberley Regional Aboriginal Health Plan [29]. There are no staff to population ratios recommended for WA however, in Central Australia, they recommend one AHW per 100 Aboriginal population, one community nurse per 250 and one doctor per 600 are likely applicable in the Kimberley [30].

The lack of AHW was deemed problematic by all service providers. AHW know local families, communities and the context in which health services are delivered, speak local languages and understand cultural protocols. This knowledge is essential to assist non-Aboriginal clinicians to encourage Aboriginal people to attend clinics. Trained AHW also have a vital role in two-way interpreting between health practitioner and patient, providing access into communities, and an explanation of reasons for non-attendance and non-compliance [34].

AHW are crucial for child health services in liaising with parents or extended family members caring for children [35] and in remote communities their roles include supervision of immunisation, medications, child health surveillance and recognition and referral of the acutely ill child. Although training programs for AHWs are well subscribed [29], few Aboriginal people are retained in these positions. Reasons for this include inadequate supervision and support at a community level, and a lack of career path. In addition, the training is conducted in Derby or Broome, which requires the AHW to separate from their family and community for the duration of the training. Some concerted focus at a regional level to improve the appeal of the role of AHW is required. Offering AHW courses in Fitzroy Crossing could potentially improve recruitment and retention.

High staff turnover results in a lack of continuity of local and cultural knowledge – especially of children and their extended families. This results in a constant need for Aboriginal people to build new relationships, which might impact on their willingness to engage with the health system at all. It leads to confusion amongst service providers as to who to contact or where to refer patients and is expensive. A regularly updated, online calendar of health services including visiting schedules, names and contact details, could have contributed to the delivery of more coordinated services in 2013. Such a calendar was developed by Patches, a paediatric outreach health and education service, and trialled in 2014 on their website but required maintenance [36]. Although the calendar exists on the Patches website, the calendar is updated infrequently. The last calendar entry for Fitzroy Crossing was June 2019, prior to that in August 2016, and for Broome was August 2017.

Providing additional housing for health workers – which requires negotiation with traditional land owners and planning involving many agencies in Fitzroy Crossing – would enable health professionals to live in Fitzroy Crossing and build relationships with colleagues working in the area. The fly-in fly-out approach has major limitations including restricting the time available to provide clinical care and professional support.

Challenges exist for families in knowing when health professionals will be in town and balancing clinic attendance with other commitments. A particular challenge for specialists and allied health teams in remote clinic contexts is in notifying families of patients of impending visits and locating children on the day. Children represent a particular challenge due to limitations surrounding inability to review children during school hours, resulting in a small window of time after school.

Conversely, as we identified, there is a complex and variable schedule by which many paediatric service providers visit Fitzroy Valley communities. This information about who is visiting and when may be confusing. It is not uncommon to find clinic appointment letters written in English scattered unread in communities. Technology including access to mobile phones and messenger applications may assist in the future.

Some practitioners observed that an opportunistic approach to assessment and treatment can work when parents bring children to the clinic for other matters – but in these instances, the Communicare™ online database containing medical records and histories for patients may not be available, making treatment uncoordinated and possibly ineffective or even risky. The paediatric nurse practitioner said that she prints out records for all referrals, and physically takes them to remote clinics, in case the online record system is not available.

Although it was difficult to measure, evidence for chronic under-resourcing can be found in the approach that services are forced to take in the Fitzroy Valley, namely a triage approach. Using this approach, the most acute patients are seen on any given day or at any given clinic, while those with chronic illness, particularly children who are difficult to access, slip down the priority list or become lost altogether. The conflict between the demands for attention to acute matters, versus the need for primary or ongoing health care, has been well-documented elsewhere in remote Australia. Gruen and Bailie noted that "according to the way in which (specialist) outreach is conducted and the service is organised, it can either support primary care or it can hinder primary care and, as a result, reduce its own effectiveness [37]."

Resources are needed for provision of quality, ongoing primary health care that is quarantined from acute demands. The intense focus on responding to acute care needs is apparent in the design of clinics recently built at considerable expense at Bayulu, Wangkatjungka and Noonkanbah. There is no space within these clinics for the provision of primary health care, nor any desk, office space or computer access for AHWs.

Studies from the Northern Territory have identified poor co-ordination and poor communication and linkages between health services as barriers to accessing health care, especially for people with chronic, complex disorders [31, 37, 38]. Our experience in the Lililwan study and reports from health service providers suggest similar problems in the Fitzroy Valley to the detriment of children and families. For example, our data showed a physiotherapist, paediatrician and occupational therapist may visit a community on three subsequent weeks to see the same child but be unaware of each other's findings. Across WA there is a recognized lack of integration and coordination between services, as well as service inconsistencies, primarily due to a lack of an overarching framework or model to describe child health and developmental service delivery [12]. Primary specialist health care must be integrated, ideally with dedicated coordinators across services [39]. Our efforts to map services in the Fitzroy Valley for children in Lililwan cohort with chronic complex neurodevelopmental needs illustrate the lack of integration and provides a baseline for development of future, better coordinated services that improve access, minimize early life health inequities and optimize child health and development [39, 40].

Other barriers to health care include poverty and other social factors [41–44] and uneven distribution of health professionals [27, 45, 46]. Models of best practice for remote settings are client-focused services delivered by a multi-disciplinary team that can demonstrate consistency and commitment over time [37, 47–60]. A multidisciplinary team approach, such as that used in the Lililwan study, makes particular sense when populations have complex health needs [23, 24, 34, 38, 55]. This approach facilitates efficient, comprehensive assessment, diagnosis and development of management plans for children with particularly complex needs. It promotes cross-disciplinary communication, limits duplication of effort and provides health professionals (many of whom are junior) with a professional support and supervisory network, likely improving staff confidence and retention.

The paediatric nurse practitioner appointed to the Fitzroy Valley in 2013 was a crucial structural element in the functionality of the system overall. This nurse acted as an intermediary between complex health systems and remote Aboriginal communities and had a coordinating role. Ideally such a position would be supported by AHWs to facilitate cultural competence and overcome language barriers.

In 2013, Patches Paediatrics, a private multidisciplinary child health enterprise, commenced work with Nindilingarri Cultural Health Service (Fitzroy Crossing) and WA government-funded health services to coordinate outreach schedules and establish a family-centred approach to addressing complex neurodevelopmental issues [26]. Patches received government, philanthropic and research funding to deliver multidisciplinary clinics that improved the coordination, efficiency and effectiveness of the current health and education services for children with complex needs in the Fitzroy Valley [26, 36]. Another initiative for the Fitzroy Valley was the Kimberley Dental Team, a not-for-profit organisation founded in 2009 that broadened its scope from the East Kimberley to the whole Kimberley from 2014 and continues to provides dental services in the region [61]. There is a new ambulance (since 2014) and clinic based at Wangkatjungka (provided by Kurungal Council Inc., June 2019) to transfer patients into Fitzroy

Crossing. In 2015, Marninwarntikura partnered with clinician-researchers at the University of Sydney to adapt and introduce the evidence-based Triple P-Positive Parenting Program which has had a positive impact on parent skills and knowledge and wellbeing of children and families in the wider community [62]. Another partnership, which commenced in October 2016 between Royal Far West and Marninwarntikura Women's Resource Centre under an initial five-year agreement, assists in providing children in the Fitzroy Valley with paediatric, psychiatric and allied health care that is FASD and trauma-informed. This includes in-person and on-going tele-paediatric and allied health service [63]. Progress is being made to improve coordination within health services (via online calendars) [36] and between health services and others such as the Department of Education in terms of sharing information and assessments, however there is still much to be done to streamline and coordinate health care services and child health review and management [64]. Furthermore, the NDIS roll-out will likely shift the landscape for service provision in the Kimberley, however this process will require time to implement and see change.

Moving to the future, there is a need for a formal, prospective audit of child health services in the region, with development of services to fill gaps in consultation with community and integration of services to maximise efficiency and minimise duplicity. Informed by our work with the Lililwan cohort, services should ideally be multi-disciplinary, trauma-informed, capable of acute and chronic complex care, culturally appropriate and inclusive of AHW. Although it was beyond the scope of our study to evaluate existing services, future work should encompass this.

Although the audit was done in 2013 in response to the clinical demand identified in the Lililwan project this should not be seen as a limitation: it remains relevant because demand is ongoing, and services remain uncoordinated and under-resourced. The strengths of the current work are that it was requested by the community and has been used by them to advocate for change. This work provides baseline information to allow comparison with current and future service provision. Personal correspondence with Royal Far West (a Sydney provider of health services in the Fitzroy Valley) in August 2019 indicated that they still refer to the data in this paper as the only clear outline of available services and providers and that no comprehensive overview of current services exists.

This audit highlights complexities in service provision for remote dwelling Australian Aboriginal children living across the 45 communities in the Fitzroy Valley. In particular, these complexities are encapsulated within physical and invisible barriers, health workforce recruitment and turnover, the intricacies of piecemeal funding across multiple levels of government and NGOs, as well as lack of integration and coordination of services and implications on accessibility of health services even if they exist.

Abbreviations

AEDC: Australian Early Development Census; AHW: Aboriginal Health Worker; CAMHS: Child and Adolescent Mental Health Service;; DOCP: Department of Child Protection; DoE: Department of Education; ENT: Ear, nose and throat; FASD: Fetal Alcohol Spectrum Disorders; FTE: Full-time equivalent; GP: General practitioner.; KAMSC: Kimberley Aboriginal Medical Services Council; KPHU: Kimberley Population Health Unit; NCHS: Nindilingarri Cultural Health Services; NGOs: Non-government organisations; PNP: Paediatric Nurse Practitioner; RAN: Remote Area Nurse; RFDS: Royal Flying Doctor Service; WA: Western Australia; WACHS: Western Australian Country Health Services; WHO: World Health Organisation.

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Availability of data and material

The data from this study are available on request from the corresponding author PJD.

Authors' contributions

PJD, KT, EJE and AM designed the study, obtained ethics, conducted, analysed and reported research and drafted the manuscript. JO and MC designed the study, obtained ethics and reviewed the manuscript. JB, JL, JF, EF and CB designed the study, wrote sections and reviewed the manuscript. All authors read and approved the final manuscript.

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Ethics approval and consent to participate

Ethics approval for the Lililwan Project was granted by the University of Sydney Human Research Ethics Committee (Lililwan Project Approval numbers 12527, 13187, 13551), the Western Australian Aboriginal Health Ethics Committee (Approval numbers 271–01/10, 319–10/10, 344–04/11), the WA Country Health Service Human Research Ethics Committee (Approval numbers 2010:01, 2010:28, 2011:04), and the Kimberley Aboriginal Health Planning Forum Research Sub-committee (Approval numbers 2010–001, 2010–001, 2010–001). The Health Services project was an extension of the Lililwan Project and was approved by the Western Australian Aboriginal Health Ethics Committee (Approval number 344–04/2011) and the WA Country Health Service Human Research Ethics Committee (Approval number 2013:18).

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

Chapter 4: Pediatric hospital admissions in Indigenous children: a population-based study in remote Australia

Foreword for Chapter 4: Pediatric hospital admissions in Indigenous children: a population-based study in remote Australia

The comprehensive multi-disciplinary clinical assessments of the Lililwan cohort during stage 2 revealed a high burden of medical conditions, many of which required treatment or referral for further management. The early stages of the Lililwan project focused on the diagnosis of chronic conditions (e.g., FASD) within this cohort of remote-dwelling predominantly Aboriginal children. However, it was clear that chronic conditions only presented half the picture, and acute medical conditions were also associated with significant burden. This chapter focuses on these.

In mapping local health services (**Chapter 3**) we identified that service delivery was challenging and poorly coordinated. To gain understanding of how services functioned in Fitzroy Crossing, we focused in on the central provider, Fitzroy Crossing Hospital. We documented and assessed lifetime hospital admissions (to age 7 years) in the Lililwan cohort, including the reasons for admission, comorbidities and outcomes and examined the relationship between hospitalisations, their demographic data and prenatal exposures to alcohol and cigarettes. In **Chapter 4**, I present the lifetime hospital admissions of a predominantly Aboriginal, remote-dwelling paediatric cohort to demonstrate the burden of ill-health they experience. In this chapter, I explore the hypothesis that alcohol exposure and poor social determinants increase admission frequency and that infections would be a common cause of admission. This paper, (***Dossetor P.J., et al. (2017). "Pediatric hospital admissions in Indigenous children: a population-based study in remote Australia." BMC Pediatrics (17): 195.)*** was published in ***BMC Pediatrics***.

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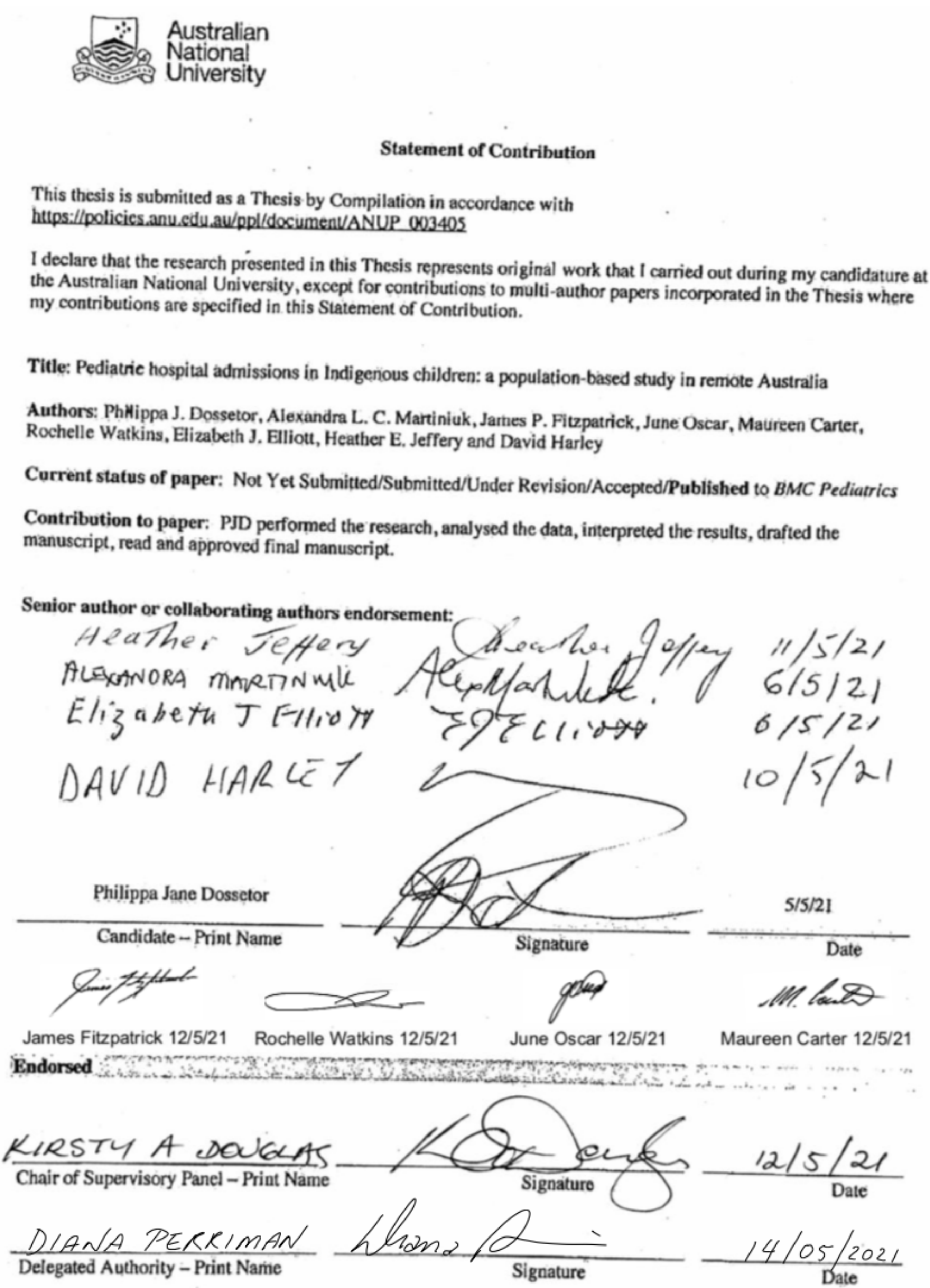

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Statement of Contribution

This thesis is submitted as a Thesis by Compilation in accordance with https://policies.anu.edu.au/ppl/document/ANUP_003405

I declare that the research presented in this Thesis represents original work that I carried out during my candidature at the Australian National University, except for contributions to multi-author papers incorporated in the Thesis where my contributions are specified in this Statement of Contribution.

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RESEARCH ARTICLE
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Pediatric hospital admissions in Indigenous children: a population-based study in remote Australia

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Abstract

Background: We analysed hospital admissions of a predominantly Aboriginal cohort of children in the remote Fitzroy Valley in Western Australia during the first 7 years of life.

Methods: All children born between January 1, 2002 and December 31, 2003 and living in the Fitzroy Valley in 2009–2010 were eligible to participate in the Lililwan Project. Of 134 eligible children, 127 (95%) completed Stage 1 (interviews of caregivers and medical record review) in 2011 and comprised our cohort. Lifetime (0–7 years) hospital admission data were available and included the dates, and reasons for admission, and comorbidities. Conditions were coded using ICD-10-AM discharge codes.

Results: Of the 127 children, 95.3% were Indigenous and 52.8% male. There were 314 admissions for 424 conditions in 89 (70.0%) of 127 children. The 89 children admitted had a median of five admissions (range 1–12). Hospitalization rates were similar for both genders ($p = 0.4$). Of the admissions, 108 (38.6%) were for 56 infants aged <12 months (median = 2.5, range = 1–8). Twelve of these admissions were in neonates (aged 0–28 days). Primary reasons for admission (0–7 years) were infections of the lower respiratory tract (27.4%), gastrointestinal system (22.7%), and upper respiratory tract (11.4%), injury (7.0%), and failure to thrive (5.4%). Comorbidities, particularly upper respiratory tract infections (18.1%), failure to thrive (13.6%), and anaemia (12.7%), were common. In infancy, primary cause for admission were infections of the lower respiratory tract (40.8%), gastrointestinal (25.9%) and upper respiratory tract (9.3%). Comorbidities included upper respiratory tract infections (33.3%), failure to thrive (18.5%) and anaemia (18.5%).

Conclusion: In the Fitzroy Valley 70.0% of children were hospitalised at least once before age 7 years and over one third of admissions were in infants. Infections were the most common reason for admission in all age groups but comorbidities were common and may contribute to need for admission. Many hospitalizations were feasibly preventable. High admission rates reflect disadvantage, remote location and limited access to primary healthcare and outpatient services. Ongoing public health prevention initiatives including breast feeding, vaccination, healthy diet, hygiene and housing improvements are crucial, as is training of Aboriginal Health Workers to increase services in remote communities.

Keywords: Hospitals, pediatric, Pediatrics, Health services, indigenous, Australia, Child, Rural health services, Oceanic ancestry group, Rural and remote

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Background

There is a health disparity between Indigenous and non-Indigenous Australians, most prominently reflected in the 'gap' in life expectancy of 10.6 years for men and 9.5 years for women [1]. The infant mortality rate is 6.1 per 1000 live births for Indigenous infants versus 3.4 for non-Indigenous Australian infants (< 12 months) [2]. There are statistically significant ($p < 0.05$) differences in child mortality rates between Indigenous and non-Indigenous children with rate ratios of 2.1 (M) and 3.0 (F) for mortality in children aged 1–4 and 2.4 (M) and 2.3 (F) for children aged 5–14 years. [3]. In 2014 the under-five mortality rate in Australia was 4.0 per 1000 live births [4]. During 2008–10, the infant mortality rate for children living in remote and very remote areas was double that of infants living in major cities (6.8 versus 3.9 per 1000 live births); and for children aged 1–14 years the mortality rate in remote and very remote areas was three times higher (31.0 versus 11.0 per 100,000 children) [5]. Remote indigenous families face challenges when seeking health care due to cultural factors, historically poor interactions with health care systems, and a lack of cultural awareness and sensitivity of non-Indigenous health workers. Additional challenges include geographical isolation, lack of transport and environmental and climatic factors [5], and limited access to specialist pediatric services, all of which are compounded by language barriers [6, 7]. Health outcomes to an extent reflect health service effectiveness [8]. The Australian Government has committed to 'Closing the Gap' and removing the health inequity experienced by Australia's Indigenous people.

The Fitzroy Valley is an area of 2500 km^2 in the Kimberley region of Western Australia (WA), 400 km east of Broome [9]. There are 45 communities within a 200 km radius of Fitzroy Crossing town, and the town and surrounding communities are all classified as 'very remote' [9] (see Fig. 1). Approximately 4500 people live in the Fitzroy Valley and the majority (93%) are Aboriginal and comprise five distinct language groups (Bunuba, Walmajarri, Wangkatjungka, Gooniyandi and Nyikina peoples) [9]. Some communities are only accessible by dirt road and access is restricted for weeks by annual flooding. Communities are located up to 190 km (3.5 h' drive) from the district hospital in Fitzroy Crossing. Other hospitals are located in Derby (259 km), Halls Creek (289 km), Broome (397 km) and Princess Margaret Hospital in Perth (2566 km) [10]. In the Fitzroy Valley many of the aforementioned barriers for access to health care exist. In addition, it is difficult to

Fig. 1 Fitzroy Crossing and surrounding communities, reproduced with permission from Frances Morphy, 2009 [9]

attract and retain health professionals because of the remote location, professional isolation and lack of accommodation.

In 2009, female Indigenous leaders from Fitzroy Crossing invited researchers and clinicians from the University of Sydney Medical School (Discipline of Paediatrics and Child Health, and the George Institute for Global Health) to help them advance a strategy they had developed to address Fetal Alcohol Spectrum Disorders (FASD) called The Marulu Strategy [11]. A partnership was formed with Nindilingarri Cultural Health Services and the Marninwarntikura Women's Resource Centre in Fitzroy Crossing. The research groups agreed to conduct a population-based study (The Lililwan Project), to determine the prevalence of FASD [12]. Lililwan is a word in the Kimberley Kriol language, which means 'all the little ones.'

Families of children born in 2002 and 2003 and living throughout the Fitzroy Valley were invited to participate in the Lililwan Project. In Stage 1 (2010) parents and caregivers were interviewed and maternal and child medical records reviewed for information on health problems and hospitalizations in the first 7 years of life. In 2011, children (aged 7–9 years) underwent comprehensive health and development assessments by a multidisciplinary team and individual management plans were developed [12].

Our primary aim was to describe the frequency, primary reasons for, and comorbidities at hospital admission for a very remote dwelling population of primary school-aged children. Secondary aims were to test the hypotheses that: 1. Indigenous children have more admissions than non-indigenous children; 2. Alcohol exposure *in utero* adversely affects child health; 3. Infections are the most common cause of admission; and 4. Poor social determinants increase admission frequency.

Methods

Identification of the Lililwan cohort

The Lililwan Project is a population-based study of FASD prevalence, using active case ascertainment and methods have been published [12–15]. Children born between January 1st 2002 and December 31st 2003 who were living in the Fitzroy Valley during 2010–11 were identified using the Fitzroy Valley Population Project and Communicare™ databases ($n = 134$). Consent for participation was obtained from a parent or caregiver for 127 (95%) of children and there were no exclusion criteria (Fig. 2) [12].

Stage 1

The cohort was characterised through structured interviews with parents or caregivers using a reliable tool developed in consultation with the local Aboriginal community [14]. Health professionals conducted interviews alongside Community Navigators and both underwent training in use of the questionnaire [14]. Data were collected on prenatal exposures, health, living conditions and schooling [12]. Parents were asked about hardships including food insecurity (times during the childhood when the parent had worried about not having enough food) and financial concerns (reports of adults not having enough money) [12]. Birth weights were plotted on WHO Child Growth Standard sex and age-appropriate centile charts to derive the birth centiles [16, 17].

Hospitalization data

For each child, admissions to Fitzroy Crossing Hospital were recorded from birth till age seven. We retrospectively searched hospital records till 2011 using the Communicare™ electronic health and practice management system and cross-checked against hard copy case note files. Data extracted included lifetime hospital admissions; date, reasons for, and comorbidities at

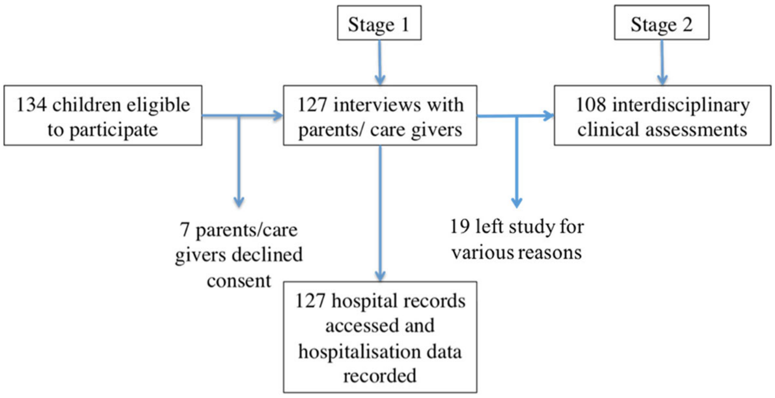

Fig. 2 Participatory flowchart of a population-based cohort of children (b.2002/3), living in Fitzroy Valley in 2010–11

admission; birth and growth parameters; and medical diagnoses.

Stage 2: FASD assessments

An interdisciplinary team conducted diagnostic assessments for FASD during 2011 [15] using the Canadian FASD diagnostic guidelines [18]. We also documented current health problems. FASD is caused by exposure to alcohol *in utero* and includes Fetal Alcohol Syndrome (FAS), partial FAS (pFAS) and Neurodevelopmental Disorder associated with Alcohol Exposure (ND-AE).

Coding of hospitalization datasets

Information from interviews and record reviews was entered into a Microsoft Access database, checked and coded. When children presented to the hospital with multiple conditions, the primary diagnosis was determined by a senior pediatrician and additional co-morbidities recorded. If information was missing or there were discrepancies, we returned to the original patient documentation to clarify diagnoses. When the full date of admission was not recorded, the first date of the stated month or year was documented. Diagnoses assigned at discharge were coded using the International Statistical Classification of Diseases and Related Health Problems, Tenth Edition, Australian Modification (ICD-10-online, World Health Organization (WHO)) [19]. Each diagnosis was categorised by a main, sub and specific code which ranged from three to seven characters including a letter and at least two numeric codes. Missing data were coded as 999. We used the most accurate code possible for each diagnosis.

Statistical analysis

Data were analysed using IBM SPSS Statistics for Mac (version 22.0.0.0 Armonk, NY, USA). Descriptive analysis was performed to obtain frequencies, medians and prevalence estimates. Chi-squared tests were used to examine associations between dichotomous variables. Although participation rates for this study were excellent (127/134), the cohort was small and continuity corrected values were reported where necessary for Chi-squared values. Independent sample t-tests were used for continuous data.

Ethics approval and consent

Ethics approval for the Lililwan Project was obtained from the University of Sydney Human Research Ethics Committee (Lililwan Project Approval numbers 12527, 13187, 13551), the Western Australian Aboriginal Health Ethics Committee (Approval numbers 271–01/10, 319–10/10, 344–04/11), the WA Country Health Service Human Research Ethics Committee (Approval numbers 2010:01, 2010:28, 2011:04), and the Kimberley Aboriginal Health Planning Forum Research Sub-committee (Approval numbers 2010–001, 2010–001, 2010–001). The Health Services project was an extension of the Lililwan Project and was approved by the Western Australian Aboriginal Health Ethics Committee (Approval number 344–04/2011) and the WA Country Health Service Human Research Ethics Committee (Approval number 2013:18).

Consent to participate was obtained for each child (7–9 years) from all parents or guardians through 'Community Navigators' (Aboriginal members of the research team with local language skills and knowledge of cultural protocols) who explained the purpose and nature of the study in local language of the parent's preference. Information statements and consent forms were additionally provided to families, or read to them, in the local Aboriginal language of their choice, Kimberley Kriol or English.

Results

Characteristics of the Lililwan cohort

This descriptive study includes a unique, predominantly Indigenous (95.3%), population of primary school aged children, who live in a very remote part of Australia and have limited access to health care services. Detailed characteristics of the Lililwan cohort have been published [18]. This study had a 95% participation rate for Stage 1, which included consent for the documentation of hospital admissions data (Fig. 2). The cohort is 52.8% male (Table 1). All children lived in very remote communities. Nearly half (45.7%) live in sub-regional hub communities (population 200 < 999) or satellite communities (population < 200).

The median age of mothers at their child's birth was 23 (range 14–43) and 87.1% ($n = 118$) of pregnancies continued to term (≥ 37 weeks gestation). Fifteen (12.7%) children were born preterm (< 37 weeks) and four children (3.4%) were extremely preterm (< 28 weeks) (Table 1). Of the children, 17.1% had low birth weight (< 2500 g) and 2.9% very low birth weight (< 1500 g) [16, 17].

The median number of residents per house was four (range 2–16) and a third (33.1%) of the cohort lived in households considered overcrowded by the parents/caregivers. In 2011 the median number of older siblings was two (range 0–7) and the median number of younger siblings one (range 0–3). Exposure to maternal alcohol (52.8%) and cigarette (65.5%) use in pregnancy was common, and 13.4% of the cohort was exposed to both marijuana and tobacco prenatally.

During the child's first 7 years 37.9% ($n = 124$) of caregivers reported financial concerns and 41.9% ($n = 124$) reported food insecurity.

Table 1 Characteristics of the Lililwan cohort

Variable	Total (*n* = 127) n (%)	Hospital Admissions (*n* = 89)	No Hospital Admissions (*n* = 38)	*P*-value (Chi^2 Test)
Indigenous (child)	121 (95.3)	88 (98.9)	33 (86.8)	0.009*
Sex male	67 (52.8)	49 (55.1)	18 (47.4)	
Place of residence at time of assessment (*n* = 127)				
Very Remote (ARIA+)[d]	127 (100.0)			
a) Town (population 1000–9999)	43 (33.9)	26 (29.2)	17 (44.7)	
b) Outer suburbs (within 30 km of remote town)	26 (20.5)	17 (19.1)	9 (23.7)	
c) Sub-regional hub (population 200–999)	31 (24.4)	22 (24.7)	9 (23.7)	
d) Satellite community (population < 200)	27 (21.3)	24 (27.0)	3 (7.9)	
a + b) Town or Outer suburbs	69 (54.3)	43 (33.9)	26 (68.4)	0.037*[e]
c + d) Hub or satellite community (*n* = 127)	58 (45.7)	46 (51.7)	12 (31.6)	
Food insecurity (Y/N) (*n* = 124)	52 (41.9)	43 (48.3)[e]	9 (24.3)[#]	0.01*
Financial concerns (*n* = 124)	47 (37.9)	37 (42.0)[e]	10 (27.0)[#]	
Number living in overcrowded households *n* = 124	42 (33.1)	33 (37.0)	9 (23.7)	
Number in household - median (range)[#]	4 (2–16)	4 (2–12)	4 (2–16)	
Number of older siblings – median (range)[#]	2.0 (0–7)	2.0 (0–7)	2.0 (0–3)	
Number of younger siblings – median (range)[#]	1.0 (0–3)	1.0 (0–3)	1.0 (0–3)	
Mothers age at pregnancy (median, range)[#]	23 (14–43)	23 (15–36)	24 (14–43)	
Gestation (*n* = 118)				
≥ 37 weeks (term)[#]	103 (87.1)	75 (84.3)	28 (73.7)	
< 37 weeks (preterm)	15 (12.7)	11 (12.4)	4 (10.5)	
< 28 weeks (extremely preterm)	4 (3.4)	3 (3.5)	1 (2.6)	
Alcohol exposed in utero (Y/N) (*n* = 122)	67 (52.8)	50 (56.2)[#]	17 (44.7)[#]	
FASD diagnosis (*n* = 108)	21 (19.4)	19 (21.3)	2 (5.7)[#]	
Microcephaly at assessment n=108[a]	16 (14.8)	12 (13.5)	4 (10.5)	
Low Birth Weight (*n* = 105)¶				
Very low birth weight (< 1500 g)	3 (2.9)			
Low birth weight (< 2500 g)	18 (17.1)			
Birth weight ≤ 3rd percentile[b]	2 (1.9)			
Birth weight ≤ 10th percentile[b]	11 (10.5)			
Growth deficiency at any age (Y/N) (*n* = 92)[b]	32 (34.8)	26 (41.3)	6 (20.6)	
Any hearing loss (*n* = 98)[c]	54 (55.1)	40 (57.1)	14 (50)[#]	
Exposure to cigarettes (nicotine) in utero (Y/N) *n* = 119	76 (65.5)	53 (63.1)[#]	23 (65.7)[#]	
Marijuana exposure in utero (Y/N) *n* = 119	16 (13.4)	12 (14.3)[#]	4 (11.4)[#]	
Both cigarettes and marijuana (Y/N) *n* = 119	16 (13.4)	12 (14.3)[#]	4 (11.4)[#]	

#indicates missing values as data due to unavailable data

¶ Data unavailable for hospitalised and non-hospitalised sub-groups

*indicates significant difference $p < 0.05$

[a] Microcephaly: head circumference < 3rd percentile using WHO Child Growth Standards

[b] Growth deficiency at any age: height or weight < 10th centile recorded at any age from birth until time of assessment in Stage 2 (7 to 9 years of age)

[c] Hearing loss: Determined by an audiologist who conducted tympanometry, audiometry, video-otoscopy and Listening in Spatialized Noise - Sentences Test (LiSN-S) for Central Auditory Processing Disorder assessments

[d] Remoteness was classified using the Australian Statistical Geography Standard (ASGC) Accessibility/Remoteness Index of Australia (ARIA+), developed by the National Centre for the Social Applications of Geographic Information Systems (GISCA) and the Commonwealth Department of Health and Aged Care (DH&AC) in order to classify remoteness of 12,000 populations in Australia based on physical road distance measurements to nearest service centres

[e] Note significance here was calculated for a + b versus c + d

Hospitalizations

Of the 127 children, 89 (70%) were admitted to hospital during their first 7 years of life (Table 2). There was a total of 314 admissions for 424 reasons, with a median of 2.0 admissions per child (range 0–12) or 5.0 (range 1–12) per admitted child. There were 108 admissions for 56 children in infancy (the first year of life). The median number of admissions for these 56 children was 2.5 (range 1–8). Males and females had a similar number of admissions both before 7 years of age and during infancy (Table 2). Additional analyses were performed to examine children who had multiple admissions by comparing children who were admitted 0 to 2 times with children admitted 3 to 12 times however no significant differences were found.

Children living in sub-regional hub (population 200 < 999) or satellite community settings (population < 200) had a higher rate of admission than children living in outer suburbs (within 30 km of a remote town) or a town (population 1000–9999) ($p = 0.037$) (Table 1). A large proportion of admissions (63.0%) occurred before the age of 2 years, one third (34.4%) in infancy, and 3.8% in the neonatal period (<28 days) (Fig. 3). Most initial admissions occurred in the first 2 years of life and there was no association with sex (Table 2).

Food insecurity was reported more commonly in children who were hospitalised (48.3%) than those who were not (23.7%), $p = 0.01$ (Table 1). None of the variables: gestational age; mother's age at pregnancy; the number living in the household; financial concerns; or microcephaly were significantly associated with hospital admissions.

For children in the Lililwan cohort who completed Stage 1 ($n = 127$) [16] and for whom we had data on alcohol exposure *in utero* ($n = 122$), there was no difference in the number of admissions between those exposed ($n = 67$; median 2.0, range 0–12) and those not exposed to alcohol ($n = 55$; median 1.0, range: 0–10) (Table 1, Fig. 4).

For participants who completed Stage 2 ($n = 108$) there was no difference between the number of admissions in children with ($n = 67$) and without ($n = 55$) prenatal alcohol exposure (PAE) and with ($n = 21$) and without FASD ($n = 87$) (Fig. 4). A majority (90%) of children with FASD had been admitted to hospital at least once.

Table 2 Lifetime (0–7 years) hospital admissions for 127 children born 2002/2003 living in Fitzroy Valley

Hospital Admissions	Children assessed Median (Range)
Childhood (0–7 years)	
Number of children with one or more admissions by 7 years (*n* = 127)	89 (70.0%)
Total number of hospital admission (number of reasons for admission)	314 (424)
Median number of admissions (range) per child by 7 years	2.0 (0–12)
Median number of admissions (range) per admitted child by 7 years (*n* = 89)	5.0 (1–12)
Number of admissions by sex	
Male median (Interquartile range)	3.0 (4)
Female median (Interquartile range)	2.0 (3)
Infancy (0–1 years)	
Number of infants with one of more admissions by 1 year (*n* = 127)	56 (44.1%)
Total number of admissions in infancy (number of reasons for admission)	108 (135)
Median number of admissions (range) (*n* = 127)	0 (0–8)
Median number of admissions (range) per admitted infant (*n* = 56)	2.5 (1–8)
Number of admissions by sex for infants	
Male median (Interquartile range)	3.0 (5)
Female median (Interquartile range)	2.0 (4)
Admissions by prenatal alcohol exposure (*n* = 122)[a]	
Prenatal alcohol exposure (*n* = 67 children) median (Interquartile range)	2.0 (4)
No prenatal alcohol exposure (*n* = 55 children) median (Interquartile range)	1.0 (3)
Admissions for children with FASD (*n* = 108)[a]	
Children with FASD (*n* = 21 children) median (Interquartile range)	3.0 (4)
Children without FASD (*n* = 87 children) median (Interquartile range)	2.5 (3)

[a] Number of children that had information available on alcohol exposure *in utero*

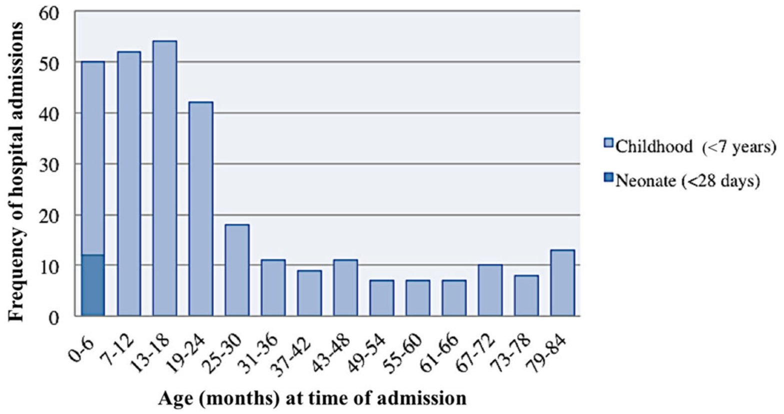

Fig. 3 Frequency and age of admissions in children (0–7 years) and neonates (<28 days)

Reasons for hospital admissions

Infection was the most frequent primary reason for admission (79%) in children aged under 7 years. Infections of the lower (27.4%) and upper (11.4%) respiratory tract, the gastrointestinal system (22.7%) and skin (5.6%) were most common. Injury (7%) and failure to thrive (5.4%) were also common primary reasons for admission (Table 3). Common comorbidities at the time of admission included upper respiratory tract infections (URTI) (18.1%), failure to thrive (13.6%), anaemia (12.7%), gastroenteritis (7.3%), asthma (3.6%) and unspecified fever (3.6%) (Table 3).

One child was admitted for meningococcal meningitis and another for acute rheumatic fever. Two were admitted with mitral regurgitation secondary to rheumatic heart disease. Two cases of post-infectious genitourinary complications were recorded (glomerulonephritis and tubulo-interstitial nephritis).

In infancy (< 1 year), infection was the predominant primary reason for admission (90%) (Table 4). The most common infections in infancy were lower respiratory tract infections (LRTI) (40.8%) and gastroenteritis (25.9%). Admissions for injury were also recorded (3.6%). Comorbidities included URTI (33.3%), failure to thrive (18.5%) and anaemia (18.5%). Injuries included traumatic brain injury; snake or dog bites; or falls resulting in head injuries, which often required sutures.

Discussion

Over two thirds (70%) of the remote Fitzroy Valley child cohort were admitted to hospital at least once during early childhood (aged 0–7 years), and over one third were admitted during infancy, with 12 admissions (4%) in the neonatal period. The proportion of males and females admitted was similar. The predominant primary reason for admission was infection (79%) including infection of the lower and upper respiratory tract; gastrointestinal system; skin; and urinary tract. Common comorbidities in childhood and infancy included URTIs (including otitis media), anaemia and failure to thrive.

Children were admitted up to 12 times in the first 7 years of life, and up to eight times in the first year of life.

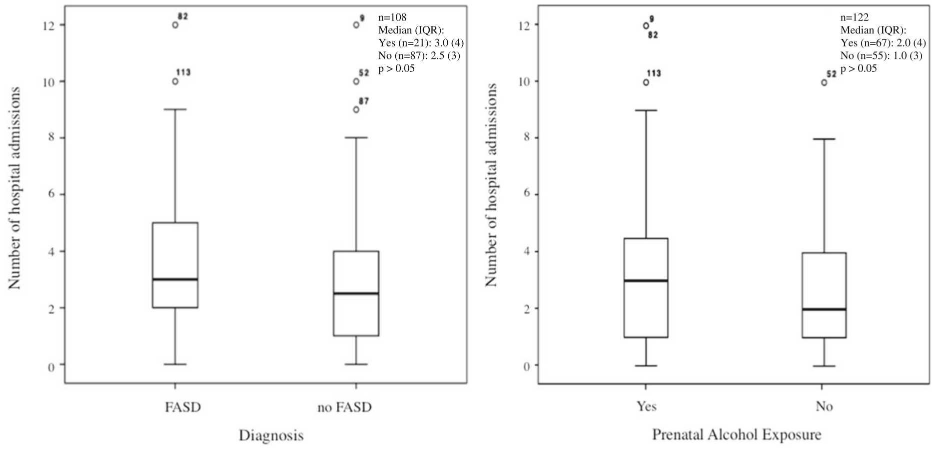

Fig. 4 Admissions in FASD ($n = 21$) and non-FASD ($n = 87$) children, and with ($n = 67$) and without PAE ($n = 55$)

Table 3 Predominant primary reasons for admission and common comorbidities at presentation in childhood (0–7 years) (*n* = 89)

	Conditions (ICD Code)	Frequency of admissions	Percentage of total
Top Primary Reasons for Presentation			
Lower respiratory tract infection		86	27.4
	Lower respiratory tract infection (J22)	74	
	Pneumonia (J18.9)	10	
	Bronchiolitis (J21.9)	2	
Gastroenteritis		71	22.7
	Infectious gastroenteritis (A09.9)	68	
	Vomiting (R11)	3	
Upper respiratory tract infection		36	11.4
	Otitis media (H66.3, H66.9, H70.019, H73.1)	15	
	Upper respiratory tract infection (J06.9)	14	
	Croup (J05.0)	4	
	Tonsillitis (J03.9, J35)	1	
	Pharyngitis (J02.9)	1	
	Epiglottitis (J05.1)	1	
Injury	Traumatic brain injury (S06.01), head injury (S09.9), fractured femur (S27.0), dislocated elbow (S53.10), finger injury (S69.7), soft tissue injury, hip (S76.7), superficial injury of leg/ft (S80.84, S90.82, S91.3), traumatic amputation of leg (T13.6), animal bite (dog or snake) (T14.1), foreign body (T16), corrosive burn (T24.0, T30.0), poison ingestion (T38.3)	23	7.0
Skin infection		18	5.6
	Impetigo (L01.0)	1	
	Cutaneous abscess, furuncle, carbuncle (L02.0–.9)	7	
	Cellulitis (L03.9)	6	
	Skin sore (L98.9)	3	
	Lymphadenitis (L04.3)	1	
Failure to thrive	(R62.8)	17	5.4
Genitourinary		14	4.4
	Urinary tract infection (N39.0)	12	
	Post infectious complications (N05.9, N12)	2	
Asthma	(J45.9)	10	3.2
Subtotal admission reasons		275	87.1
Other		39	12.9
Total Admission reasons		314	100
Top Comorbidities at Presentation			
Upper respiratory tract infection	H66.3, H66.9, J03.9, J05.0, J06.9	20	18.1
Failure to thrive	R62.8	15	13.6
Anaemia	D64.9	14	12.7
Gastroenteritis	A07.1, A08.0, A09.9, E87.2 (acidosis)	8	7.3
Asthma	J45.9	4	3.6
Fever, unspecified	R50.9	4	3.6
Subtotal comorbidities		65	58.9
Other		45	41.1
Total comorbidities		110	100

Table 4 Predominant primary reasons for admission and common comorbidities at admission in infancy (0–1 years) (*n* = 56)

	ICD Codes/Conditions	Frequency of Admissions	Percentage of Total Admissions
Top Reasons for Primary Admission (<1 YEAR)			
Lower respiratory tract infection		44	40.8
	Lower respiratory tract infection (J22)	42	
	Bronchiolitis (J21.9)	2	
Gastroenteritis		28	25.9
	Infectious gastroenteritis (A09.9)	27	
	Vomiting (R11)	1	
Upper respiratory tract infection		10	9.3
	Otitis media (H66.3, H66.9)	5	
	Upper respiratory tract infection (J06.9)	4	
	Croup (J05.0)	1	
Genitourinary	Urinary Tract Infection (N39.0)	5	4.6
Injury	Traumatic brain injury (S06.01), head injury (S09.9), fractured femur (S72.9), dog or snake bite (T14.1)	4	3.6
Subtotal admission reason		92	84.2
Other		16	15.8
Total Primary admission reason		108	100
Top Comorbidities at Admission			
Upper respiratory tract infection	H66.3, H66.9, J06.9	9	33.3
Failure to thrive	R62.8	5	18.5
Anaemia	D64.9	5	18.5
Subtotal comorbidities		19	70.3
Other		8	29.7
Total comorbidities		27	100

The number of neonatal admissions may be lower than expected, considering the high proportion (17.1%) of new-borns with low birth weight. Such children often have had a prolonged duration of hospitalization after birth and therefore rates of neonatal admissions may be under-represented, particularly in remote areas where distances to hospital are greater, [20]. In addition, care seeking is likely less common in remote than metropolitan areas where health care facilities are readily accessible [21].

Families living in the remote Fitzroy Valley region experience multiple barriers to accessing health care services including lack of transport, lack of infrastructure, long distances, and environmental factors resulting in some communities being cut off from road access during the wet season [8, 22]. If children live considerable distances from a hospital they are likely to present late with more severe illness. Conversely, children from remote areas who present to hospital with less severe illness may be admitted because the remoteness of their homes renders adequate follow up difficult [8, 22]. This concept is explored for pregnant women in the Three Delays Model in low- and middle-income countries in which there are three potential levels of barriers to health care which could also be applied to our cohort: a mother's decision to seek health care; reaching health facilities; and receiving adequate treatment [7, 23].

Our findings are consistent with national data regarding hospital separations in Indigenous Australians, in remote locations and for male children. In Australia in 2013, in the 0–14 age group, hospital separations were more frequent in Indigenous (10%) than non-Indigenous children (6%) [24]. Hospital separation rates were 551 per 1000 persons for very remote settings and 251 for major cities; and boys aged under 14 years are more likely to be admitted to hospital than girls of the same age [24].

Low-moderate PAE is associated with low birth weight (< 2500 g) [25, 26] and birth weight is a key indicator of health status [27]. Of 127 children in the Lililwan cohort, 52.8% were exposed to alcohol *in utero* and 17.1% were low birth weight. This is much higher than low birth weight rates nationally (12.6% for Indigenous and 6.0% for non-Indigenous births in 2011 [28]) and for WA (6.1% in 2012) [29]. Programs to reduce the prevalence of maternal risk factors, particularly alcohol use, smoking and under-nutrition would increase fetal and neonatal weight. In addition, rural and remote residence has been associated with placental inflammation which is perpetuated by anaemia, genitourinary infections and smoking [30]. Microcephaly was common in our cohort (14.8%) and is likely related to reflect high rates of PAE and FASD [31].

Many of the conditions that precipitated admissions in our cohort were feasibly preventable. The Australian Institute of Health and Welfare estimates that for Indigenous Australians the overall rate of potentially preventable hospitalizations is greater than three times the rate in non-Indigenous Australians [24]. Globally, a large proportion (36%) of deaths in children aged under 5 years result from LRTI and gastroenteritis, and are preventable through breast feeding, vaccination, nutrition, sanitation and clean water programs [32–34]. In 2014 globally, LRTI ranked second, and diarrhoeal disease was fifth for Years of Life Lost (YLL). However, due to interventions there was a 30% global decrease in YLL from LRTI and a 40% global decrease from diarrhoeal diseases between 2000 and 2012 [35]. LRTI and gastroenteritis are also high contributors to the burden of ill health in remote Australian Indigenous children and are typical of the burden of disease in children in low- and middle-income countries.

Gastroenteritis was one of the most common reasons for admission in both childhood (0–7 years) and infancy (<1 year) in our study. Admissions attributable to vaccine preventable diseases are 6 times higher in Indigenous than non-Indigenous Australians [24]. *Rotavirus* is the most common cause of gastroenteritis in children globally [36]. The National Rotavirus Immunisation Program only became universal in WA in 2007 [37]. The cohort we studied was born 2002–2003 before Rotavirus vaccine became available and it is likely that the vaccine will substantially decrease rates of gastroenteritis requiring hospitalization among children born after 2007. It was estimated that in 2014 over 90% of children living in WA had full immunisation coverage [37].

Free vaccinations for *Haemophilus influenzae* type B, *Streptococcus pneumoniae* (7vPCV and 23vPPV), and *Bordetella pertussis* (from the Pertussis component of the Diptheria, Tetanus and Pertussis (DTPa-IPV) vaccine) were made available to Indigenous children in WA in 2000, 2001 and 2005 respectively [37]. Immunization records and coverage data were not available for the Lililwan cohort (born in 2002–3), however with good immunization coverage we would expect to see falls in the rates of URTI and LRTI requiring hospital admission [37]. Influenza is a common infection in childhood, but vaccination did not become available to Aboriginal children in WA until 2008 [37]. Rare infections experienced by some children in our cohort, such as meningococcal meningitis, are also vaccine preventable [37].

Some LRTI and gastroenteritis cannot be prevented with vaccines. Similarly, some conditions detected in our cohort, for example failure to thrive and anaemia, have multiple causes including infections, low birth weight, overcrowding, inadequate hygiene, and poor nutrition [5, 8, 10, 38]. In our study, children living with food insecurity had a significantly higher admission rate. Thus, additional disease prevention strategies include early and exclusive breastfeeding during infancy, skin-to-skin kangaroo mother care (KMC) for preterm infants, improvements in nutrition, zinc supplementation, improved hygiene, decreased exposure to cigarette smoke, improved sanitation, clean water supply (for diarrhoea and skin conditions), use of oral rehydration therapy and decreasing indoor air pollution (for pneumonia) [34]. Both breastfeeding [33] and KMC [39] provide economically positive and low cost methods to reduce hospitalizations.

The AIHW reports that injuries requiring hospital admission are more than twice as common in Indigenous than other Australians (41 versus 20 per 1000 admissions, respectively) [24]. Many of the injuries documented in our cohort – snake and dog bites, corrosive burns, traumatic amputation following a motor vehicle accident, falls, poison ingestion, dislocations, head injury and fractures could potentially have been prevented by better supervision of young children, better road and motor vehicle standards, child proof containers for toxins, and other strategies. Data limitations in our study prevented us from understanding fully the circumstances for injuries. Preventive strategies to lessen Indigenous disempowerment and reduce social and family dysfunction may also have a role.

Previous studies examining presentations to a primary health care facility in a remote dwelling Aboriginal child cohort in the NT similarly documented high rates of LRTI, URTI and gastroenteritis [21]. In addition, a high prevalence of scabies and tinea was reported, as were rare conditions including acute post-streptococcal glomerulonephritis and acute rheumatic fever [21]. In our cohort, adequate treatment of Group A *Streptococcus* throat and skin infections could have prevented both rheumatic fever and its complications, including cardiac valvular disease, and post-streptococcal glomerulonephritis.

A Northern Territory study of community clinic presentations reported higher rates of skin infections and scabies than we measured during hospital admissions [21], however this may be due to high frequency and consequent under-reporting. Furthermore, only severe skin infections require hospitalization [21]. Preventative strategies include clean water and hygiene programs.

This project was community led and all interactions between researchers and locals were broached by local

Aboriginal language speakers (Community Navigators). The project was population-based so every eligible child was invited to participate and a process of active case ascertainment was used. Although the Lililwan cohort was dispersed across the wide geographic area of the Fitzroy Valley, community leadership resulted in a high consent and participation rate (95%) for Stage 1, which included the hospitalization data.

The questionnaire used in this study was reliable and culturally appropriate, and we used internationally accepted criteria to diagnose FASD [14, 40]. Additionally, a validated instrument was employed to obtain information about alcohol use in pregnancy (AUDIT-Scoring) [15].

There are few studies like ours that describe the lifetime hospitalization of children in remote Australia. We used the only available dataset on hospital admissions but do not have records on length of hospital stay. Each episode of hospitalization was classified according to the primary diagnosis and comorbidities at admission. The reasons for admissions were subsequently coded using the International Classification of Diseases (ICD-10-online), for international comparability. A limitation of the data was the restricted diagnostic laboratory capacity at remote hospitals. Pathological confirmation of diagnoses would have enriched our data, however limited testing is done at Fitzroy Crossing Hospital. Also, this dataset only provides information on children admitted to Fitzroy Crossing hospital, not on children who were transferred and admitted directly to other hospitals in Western Australia (Broome, Derby, Halls Creek or Perth) or Northern Territory (Darwin) and thus may underestimate the true rates of hospitalization.

Nevertheless, our study provides a unique snapshot of the lifetime hospitalizations and needs of children in 45 very remote communities in WA. We acknowledge that the small sample size is a limitation of this study. However, it is a population-based sample in which we have included over 95% of all eligible children in two entire birth cohorts. These data, although not generalizable to all of Australia are likely to be representative of other remote Aboriginal communities in WA, NT, SA, Northern QLD and Western NSW. In these areas there are similar challenges concerning health needs, limited access to health services (transport, geography, climate, infrastructure), and difficulties with attracting and retaining trained health professionals. Rates of hospital admission do not directly reflect the full burden of disease because some conditions prevalent in the community do not require admission [8].

Conclusion

There is a significant amount of published research about Indigenous health in Australia, particularly at national and state levels. However, community level studies that focus on the morbidity of Indigenous populations, particularly children, are rare, as are studies that describe the utilisation of health services.

We know that Indigenous children in remote settings suffer a range of diseases and infections that are rare in other Australian children [21]. Indigenous children in remote settings often have a complex range of health and developmental issues. Indigenous child health service needs and the context in which services are delivered may thus be radically different from those required in other settings.

Our findings, illustrate the high burden of disease in Aboriginal children living in remote communities and have implications for clinical service delivery, national Indigenous policy, and prevention. We have documented the nature and high rate of hospitalizations in very remote dwelling Indigenous children. The challenge is to design and deliver clinical and public health services and social policies to manage and ameliorate the health burden for Aboriginal children in remote communities. While high quality clinical services remain crucial, high priority should be given to social determinants of health.

Abbreviations

AIHW: Australian Institute for Health and Welfare; CNS: Central nervous system; FAS: Fetal Alcohol Syndrome; FASD: Fetal Alcohol Spectrum Disorders; IQR: Inter-quartile range; LRTI : Lower respiratory tract infection; NSW: New South Wales; NT : Northern Territory; PAE: Prenatal Alcohol Exposure; pFAS: Partial Fetal Alcohol Syndrome; QLD: Queensland; SA: South Australia; URTI: Upper respiratory tract infection; WA: Western Australia; WHO: World Health Organisation; YLL: Years of Life Lost

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Availability of data and materials

The data that support the findings of this study are available on request from the corresponding author PJD. The data are not publicly available because information could compromise research participant privacy/consent.

Authors' contributions

PJD performed the research, analysed the data, interpreted the results, drafted the manuscript, read and approved final manuscript. ALCM conceived the study, designed the study, and performed the research. JPF conceived the study, designed the study, and performed the research. RW analysed the data. EJE conceived the study, designed the study, performed the research, read and approved the final manuscript. JO conceived the study, designed the study, and performed the research. MC conceived the study, designed the study, and performed the research. HEJ interpreted the results, drafted the manuscript, and read and approved the final manuscript. DH interpreted the results, drafted the manuscript, and read and approved the final manuscript. All authors have contributed to and approved the final manuscript.

Ethics approval and consent to participate

Ethics approval for the Lililwan Project was obtained from the University of Sydney Human Research Ethics Committee (Lililwan Project Approval numbers 12527, 13187, 13551), the Western Australian Aboriginal Health Ethics Committee (Approval numbers 271–01/10, 319–10/10, 344–04/11), the WA Country Health Service Human Research Ethics Committee (Approval numbers 2010:01, 2010:28, 2011:04), and the Kimberley Aboriginal Health Planning Forum Research Sub-committee (Approval numbers 2010–001, 2010–001, 2010–001). The Health Services project was an extension of the Lililwan Project and was approved by the Western Australian Aboriginal Health Ethics Committee (Approval number 344–04/2011) and the WA Country Health Service Human Research Ethics Committee (Approval number 2013:18).

Informed written consent was obtained from all parents or primary caregivers of participants (aged 7–9 years). The purpose and nature of the study were explained by 'Community Navigators' (Aboriginal members of the research team with local language skills and knowledge of cultural protocols). Consent forms and participant information statements, developed in consultation with Aboriginal community leaders, were provided and read to parents or caregivers in English, Kimberly Kriol or the local Aboriginal language of their choice.

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests.

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Chapter 5: Emergency department presentations by children in remote Australia: a population-based study

Foreword for Chapter 5: Emergency department presentations by children in remote Australia: a population-based study

Following review of lifetime hospital admissions by a child cohort in remote Australia, presented in **Chapter 4**, we explored use of the Fitzroy Crossing emergency department across five years (2007-11) by the same cohort. This period was chosen because it followed introduction of the electronic healthcare database, Communicare^{TM}. We documented the reasons for presentation, comorbidities, and encounter outcomes and the associations between ED use, demographic data from interviews with parents of the Lililwan cohort, and outcomes of the children's neurodevelopmental assessments.

Together with the data from **Chapter 4**, we have documented utilisation of Fitzroy Crossing Hospital across a childhood lifespan (the ten-year period of 2002-11) by a cohort of predominantly Aboriginal children.

It was hypothesised that services would experience high demands, appear under-resourced to meet these demands and be providing fundamental primary health care services.

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Statement of Contribution

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I declare that the research presented in this Thesis represents original work that I carried out during my candidature at the Australian National University, except for contributions to multi-author papers incorporated in the Thesis where my contributions are specified in this Statement of Contribution.

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Emergency Department Presentations by Children in Remote Australia: A Population-based Study

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Abstract

Background. Aboriginal leaders invited us to examine the frequency and reasons for emergency department (ED) presentations by children in remote Western Australia, where Prenatal Alcohol Exposure (PAE) is common. *Methods.* ED presentations (2007-11 inclusive) were examined for all children born in the Fitzroy Valley in 2002-03. *Results.* ED data for 127/134 (94.7%) children (95% Aboriginal) showed 1058 presentations over 5-years. Most (81%) had at least 1 presentation (median 9.0, range 1-50). Common presentations included: screening/follow-up/social reasons (16.0%), injury (15.1%), diseases of the ear (14.9%), skin (13.8%), respiratory tract (13.4%), and infectious and parasitic diseases (9.8%). PAE and higher presentations rates were associated. Commonly associated socio-economic factors were household over-crowding, financial and food insecurity. *Conclusion.* Children in very remote Fitzroy Crossing communities have high rates of preventable ED presentations, especially those with PAE. Support for culturally appropriate preventative programs and improved access to primary health services need to be provided in remote Australia.

Keywords

Aboriginal, emergency department presentation, pediatric, rural and remote, Australia

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What we already know?

Aboriginal health in Australia has received much research attention, however little focus has been given to community level studies which provide opportunities to influence local policy development and implementation. There are few peer-reviewed publications describing Emergency Department (ED) presentations by Aboriginal children in very remote Western Australia. Furthermore, whole Indigenous Australian pediatric population group studies or studies that describe service use are rare.

What this article adds?

This project aimed to fill these gaps to inform solutions for this and similar communities nationally, and to allow for comparison with similar population

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groups internationally. We aimed to describe the reasons for presentation and outcomes of emergency department presentations to Fitzroy Crossing Hospital by children in the Lililwan cohort (95% of all children born between 2002-3 and living in the valley in 2010-2011). As this cohort were comprehensively assessed for Fetal Alcohol Spectrum Disorders (FASD), we hypothesized that a correlation between Prenatal Alcohol Exposure (PAE) or FASD and frequency of emergency department presentations would exist. We found that presentations to emergency department with preventable conditions are frequent for young Aboriginal children in very remote Australian communities, with higher rates in children with PAE however, there was no correlation between FASD diagnoses and higher rates of presentations. This indicates need for culturally appropriate health literacy, better living conditions, and improved access to primary health services and prevention programs.

Background

Indigenous Australians comprise 3% of Australia's population and 80% reside in rural or remote Australia.[1] In very remote locations, the proportion of the population who are Aboriginal is over 45%[2] and in the Fitzroy Valley the proportion is 93%.[3] The Aboriginal age pyramid in remote settings is skewed toward children. In 2011, 36% of Aboriginal Australians were aged 0 to 14 years.[2]

Despite a 33% decrease in the gap in mortality rates between Aboriginal and non-Indigenous children aged under-5-years from 1998 to 2015, rates remain 3.5 times higher for Indigenous children in Western Australia (WA), at 189 versus 54 per 100, 000.[2]

In the very remote Kimberley region of northern WA lies the Fitzroy Valley, a 2500 km^2 area, home to approximately 4500 people. Fitzroy Crossing is the service town for the Fitzroy Valley and the site of the only hospital, servicing about 45 very remote communities within approximately a 200 km radius. In 2013, 1400 people living in the Fitzroy Valley were children aged under 16 years.[3] These Aboriginal people belong to 5 main language groups (Bunuba, Walmajarri, Wangkatjungka, Gooniyandi, Kija, and Nyikina) and maintain traditional practices.[3]

In 2016/17 there were 67, 032 ED presentation across all Kimberley hospitals.[4] Fitzroy Crossing Hospital is a 12-bed inpatient facility with an associated emergency department (ED). The hospital is funded for 4 doctors and 15 nurses, however recruitment and retention of staff is challenging in remote Australia, so the workforce did not always have full capacity. On average the hospital was staffed by 3 doctors and 8 nurses.[5] Five separate consultation rooms are used for outpatient GP and visiting specialist consultations. GP consultations are available within restricted hours, for walk-in visits and a limited number of booked appointments. Some remote communities outside Fitzroy Crossing town have nurse-run health clinics and receive intermittent GP services from the RFDS.[5] The Lililwan Project was a collaborative, community-led, population-based prevalence study of Fetal Alcohol Spectrum Disorder (FASD), Prenatal Alcohol Exposure (PAE), early life trauma and health of children in the Fitzroy Valley that arose from the locally developed Marulu Strategy.[6,7]

In Stage 4 of the Lililwan Project we aim to describe reasons for and outcomes of ED presentations to Fitzroy Crossing Hospital by children in the Lililwan (all the little ones in Kimberley Kriol and representing the cohort who underwent complex multi-disciplinary assessments for Fetal Alcohol Spectrum Disorders) cohort, assess for correlations between PAE and/or FASD and frequency of emergency department presentations. We hope to highlight the implications for child health, health care and service delivery in remote Australia, and inform solutions for similar communities by comparison.

Methods

The Lililwan Project

This population-based study of children (Lililwan cohort) in the Fitzroy Valley was conducted between 2010 and 2013 (Figure 1). As previously described, the aim of the Lililwan project was to determine FASD prevalence using validated, multi-disciplinary neurodevelopmental assessments. This age group was selected because they were old enough to participate in the FASD assessment, yet young enough to benefit from medical, educational, and behavioral interventions. Also, this cohort was born before the introduction of alcohol restrictions throughout the Fitzroy Valley in 2008 hence PAE was more likely.[8] Identification and characterization of the cohort, definition of terms, culturally safe consent process utilizing "community navigators" and local languages, and results from the FASD prevalence study (Stages 1&2) are published elsewhere.[8-11] Demographic data (Table 2) were gathered during interviews with parents or carers using a standardized data form during Stage 1[8] and FASD diagnoses were made during Stage 2.[6] In Stage 3 we mapped health services.[5] In Stage 4 we documented lifetime hospitalizations

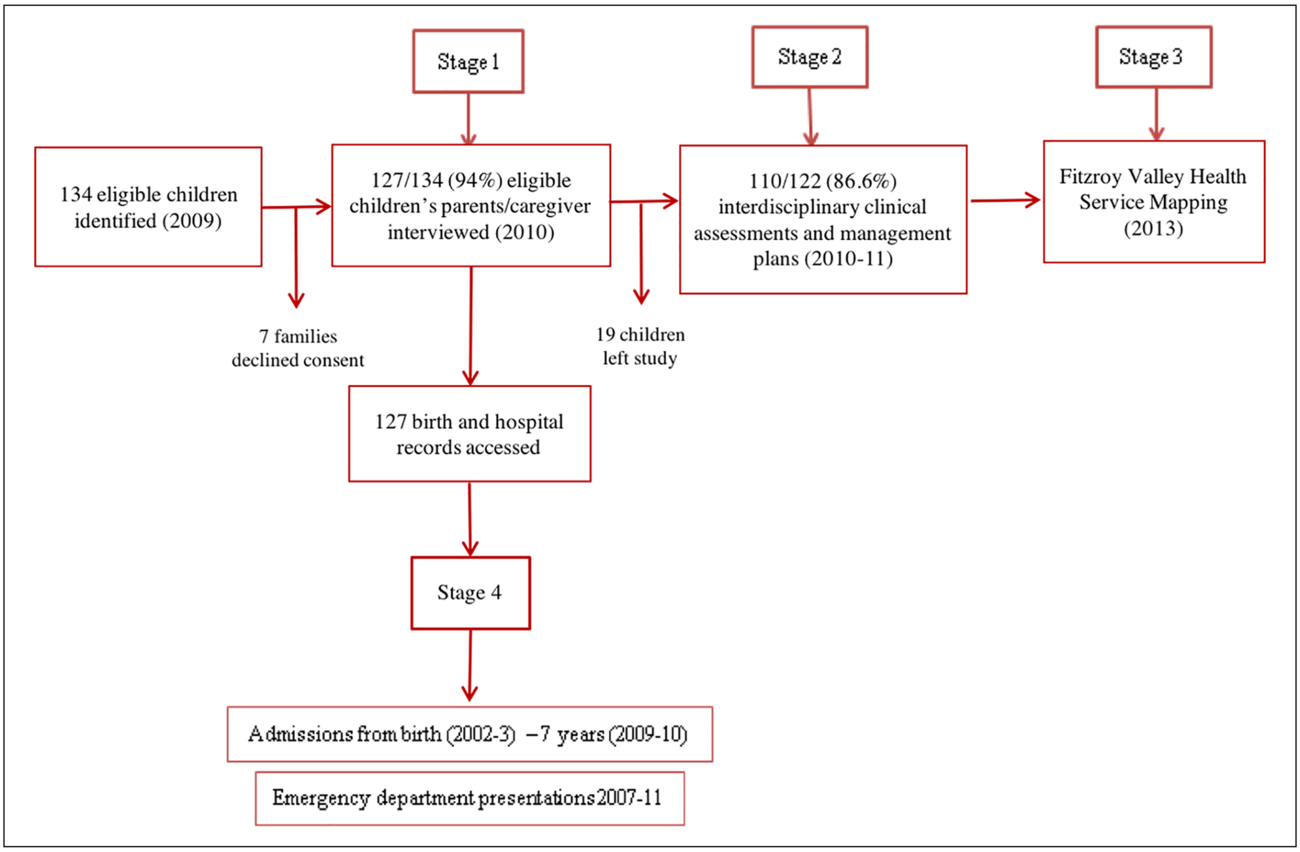

Figure 1. Flowchart of the Lililwan Project timeline: Identification and characterization of the Lililwan cohort, definition of terms, culturally safe consent process utilizing "community navigators" and local languages, and results from the FASD prevalence study are detailed elsewhere.[7-9] Stage 1 (2010) involved interviews with 127 (94.7%) parents or caregivers of 134 eligible children born 2002-2003, conducted with "community navigators" trained in use of a reliable, culturally appropriate questionnaire.[7,8] Stage 2 (2010-2011) included comprehensive multidisciplinary clinical assessments for 110 (86.6%) of the 127 children from Stage 1 and development of individualized management plans.[8,10,11] For Stage 3 (2013) we mapped the available health services in the Fitzroy Valley.[5] Stage 4 examined the cohorts use of the emergency department and lifetime (to age 7) hospitalizations.

(age 0-7 years)[9] and existing health problems (in 2011) and ED presentations during 2007 to 2011, the focus of this paper.

Emergency Department Presentations

We retrospectively hand-searched electronic (Communicare™ database, implemented at Fitzroy Crossing in 2007) and hard copy health records at Fitzroy Crossing Hospital for all 127 children (born 2002-3). Data extracted on ED presentations between January 1st 2007 and December 31st 2011 included the date and primary reason for presentation, outcome (managed and discharged, admitted, transferred to the nearest tertiary hospitals in Perth), and additional conditions managed at each presentation. Two doctors coded the reasons for presentation using the International Classification of Diseases Tenth Edition (ICD-10-online, World Health Organization (WHO)),[12] and entered into a Microsoft Access database. Diagnoses were classified by their main, sub, and specific code, providing 3 to 7 characters for classification. Missing data were coded as 999. Discussion with community members and health care professionals based in Fitzroy Crossing, and review of local newspaper articles for significant regional events during this time period, informed our understanding of the local context.

Data Analysis

IBM SPSS Statistics for Mac (version 23.0.0.0 Armonk, NY, USA) was used for data analyses. Frequencies, medians, and prevalence estimates were obtained using descriptive analyses. Chi-squared tests were used to test associations between dichotomous, categorical variables, with Fisher exact test used where cell sizes were

Table 1. Emergency Department Presentations to Fitzroy Crossing Hospital, 2007-211.

	Children assessed		
Emergency department presentations	Median	Inter-quartile range	Range
All children (n = 127)			
Presentations (total = 1058)	7	2-13	0-50
ICD-10 codes (total = 1743)	11	3-22.5	0-80
Children who presented at least once (n = 103)			
Presentations (total = 1058)	9	4-14	1-50
ICD-10 codes (total = 1743)	14	7-25	1-80
Number of presentations by sex (n = 127)			
Males	9	2-16	0-50
Females	6	3-15	0-25
Presentations by prenatal alcohol exposure (n = 100)[a]			
Prenatal alcohol exposure (n = 59)	9	3.5-14	1-50
No prenatal alcohol exposure (n = 41)	6	1-11	1-33
Presentations for children with FASD (n = 103)[a]			
Children with FASD (n = 21)	9	3-14	0-50
Children without FASD (n = 82)	8	4-14	0-33
Presentations by wet (October-March) and dry (May-September) seasons	Wet	Dry	Total
2007	17	34	51
2008	106	64	170
2009	178	120	298
2010	125	140	265
2011	128	146	274
Total	554	504	1058

[a]Number of children that had information available on alcohol exposure in utero and at least 1 ED presentation.

small (<5).[13] Risk ratios (with 95% confidence intervals) for associations with demographic variables were calculated for children with 11-50 ED presentations and 1-10 presentations compared to children with no presentations. The 10 children who presented most often were analyzed descriptively to identify factors associated with very high presentation rates.

Ethics Approval

Stage 4, a planned extension of the Lililwan Study, was approved by the WA Aboriginal Health Ethics Committee (Approval 344-04/2011); the WA Country Health Service Human Research Ethics Committee (Approval 2013:18); and the Australian National University Higher Research Ethics Committee (Approval 2016/432).

Results

The Lililwan cohort of 127 remote dwelling children born in 2002-3 comprised 94% of the primary school aged children born in 2002-3 and living in the Fitzroy Valley in 2010-11. The majority of these children were Aboriginal (95%). The participation rate was high despite 45.7% of children living in very remote communities of less than 1000 people. Prevalence of FASD (19%) and its co-morbidities and hospital admissions rates were high.

In 5 years 2007-11 inclusive, there were 1058 presentations for 1743 conditions in 127 children. There were more presentations in 2009, 2010, and 2011 (274, 265, 298) than 2007 (51) and 2008 (170) with no significant difference in ED presentations numbers between the dry (May-September) and wet seasons (October-March).

Most (89.7%) conditions were managed in the ED and children were then discharged home. Only 5.9% of presentations led to hospital admission and 4.0% were referred to external services. Less than 1.0% of children were transferred to a tertiary pediatric hospital in Perth, WA.

Of 127 children, 103 (81%) had at least 1 ED presentation. For children who presented at least once, the median number of ED presentations, over the 5 years, was 9 (range 1-50). Of the 103 children presenting to ED, 51.2% had over 6 presentations, 32% had over 11, and 10 had over 18 (Table 1). Based on ICD-10 codes, the median number of reasons for presentation was 14 (range 1-80, n = 103) per child over 5 years. Males and

Table 2. Risk Ratios, Confidence Intervals, and *P* values (Chi^2) for Specific Characteristics of the Lililwan Cohort for Children Who Had 1 to 10 and 11 to 50 Emergency Department Presentations Compared to Those Who Had None.

		1-10 ED presentations (n = 62)			11-50 ED presentations (n = 41)		
Variable		Risk ratio	Confidence intervals (95%) lower, upper	*P*-value	Risk ratio	Confidence intervals (95%) lower, upper	*P*-value
Primary hypotheses							
Prenatal alcohol exposure (n = 122)	No	1.22	0.93, 1.59	.15	1.54	1.02, 2.33	.02*
	Yes						
FASD (n = 108)	No	1	0.84, 1.19	1.0	1.00	0.77, 1.29	1.0
	Yes						
Secondary analysis							
Aboriginal or non-Indigenous	Non-Indigenous	3.77	0.65, 21.83	.04*	3.33	0.57, 19.41	.12
	Aboriginal						
Sex	Male	1.07	0.82, 1.39	.63	0.94	0.64, 1.37	.73
	Female						
Place of residence	Outer suburbs or larger	1.16	0.89, 1.51	.27	0.89	0.59, 1.33	.54
	Hub or satellite community						
Financial concerns[a] (n = 124)	No	1.03	0.78, 1.37	.84	1.17	0.81, 1.70	.4
	Yes						
Food insecurity[b] (n = 124)	No	1.13	0.86, 1.48	.4	1.44	0.99, 2.08	.06
	Yes						
Overcrowded[c] home (n = 125)	No	1.06	0.80, 1.41	.68	1.13	0.78, 1.64	.54
	Yes						
Growth deficiency any age[d] (n = 92)	No	1.13	0.78, 1.63	.55	1.23	0.84, 1.80	.32
	Yes						
Support required at birth (n = 92)	No	0.81	0.65, 1.02	.14	0.77	0.57, 1.051	.1
	Yes						
Smoke or marijuana (n = 120)	No	0.87	0.67, 1.14	.34	0.72	0.49, 1.05	.10
	Yes						
Smoke during pregnancy (n = 119)	No	0.9	0.68, 1.18	.47	0.75	0.51, 1.09	.15
	Yes						
Marijuana during pregnancy (n = 119)	No	1.06	0.74, 1.51	1.0	0.91	0.46, 1.78	1.0
	Yes						
Microcephaly[e] (n = 108)	No	1	0.84, 1.19	1.0	0.83	0.47, 1.47	.76
	Yes						
Hearing loss[f] (n = 98)	No	0.76	0.25, 2.34	.64	0.89	0.62, 1.30	.56
	Yes						
Gestation[g] <37 weeks (n = 118) (premature)	No	0.73	0.40, 1.32	.34	0.87	0.51, 1.50	.85
	Yes						
Gestation[g] <28 weeks (extremely premature) (n = 118)	No	0	N/A	.52	0.87	0.51, 1.50	1.0
	Yes						

[a] Financial concerns: report by parents or caregivers that there are times when adults in the child's household worry about not having enough money.

[b] Food insecurity: reports by parents or caregivers that there were times when adults in the child's household worry about not having enough food.

[c] Overcrowding: determined by number living in household and whether the parent or caregiver of the child felt there were too many people living in 1 house.

[d] Growth deficiency at any age: height or weight <10th centile recorded at any age from birth until time of assessment in Stage 2 (7-9 years of age).

[e] Microcephaly: head circumference <3rd centile as per WHO Child Growth Charts.

[f] Hearing loss: determined by an audiologist who conducted tympanometry, audiometry, video-otoscopy and Listening in Spatialized Noise—Sentences Test (LiSN-S) for Central Auditory Processing Disorder assessments.

[g] Gestation based on WHO definitions.

*Indicates significant difference $P < 0.05$.

females had similar numbers of presentations (median 9 vs 6, $P=0.63$). Children were aged 4 to 9 years at the time of ED presentation, but most (72.2%) presentations occurred in children aged 6 years and over.

There were no significant demographic differences between children with 1 to 10 compared to 11 to 50 presentations. No difference in frequency of ED presentations was noted between children with and without FASD (Table 2).

Children with Prenatal Alcohol Exposure (PAE) (n = 59) had a higher number of presentations than children without PAE (median 9.0 vs 6.0, respectively), Table 1, and this was significantly associated with more frequent (11-50) than lower (1-10) presentations (RR = 1.54, 95% CI: 1.02-2.33, $P=0.02$) (Table 2).

Aboriginal children (95.3% of 127 children) were more likely to present 1 to 10 times to the ED than non-Indigenous children (n = 1 vs n = 1 vs n = 4 for non-Indigenous children with 1-10, 11-50, and no presentations, respectively) (RR 3.77, 95% CI: 0.65-21.83, $P=0.04$ using Fisher Exact test for small sample size (<5)).

The 10 children with the highest number of presentations each had a minimum of 18 ED presentations over the 5 years. This sub-group was predominantly Aboriginal (90%) and male (80%) with significant existing medical issues and poor socio-economic conditions. The 10 children had 275 ED presentations (range 19-50, median 25.5) for 430 reasons (range 32-79, median 39). In these children, 167 presentations for single reasons and comorbidities existed for 39% of these presentations (range 1-4 additional comorbidities per visit). Disease of the ear (20.4%), injury (16.3%), skin (15.8%), and respiratory infections (15.4%) were the most common primary reasons for ED presentation.

The most frequent reasons for ED presentation (n = 1058) by ICD10 chapter code were conditions coded as “factors influencing health status and contact with health services” (16.0%) (Table 3). These are typically deemed primary care conditions, usually seen in a GP clinic. For example: continued care for an ongoing ailment, vaccination, issues influencing health status, or problems not classified as disease or injury, for example, social issues. In our study, these presentations included sub-acute follow up of a condition (47.3% of these ICD chapter presentations, 7.6% of all presentations), hearing or ear checks (23.1%, 3.7%), screening (eg, for STIs, trachoma, anemia, diabetes) (13%, 2.0%), and growth checks (10.1%, 1.6%).

Injury or poisoning represented 15.1% of presentations. Of the injuries, wounds accounted for 48.0% of presentations (and 7.6% of all presentations), fractures and dislocations for 12.1% (1.9%), head injury with concussion 9.0% (1.42%) (Table 3).

In the group with between 11 and 50 presentations, wounds were responsible for 8.6% of injury presentations compared to 5.3% for the group with 1 to 10 presentations. All other injuries were proportionally more frequent in the lower presentation group (1-10) than the higher presentation rate group (11-50).

Diseases of the skin and subcutaneous tissue comprised 13.8% of all ED presentations and the majority 91.1% were infections (which alone accounted for 12.6% of all presentations). Diseases of the ear and mastoid process, mostly otitis media, accounted for 14.9% of presentations. Furthermore, 13.4% of ED presentations were for diseases of the respiratory system including upper and lower respiratory tract infections (Table 3).

Of all ED presentations (n = 1058), 50.9% were the direct result of infection (47.7% in the group with 11-50 admissions and 57.7% in the group with 1-10 admissions). Almost two thirds (63.8%) of infectious presentations occurred within the high presentation group (11-50).

Of ED presentations, 9.8% were for infectious and parasitic diseases, for example, gastroenteritis (39.4% of infectious or parasitic disease, n = 41), trachoma (28.9%, n = 30), strongyloidiasis (n = 6), meningococcal meningitis (n = 2), fungal infections such as tinea (n = 5), head lice (n = 3), scabies (n = 3), cutaneous larva migrans (hookworm) (n = 3), and necrotizing ulcerative stomatitis (n = 1) (Table 3). Other symptoms, signs and abnormal laboratory or clinical findings (eg, cough, fecal incontinence, headache, lethargy, edema, failure to thrive) accounted for 6.8% of presentations.

Presentation rates did not differ significantly for any ICD chapter code between groups with low (1-10) and high (11-50) numbers of presentations.

Discussion

Over a 5-year period, there were high numbers of ED presentations in a cohort of remote dwelling, predominantly Aboriginal children. Most (82%) children presented at least once and a third (32%) had more than 11 presentations over 5 years. Presentations (n = 1058) were typically for: infections of skin (12.5% of total presentations), middle ear (12.2%) and upper respiratory tract (9.8%); follow-up (7.5%); and wounds (7.5%). The high rate (89.7%) of discharges home after management in ED suggests low acuity presentations. Many of these children could potentially have been seen by GPs or community health workers, however such services were limited, necessitating ED use. There was an increase in the number of presentations during 2009-11 compared to 2007-8, but seasonality did not affect numbers. There

Table 3. Most Common Reasons for ED Presentation (n = 127 Children, N = 1058 Presentations) by ICD 10 Chapters and Most Frequently Represented Sub-Categories.

ICD chapter title	Number of cases	Percentage (%) of all presentations (N = 1058)	ICD code sub-category	Cases in chapter (%)	Percentage (%) of total cases (N = 1058)
Factors influencing health status and contact with health services	169	16.0	Sub-acute follow up of a condition	47.3	7.6
			Hearing or ear checks	21.3	3.7
			Screening for STIs, trachoma, anemia, diabetes	13.0	2.0
			Growth checks	10.1	1.6
Injury or poisoning	160	15.1	Wounds	48.0	7.6
			Fractures and dislocations	12.1	1.9
			Head injury and concussion	9.0	1.42
			Animal including insect bites	8.4	1.3
			Foreign body removal	8.4	1.3
			Burns	6.0	1.0
Disease of skin and subcutaneous tissue	164	13.8	Infections, eg, cellulitis	91.1	12.6
Disease of ear and mastoid	158	14.9	Otitis media	81.1	12.2
Diseases of respiratory system	142	13.4	Upper: Pharyngitis (n = 4)Tonsilitis (n = 17)Epiglottitis (n = 1)	73.2	9.8
			Lower: Pneumonia (n = 18)Bronchitis and asthma (n = 11)	12.0	1.6
Infectious or parasitic diseases	104	9.8	Gastroenteritis (n = 41)	39.4	3.9
			Trachoma (n = 30)	28.9	2.8
			Other: strongyloidiasis (n = 6), meningococcal meningitis (n = 2), varicella zoster virus (n = 1), fungal infections such as tinea (n = 5), head lice (n = 3), scabies (n = 3) cutaneous larva migrans (hookworm) (n = 3), necrotizing ulcerative stomatitis (n = 1)	23.1	2.2

were higher numbers of presentations in children with PAE and in Aboriginal children but no association with age or gender.

Reflecting the population in the Fitzroy Valley, a higher proportion of children in our study (95.3%) was Aboriginal compared to the proportion in studies from tertiary hospitals in Australia and New Zealand (3%)[14] and the Northern Territory (31%).[15] However, the reasons for presentation were similar, most commonly acute, viral gastrointestinal, and respiratory infections. Similar to the NT study,[15] injury and skin infections were common reasons for presentation in the Fitzroy Valley but in our young children acute psychiatric presentations were not well-documented. Our findings are also consistent with previous studies that examined reasons for Aboriginal child presentations to remote primary health care services in the Northern Territory (NT)[16] and Sydney.[17]

Over half (50.9%) of presentations in our cohort were for potentially preventable infectious conditions, consistent with common causes for ED presentation for Aboriginal people of all ages in the Kimberley in 2008-9.[18] The 2004 Aboriginal Child Health Survey of children aged 0 to 17 living in WA, provides congruent data and shows that infectious conditions were highest in young children.[19]

Infectious diseases are closely interlinked with poverty. Poverty contributes to a spiral of lifelong adverse outcomes including social stigma, poor housing and sanitation, low education levels, unemployment, and poor nutrition which in turn increase the risk of acute and chronic illness and disability.[20] As discussed in the Kimberley Aboriginal Primary Health Plan 2012-15, many infections could be prevented by better living conditions, including reducing overcrowding and ensuring clean drinking water, sanitation, and vaccination.[18] Many presenting conditions in our cohort (eg, hookworm, strongyloidiasis, meningococcal meningitis, trachoma, and rotavirus gastroenteritis) have been almost eradicated elsewhere in Australia.

Hygiene and education programs should be developed and managed by primary health care and education systems.[18] In Fitzroy Crossing, Nindilingarri Cultural Health Services play an important role in health promotion. Skin and throat infections are common in this population and sometimes lead to systemic infections and rheumatic heart disease.[21] Since we commenced our study, the Telethon Kids Institute with Western Australia Country Health Service (WACHS) and Kimberley Aboriginal Medical Services (KAMS), initiated the SToP Program (see, Treat and Prevent skin sores and scabies) in the Kimberley region with the intention of decreasing skin infection rates to under 5%.[22] There is also a “no school, no pool” rule; the chlorinated pool decreases rates of otitis media and scabies.[23]

Strong coverage from immunization programs prevent infectious diseases and their spread. Children in the Lililwan cohort were eligible for free vaccination under the National Immunisation Program[24] however we did not obtain immunization records for this cohort. In 2019, the national coverage rate for vaccinations in 5-year-old Indigenous Australian children was 96.8%.[25]

Injury rates could be decreased using culturally appropriate preventative education for leading causes and complications of injury in Fitzroy Crossing (eg, head injuries, burns, and snake bite), and awareness of non-accidental injuries.[26] Interventions should include health and safety promotion including hygiene, wound care, and improved environmental safety.[26]

The potential reasons for increased ED presentations from 2009 to 2011 include decreased access to primary health care in the community[5] and increased health literacy. Health literacy is an individual’s capacity to understand and use health information to meet health needs.[27] Poor health literacy in parents is associated with increased and inappropriate engagement with EDs.[27] Community-led alcohol restrictions and education programs were implemented in September 2007; the Marulu strategy commenced in 2008; and Stages 1&2 of the Lililwan Project were completed in 2009-12. These activities included culturally appropriate health education in local Aboriginal languages, which likely improved parents’ awareness about child health and wellbeing and their willingness to engage with health services, compared to 2007-8. Children with PAE (49%) had higher rates of ED presentations compared to children with no PAE and this may reflect issues associated with continued alcohol use at home.

When primary health care services are limited and access is difficult, for example, in this very remote context with extreme climate and limited transport, use of the emergency department becomes a proxy for primary health care use, particularly for conditions that would be deemed low acuity at triage and should be treated in the community.[18] Our data is supported by WACHS 2018 report which demonstrates that from 2011 to 2015 the majority (74%) of Kimberley wide ED attendances were triage 4/5 (which is indicative of issues that could be managed by primary health care services) and that similar challenges occur in other remote communities across the Kimberley.[4] Despite discussions with local health care workers and review of reports from this time period, it was difficult to accurately ascertain the numbers of GPs or remote community nurse practitioners servicing the Fitzroy Valley over the 5-year period 2007-11.[9] Our 2013 review of child health services showed high rates of potentially preventable hospital admissions.[9] A previous NSW study demonstrated that absence of a GP increased ED presentations for low acuity patient presentations by up to 54.7% in inner regional areas and that the number of presentations was higher in younger patients.[28] At some periods during our study, due to a scarcity of doctors, the ED was staffed by nurses only who did not document diagnoses. Since our data were collected, the Fitzroy Crossing ED has undergone restructuring in an attempt to encourage low acuity patient presentations out of the ED into GP clinics. This followed community consultation and increased GP attendance rates from 67% in August 2010-11 to 85% in August 2011-March 2012, accompanied by a decrease by about 300% in lower acuity triage presentations to ED.[18]

Environmental factors, including a large dust storm, cyclone Yvette, and the fire that burnt down the Fitzroy Crossing Shopping Centre in July 2009 may explain reduced ED presentations that year. The similar number of ED presentations in the dry and wet seasons was surprising, considering the wet season deems roads impassable for weeks. However, there are year-round barriers to accessing health service including long distances, few private cars or drivers and a lack of public transport that may account for this stability across seasons.[5]

Although our study is limited by a lack of data on triage categories and the challenge of not having an age matched comparative cohort, we believe it is important as it documents use of a hospital ED over 5 years by a near complete, population-based sample of predominantly Aboriginal children in a very remote setting. This study is strengthened by the lack of selection bias and the fact that ED use in Fitzroy Crossing is likely representative of similar remote-dwelling cohorts in Australia. The high rates of ED use indicate need for better preventative strategies for infection and injury, identifies gaps in primary care services, and could inform policy and practice in this and other remote communities.

This research was requested and led by Aboriginal women leaders in the community following years of community consultation. We achieved high participation rates despite vast geographical distances, due to use of community navigators (respected locals who brokered all contacts between researchers and communities). A validated research tool was used to collect information on PAE and a reliable and culturally appropriate questionnaire was used to obtain demographic details from families.[8,11]

The Kimberley population is the fastest growing population in WA, expanding at an average rate of 2.7% per annum.[29] The skewed Aboriginal Australian population pyramid, in favor of young people (56% aged 0-24 years (2006 Australian Census)), means an ongoing and increasing demand for child health services in the Kimberley Region.[18] This paper adds novel data on the context and underlying reasons for ED presentations for children in Fitzroy Crossing and will inform educational tools and development of adequate infrastructure to better support these communities and similar remote communities in Australia and overseas. We have previously demonstrated high rates of disability including FASD,[6] high rates of hospital admissions,[9] and limited child health services in the region.[5] We have also documented modifiable determinants of ill-health, including poor housing and sanitation and the need for clean water, parental education, and health literacy. Knowledge of health needs and service gaps, both preventive and clinical, will allow future service planning, in consultation with and ideally driven by the local population, to improve child health and well-being.

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Author Contributions

PJD performed the research, analyzed the data, interpreted the results, drafted the manuscript, read and approved final manuscript. EFMF performed the research, collecting and interpreting the data, proofed and approved the final manuscript. KG interpreted results, drafted manuscript, and read and approved final manuscript. RW analyzed the data. JO conceived the study, designed the study, and performed the research. MC conceived the study, designed the study, and performed the research. HEJ interpreted the results, drafted the manuscript, and read and approved the final manuscript. KD interpreted the results, drafted the manuscript, and read and approved the final manuscript. DH interpreted the results, drafted the manuscript, and read and approved the final manuscript. EJE conceived the study, designed the study, performed the research, read and approved the final manuscript. ALCM conceived the study, designed the study, and performed the research, read, reviewed, edited and approved the final manuscript. All authors have contributed to and approved the final manuscript.

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Chapter 6: Conclusions

6.1. Thesis overview

There is minimal information available on child health outcomes and service use in remote Australian Aboriginal communities. The aim of this thesis was to investigate paediatric health service requirements and utilisation in remote Australia, with particular reference to the very remote Fitzroy Valley of northern Western Australia. To do this, several research studies were undertaken using different research methods. This thesis builds on, and extends beyond, the Lililwan project which was initiated in 2009 to investigate the prevalence of prenatal alcohol exposure (PAE) and fetal alcohol spectrum disorders (FASD) in the Fitzroy Valley. My work was conducted in response to priorities identified by Aboriginal leaders and in partnership with Aboriginal communities.

A literature review (**Chapter 2,** *Aim 1*) was performed on paediatric health services and health service utilisation in remote Australia to synthesise what was previously reported in the grey and academic literature on this topic and to highlight knowledge gaps that could be addressed by this thesis. The review identified components of a gold standard model of care relevant for future health service delivery and highlighted many current challenges in providing health services for children living in remote communities, including recruitment and retention of health workforce, funding, and access to health care.

The health services available to children of the Fitzroy Valley were audited and mapped (**Chapter 3,** *Aims 2&5*), providing, for the first time, one reference document for use by health practitioners and patients outlining the timing and nature of community visits by different health providers and organisations. An illustrative clinical case was developed to demonstrate the challenges faced by a child, with both acute and chronic complex health issues and disabilities, in obtaining access to and benefits from health services.

Utilisation of local health services over a decade (2002-2011) was assessed in the Lililwan cohort by documenting lifetime (0-7 years) hospital admissions (**Chapter 4**, *Aims 3&5)* and emergency department (ED) presentations (**Chapter 5,** *Aims 4&5)* over a five-year period (2007-11). This demonstrated high rates of hospitalisation and ED use, often for treatment of potentially preventable infections. Many of these conditions could be managed in primary health care facilities e.g., general practice (GP) and remote community-based child health clinics, rather than a hospital setting, if these existed. Primary prevention of these conditions requires modification of social determinants of health, including housing and sanitation. The data from this thesis quantify, for the first time, the association between prenatal alcohol exposure (PAE) and health service utilisation in predominantly Aboriginal children living in remote Australia.

The research data reported within this thesis were obtained by me during several visits to Fitzroy Crossing and from data collected during stages 1 and 2 of The Lililwan Project, on a cohort of primary-school aged children born in 2002-3. Results of the Lililwan Project relating to PAE, FASD and neurodevelopmental outcomes are published elsewhere (117-119). This research is important because Aboriginal children are amongst the most disadvantaged groups nationally and many have poor health outcomes. Although advancements in knowledge and improvements to health outcomes have occurred over the last decade, identifying service use and opportunities for improving service access and quality will inform future health policy, prevention strategies and service development.

6.2. Summary of Key Findings

In **Chapter 1,** the thesis is introduced in the context of the Lililwan Project. In the Lililwan cohort, 55% of children had prenatal alcohol exposure, 93% of this group being exposed to high risk levels of PAE (36). The most common drinking pattern during pregnancy was 10 or more standards drinks at least 2-3 times per week (36). Of the cohort, 19% were diagnosed with FASD using strict, internationally recognised criteria (117). This is one of the highest prevalence rates of FASD reported globally (190/1000 population) (117, 120). The findings are consistent with identified high risk groups for FASD internationally, including children in Indigenous communities, juvenile justice, and adoptive and foster care (34, 35). Many children in the Lililwan cohort had chronic, complex health, learning and behavioural problems (117, 119, 121).

Chapter 2 is a review of the academic and grey literature published in the two decades before commencement of this thesis. The aim was to describe health needs and existing services for Indigenous children living in remote Australia. We located over 100 documents deemed highly relevant to our research aims and from these describe health service provision and utilisation by children in remote Australia. We compared existing services to best practice models and identified opportunities for improvements.

This review highlighted key gaps in measures to evaluate existing health services. There is 1) no standardised tool for measuring access to health care in Australia, 2) no established optimal staffing level for health services in remote Australia, and 3) no standardised framework for measuring the effectiveness of health service delivery in remote Australia.

Key findings from the review (**Chapter 2**) identified that significant challenges exist in service delivery. Access is impeded by the geographical location of both communities and health services, and their relation to one another. Inadequate public and private transport, high staff turnover, and environmental factors compound these challenges. Service delivery is further impacted by poor infrastructure, including lack of access to internet and telephone services, poor sewerage, unreliable water supplies and unreliable electricity sources which can jeopardise refrigeration of essential medications. Resource shortages (e.g., workforce, equipment, accommodation) mean limitations are placed on clinical time with patients, and energy is diverted to administrative tasks. Economic factors (e.g., high cost for remote transport, food, accommodation) impact service access and delivery. Issues of cultural competency and language barriers impair patient-clinician communication due to insufficiencies in the numbers of available interpreters and Aboriginal Health Workers (AHWs).

We identified no standard measurement for access to health care for Indigenous children and families in rural and remote Australia (**Chapter 2**). In New South Wales (NSW), 50km is defined as the ‘critical maximum distance’ within which a patient should live from a health professional, at which point the patient becomes less likely to travel to access services (74). Our entire cohort live in an area classified as very remote (23), and approximately half (45.7%) of our cohort live in hub or satellite communities that are beyond this ‘critical maximum distance’ from the main service town Fitzroy Crossing (122). Fitzroy Crossing town is a further 1474km and 2548km from the nearest major hospitals, in Darwin and Perth respectively.

The remote workforce experience stress from high workloads. There are no established optimal staffing levels for remote Australia (**Chapter 2**). We found that although the 1997 Kimberley Regional Aboriginal Health plan recommended one AHW per 100 Aboriginal people, one community nurse per 250 people, and one doctor per 600 people, these benchmarks have not been met (93, 122). There are ongoing struggles related to building, retention and funding of the workforce, as well as a lack of transport and accommodation (122).

Best practice models demonstrate that an increased utilisation of child health services occurs when there is integration of maternal and child health services and increased cultural awareness and training for non-Indigenous staff (62). Effective primary health care models in rural and remote Australia have been demonstrated to possess the following features: proper governance, effective management, community involvement, strong leadership and adequate financing, infrastructure and workforce supply (94).

Chapter 3 describes child health services in the Fitzroy Valley in 2013 following stage 2 (multi-disciplinary assessments) of the Lililwan Project. We interviewed 17 key health providers from all existing child health services, who identified their staff and described the frequency and location of their services and barriers to service delivery. Before this exercise there was no document that collated the totality of all paediatric services (e.g., face-to-face, outreach, primary health care, specialist and allied health), the details of services provided (including to whom, when and where) in a widely utilised and easily accessible format for use by either health service providers or patients. Our work highlighted limitations in service delivery, including lack of service integration and coordination; infrastructure and staffing needs; funding complexities; and the challenges of working across large geographical areas in remote and environmentally complex communities.

Interviewees confirmed that funded positions often remained unfilled, and thus provider capacity was significantly less than might be assumed by the number of available positions. They identified the challenges of providing care when there is high staff turnover and hence lack of continuity. Poor communication between and duplication of services reflected the lack of shared health records. We identified no multi-disciplinary child health teams in 2013, with allied health professionals and paediatricians often working in isolation and visiting communities on different weeks. This resulted in poor communication, duplication of assessment and treatment for children, demands on families (e.g., time, travel, cost) and denied health professionals the training, support and mentoring that is inherent in working in a multi-disciplinary team (**Chapter 3**).

Of note, we identified a scarcity of skilled Aboriginal Health Workers (AHWs) in the Fitzroy Valley. There were only 6 AHWs per 10,000 population, compared with the gold standard recommendation of 100 AHWs per 10,000 population (93) (**Chapter 3**). We identified barriers to individuals completing AHW training including: the cost; requirement to travel to Broome (397km) and undergo separation from their family, community and country for the duration of the training program (eight blocks of two weeks in a 12-month period); inadequate supervision and support within the community following training; and lack of opportunities for career progression (123). AHWs are vital in ensuring cultural safety; providing translation of Aboriginal languages; delivering primary care including disease screening; implementing infection control policies; supervising medication use; and supporting children and families by assisting with transport to health appointments since there are limited or no public or private transport options (123).

In **Chapter 4** and **Chapter 5,** I examined hospital use in the main service town of Fitzroy Crossing by a population-based cohort of children. This cohort (n=127) of predominantly Aboriginal (95%), primary school aged children (the Lililwan cohort) is significantly disadvantaged. Over 45.7% live in very remote communities (of <1000 people), a third (33%) live in overcrowded houses, 38% of families have financial concerns and 42% experience food insecurity. Over half (55%) of the cohort had prenatal alcohol exposure, with 19% receiving a subsequent FASD diagnosis. Many (65%) had prenatal cigarette (nicotine) exposure and there were high rates of low birth weight (17% <2500g). Despite these challenges, 95% of all eligible children born in 2002-3 agreed to participate in the Lililwan project, largely because: this project was led by Aboriginal people who partnered with researchers in every phase of the study; local Aboriginal 'community navigators' brokered all relationships with researchers and ensured cultural safety; and consent was obtained in local languages.

The hospital admissions paper (**Chapter 4)** demonstrated that 70% of children born in the Fitzroy Valley (2002-3) were admitted to hospital at least once in the first 7 years of life (median 5 admissions, range 1-12). A third of these admissions occurred before two years of age. Comorbidities at admission were common. We also showed that children who were Indigenous (p=0.009), lived in Fitzroy Crossing town or outer suburbs compared to communities with a population of under 1000 people (p=0.04), and children with markers of disadvantage had higher hospitalisation rates. For example, 48.3% mothers of children admitted to hospital reported food insecurity compared with 24.3% whose children were not admitted to hospital (p=0.01). There was no association between hospital admissions and prenatal alcohol exposure, however 90% of children with FASD had at least one hospital admission before the age of 7 years.

Most (79%) of the primary reasons for hospitalisation were potentially preventable infections (including lower (27.4%) and upper (11.4%) respiratory infections and gastrointestinal infections (22.7%)). Common comorbidities included upper respiratory infections (18.1%), failure to thrive (13.6%), anaemia (12.7%) and skin infections (5.6%). Injury accounted for 7% of admissions. Conditions that are rare in non-Indigenous Australians were also identified as causes for admission, including meningococcal infection (sepsis and meningitis), acute rheumatic fever (ARF), mitral regurgitation linked to rheumatic heart disease and post-infectious glomerulonephritis. Post-infectious glomerulonephritis and ARF are commonly triggered by Streptococcal infection, usually following throat or skin infections, and are potentially preventable. Infection with meningococcus types A, B, C, W and Y is now preventable by vaccination (124). In infants (aged <1 year), 90% of admissions were for infections, of which 40.8% were attributable to lower respiratory tract and 25.9% to gastrointestinal infections.

In **Chapter 5,** I reviewed presentations by the Lililwan cohort to Fitzroy Crossing Hospital emergency department (ED) over the course of five years (2007-11). These data, collected from the Fitzroy Crossing Hospital Communicare^{TM} database, show very high rates of presentations to the ED (N = 1058) in the cohort of 127 children.

Similar to hospitalisations, the majority of children (81%) had at least one ED presentation and some required as many as 50 presentations to the ED over five years (2007-11). Over half the cohort presented more than 6 times and two thirds had over 11 presentations. Over half (50.9%) of the total presentations were for infections, predominantly of the ear, skin and respiratory system. Comorbidities were commonly recorded (median 14, range 1-80). Injuries accounted for 15.1% of presentations and 48% of these were attributable to wounds, 12% to fractures or dislocations and 9% to head injuries.

Most presentations were for potentially preventable conditions (e.g., infection or injury) or for low acuity reasons (e.g., disease screening, follow up). Of these, 87.9% were managed in ED and discharged home and would be better suited to Primary Health Care (PHC) management. The frequent use of ED reflects the paucity of PHC services available in the Fitzroy Valley, particularly in outlying communities.

Of significance, children with prenatal alcohol exposure (PAE) presented to ED more frequently (11-50 presentations versus less than 11 presentations; p=0.02). No significant association was shown between presentation rates and FASD.

Some presenting conditions in our cohort (including hookworm, strongyloidiasis, meningococcal meningitis, trachoma, and rotavirus gastroenteritis) are preventable and treatable and have been almost eradicated elsewhere in Australia. Many children with these infections could potentially have been seen and managed by GPs, Aboriginal, or community health workers, however such services are limited, necessitating ED presentation.

The benefits of prevention programs can be directly observed from reviewing the impacts of culturally appropriate health and education programs delivered in local languages and alcohol restrictions introduced in the Fitzroy Valley in 2008 (121, 125). When evaluated in 2009, alcohol restrictions had resulted in a sustained reduction in alcohol-related admissions (27). These restrictions were introduced 5-6 years after the Lililwan cohort was born and the

Lililwan research data have supported continuation of the restrictions, demonstrating the value of research with Indigenous communities (121, 125, 126).

My work confirms the association between difficulties in accessing health services (in the context of extreme climate, remote locations and limited transport options) and the substitution of secondary or tertiary health service use (including hospital admission and use of emergency departments) for primary health care. This applies even to low acuity conditions that could be managed in the community (127).

6.3. Strengths and Limitations

6.3.1. Aboriginal Consultation and Collaboration

A core strength of this project was the intimate involvement of Aboriginal leaders from the Fitzroy Valley in Western Australia throughout the entire research process. The Lililwan Project research group was invited into the Fitzroy Valley community to help address a community priority and the research was performed at the request of, and in genuine partnership with, Aboriginal leaders. The research was initiated following comprehensive community consultation and after consent was obtained from Aboriginal community leaders, organisations and individual participants, as is best practice (30, 128, 129). The goals of this research were determined and directed by Aboriginal leaders and tailored to target the community's greatest areas of need. Service delivery (diagnosis, treatment and referral), community education, training and capacity-building, and employment of local Aboriginal people were integral to the research, allowing reciprocity and cultural guidance (30).

The Community Navigators (well respected, senior, local Aboriginal people from each language group) were central to the research team. They provided introductions to communities, support in the form of cultural safety, and interpretation of local languages. Community navigators brokered all conversations between non-Indigenous researchers and Aboriginal people to ensure cultural safety was maintained throughout. As a result of the extensive community engagement and inclusion of Community Navigators, there were very high participation rates in all stages of the Lililwan project.

Community consultation continued throughout the project. Feedback of results was provided to Aboriginal community-led organisations, including our research partners, in the form of presentations, easily understood pamphlets and infographics (Appendix 1), informal yarning circles, and academic papers. No results were disseminated without prior approval from Aboriginal team members. Specific documents, such as the health service schedule, were made available to the Fitzroy Community prior to publication, for immediate benefit of children and families. Ongoing consultation allowed for the development of additional research projects that continue to provide positive outcomes for children of the Fitzroy Valley. As outlined in our research memorandum of understanding, the Aboriginal community has custodianship of all data, ensuring they will have ongoing access to data if future research questions arise. Duplicate, de-identified data are held by the University of Sydney and Marninwarntikura Women's Resource Centre.

This work highlights the importance of being respectful of Aboriginal people, culture, traditions, and country, and demonstrates what can be achieved through research partnerships, reciprocity, and mutual guidance (30). In his 2010 report, Social Justice Commissioner, Mick Gooda described the Lililwan research project as 'a genuine partnership - one where research is done with the community and not just about the community,' that it is 'guided by a relationship underpinned by meaningful, respectful engagement and collaboration' (25).

6.3.2. Context for the study: barriers to the conduct of research

Research in remote Indigenous Australian communities presents unique challenges. There are long distances, unsealed roads, extreme climatic conditions (high temperatures and flooding for 4 months each year) and invisible barriers (such as a lack of accommodation, high costs, cultural and language barriers) to research. Children in these locations are often mobile, moving between communities according to the season, and difficult to contact due to a lack of technology (few have internet access or computers, and phone coverage is limited). There is no public transport. Unaccompanied entry to remote communities is not permitted. Flexibility is required to accommodate competing family and other responsibilities, including sorry business, experienced by Aboriginal staff. In addition, obtaining ethics approval is a long process that, for this project, involved four separate ethics committees.

Although the cohort sample size is small, the population-based nature of the study (comprising 95% of all eligible children born in 2002 and 2003, and representing all five predominant language groups), means data will be representative of other primary school aged children living in the Fitzroy Valley and born before the alcohol restrictions in 2008. The colonial history, level of disadvantage, geography, use of alcohol, and reported health outcomes in other remote Aboriginal communities in northern Australia are similar to Fitzroy Valley, so results are likely to be generalisable.

6.3.3. FASD assessments

The Lililwan cohort was the first population-based cohort in Australia to be assessed for prevalence of PAE and FASD. It comprised two entire age groups (born 2002-3) and demonstrated high rates of PAE (550 per 1000 population) and FASD (190 per 1000 population). Consent was obtained for parent interviews (stage 1) and multi-disciplinary neurodevelopmental assessments (stage 2), which were conducted with the aid of Community Navigators. Assessments of clinical outcomes and PAE were performed using internationally recognised and validated tests that were reviewed by our Aboriginal partners for language and cultural suitability. Information on alcohol consumption during pregnancy was collected using the Alcohol Use Disorders Identification Test-Consumption (AUDIT-C), and a reliable and culturally appropriate questionnaire was developed to obtain demographic information from families (130, 131). The FASD diagnosis was made following a comprehensive neurodevelopmental assessment by a multi-disciplinary team comprising a paediatrician, child psychologist, speech pathologist, physiotherapist and occupational therapist. Ear and eye assessments were performed by medical specialists, trained audiologists and optometrists (2).

6.3.4. Literature Review

The literature review is limited to publications before 2014. The timeframe (1990-2013) for this body of work was chosen to survey gaps in the literature prior to commencement of this thesis and to inform the aims. Nevertheless, the review was rigorous, including a systematic assessment of all peer-reviewed academic and grey literature documents published about child health services in remote Australia over a twenty-year period. The initial search identified over 1500 documents, of which 92 were eligible for inclusion. Each paper's eligibility was reviewed by two authors and strict inclusion and exclusion criteria were applied (Sections 2.3.6. and 2.3.7.). The review was limited by the quality and relevance of the published literature. I identified gaps in the literature, including a lack of detailed clinical data on young children in remote Australia and a lack of population-based cohorts that address specific community priorities. This paper is the first of its kind in Australia to summarise both the grey and academic literature and highlight issues of access to and use of health services for remote dwelling children. I also identified significant barriers to delivery of effective child health services in remote Australia, noting that the existing services cannot meet current demands. I found no comprehensive gold standard models for service delivery that incorporate community engagement and collaboration. Such models must be developed. The review also highlights the need for better resourced primary care, and health promotion. Many gaps highlighted by this review persist in 2021, confirming its ongoing relevance. For example, there are still no standardised tool for measuring remote health service access; prescribed optimal workforce numbers; nor a standardised framework for measuring the effectiveness of health service delivery in remote Australia.

6.3.5. Health Service Mapping

This paper represents the first attempt to map all health, allied health, outreach and specialist services for children, that are delivered in the Fitzroy Valley by state funded, independent non-government organisations and Aboriginal medical services, and to collate these into a single document. We also sought information on barriers to health service delivery. None of this information was easily obtained in published or grey literature. Therefore, interviews were conducted with all relevant local health service providers. These interviews highlighted issues such as workforce shortages due to a failure to fill all positions funded in the region that were not documented elsewhere. Interviews demonstrated a clear need for training of more AHWs, who are invaluable in primary health care delivery but are dramatically underrepresented (based on recommendations from the 1997 Kimberley Regional Aboriginal Health Plan and figures from the Northern Territory's central desert) relative to population-based numbers (93). AHWs play a key role in the community including, but not limited to, facilitating service access and delivery via translation of local languages, understanding cultural protocols, and facilitating transport to and from appointments (123). Barriers identified in interviews with local health workforce are consistent with those identified in the literature. Because this work was requested by the community it has helped them advocate for services to fill gaps, including development of the Marulu Unit to support families living with FASD and the introduction of Jandu Yani U, the Indigenous Stepping Stones Triple P – Positive Parenting Program (132). It identified the importance of multi-disciplinary assessments, providing a model to guide newer services such as Patches Paediatrics (133).

The work provides a snapshot of service availability and funding for 2013 and allows a baseline for comparison with future service provision.

A limitation of this health service audit is that it was performed in 2014, retrospectively utilising data from January to December 2013. This was done to estimate the capacity of services following increased referral rates to services from the Lililwan assessments. This work did not evaluate the effectiveness of services and this is an important future research priority. My work remains current as demonstrated by data access requests and citations. Personal communications with Royal Far West in August 2019 indicate that health professionals still refer to data in this paper to inform their work in the Fitzroy Valley, because no subsequent comprehensive overview of services has been performed. Health services remain disjointed, uncoordinated, and under-resourced. Patches Paediatric Health Service attempted to formalise a regularly updated, online, schedule for visits by child health services to the Kimberley communities, however this no longer exists.

6.3.6. Data on hospitalisations and ED use in Fitzroy Crossing

There are few papers which focus on utilisation of hospitals and emergency departments by remote-dwelling Aboriginal children. Population studies of remote service usage are rare. My work provides a snapshot of health service utilisation by a population of children in remote Australia across a decade. This work is strengthened by a lack of selection bias and examination of the use of a single health service (Fitzroy Crossing Hospital) that is likely representative of hospitals in other service towns for remote communities across Australia. This is the first Australian work to examine the relationship between hospital admissions and emergency department presentations and PAE, contributing to the knowledge base on the harmful effects of drinking during pregnancy.

Two medically trained researchers (including PJD) developed a database and extracted information on hospitalisations and ED presentations, diagnoses, and comorbidities for all children at the Fitzroy Crossing hospital. Data were obtained from the Communicare™ database following ethics approval, then cleaned and coded using the International Classification of Diseases (ICD-10). Contentious diagnoses were discussed with a senior paediatrician.

In documenting high rates of potentially preventable communicable diseases and injuries in this whole population cohort, we highlight the large numbers of emergent and acute conditions that are overwhelming hospitals in remote settings. We suggest that children with complex chronic conditions, e.g., FASD, are likely to be neglected when services face high demand for acute problems. In the Lililwan project, many medical conditions were detected and treated in children assessed for FASD, potentially preventing later medical complications. Over 400 referrals were made for this cohort to allied, paediatric, and mental health services, however many appointments were not taken up either because waitlists were long, or parents were unable to access services. The barriers for uptake of referrals will be explored in the Bigiswun Kid Project, a 10-year follow up of the Lililwan cohort currently underway in the Fitzroy Valley.

The health service utilisation data were limited by a lack of comparative data in an age matched cohort. When possible, data from our cohort were compared to national and state data for equivalent age groups. Future researchers should strive to find comparison groups, however the conditions faced by this cohort are challenging to mirror. Very few non-Indigenous Australians live in such a remote context or experience such extreme disadvantage. Another limitation with the hospitalisation and ED presentation data was that I was sometimes unable to attribute the full ICD-10 code (to the 4th digit) to a diagnosis because original diagnoses were often made by nursing staff and incompletely documented. Therefore, some comorbidities could have been missed and this data may underestimate the burden of acute disease experienced by our cohort. I did not have a record of triage categories, so had to extrapolate the severity of diagnoses from clinical descriptions. I classified many presentations as category 4 or 5 presentations (low acuity), which could have been managed in the primary health system.

6.3.7. Summary

Although individual papers do not fully demonstrate the scope or complexity of the needs faced by this disadvantaged cohort of predominantly Aboriginal children living in remote Australia, data from each chapter of this thesis gives a good overview of the many health challenges children face. Our illustrative case (*Figure 3.3*) portrays a child with both acute and complex chronic health needs and disabilities and outlines the challenges they face in accessing the health services they require. Furthermore, it shows the complexities of the environment in which they are seeking health care and the complexities of engaging with multiple overlapping health services. For this cohort, another layer of complexity in obtaining services is added by language and cultural barriers.

This work demonstrates an association between social determinants of health, ill-health and increased rates of hospital admissions and ED presentations. These data may underestimate disease burden because they only incorporate one hospital (Fitzroy Crossing) and children may have presented to other hospitals (Derby, Broome, Halls Creek) or have been transported to tertiary hospitals (Perth, Darwin) by services such as the Royal Flying Doctor Service in emergency situations.

Nevertheless, this work indicates key health service needs including development of preventative strategies. This work will inform solutions and benefit the Fitzroy Valley and other remote communities.

6.4. Contextual change since this thesis began

6.4.1. Impacts of The Lililwan Project to date

Since I began this thesis, the community reports that the Lililwan Project has provided huge benefits on a local, national, and international level regarding understanding the impacts of PAE and FASD. Within the Fitzroy Valley community this has translated into increased awareness of the harms of PAE and decreased use of alcohol during pregnancy. The film Tristan, which traces the challenges of an Aboriginal boy with FASD living in Fitzroy Crossing, has been shown nationally and internationally, including at the United Nations Indigenous forum (134). The Lililwan project has produced four PhDs (the first evaluated the prevalence of alcohol use and FASD (36, 117), one assessed gross motor skills (119), one reviewed fine motor, graphomotor, visuospatial and sensory abnormalities (135), one addressed issues relating to consent for research in Indigenous communities (30) and mine will form the 5th). There are over 20 peer-reviewed publications, for which of three I am the primary author (50, 51, 122). The findings from the Lililwan Project were used to gain funds to develop an early childhood centre, Baya Gawiy; to develop the Marulu Unit for support of families living with FASD; and to develop education resources and culturally appropriate diagnostic and screening tools for FASD (130), all under the auspices of the Marninwarntikura Women's Resource Centre (MWRC) in Fitzroy Crossing. My data have informed the need for co-ordinated, multi-disciplinary health services to address both acute medical and chronic neurodevelopmental problems and enhanced programs in primary and preventative care (see Implications, section 6.5.1).

Three recent NHMRC grants have been awarded to researchers and their Aboriginal partners working in the Fitzroy Valley community. In response to concerns about children's behaviour identified at home and school in the Lililwan study, MWRC partnered with researchers from The Universities of Sydney and Queensland to train local Aboriginal people in delivery of the Indigenous Positive Parenting Program (Triple P), the Jandu Yani U project. Following the Triple P Program, parents reported improved parenting confidence, skills and knowledge in addressing challenging behaviours; decreased stress, anxiety, and depression; decreased challenging child behaviours; and increased feelings of empowerment in the home and community. In the second study, the Alert Program was introduced into schools to assist children with impulse control. The third study, Marrura-U, also a partnership with our group, will address optimal models of early-life trauma-informed care to support children with FASD and other neurodevelopmental disorders in remote communities.

In another community-initiated study MWRC invited our group to conduct a 10-year follow-up study of the Lililwan cohort (The Bigiswun Kid project). This will identify the outcomes, aspirations and needs of children (including with PAE and FASD) at age 17-19 years. Data from the Lililwan study have also been used to support continuation of community-led alcohol restrictions.

The work of the Lililwan Project attracted the attention of politicians, prompting a Senate Inquiry into FASD in Australia in 2012. This Inquiry resulted in a commitment of $A20 million dollars of government funding for development of a national strategy for prevention, diagnosis and management of FASD (2013-14), a FASD Hub, FASD register and a Guide to Diagnosis of FASD, and resources for educators and justice professionals. A strategic plan developed for 2018-28 and a 2020 Senate Inquiry resulted in additional government commitment of ~$A55 million.

6.4.2. National Disability Insurance Scheme (NDIS)

The National Disability Insurance Scheme (NDIS) was the result of an Australian Government Inquiry into long-term disability care and support schemes. It highlighted a paucity of services and supports. In March 2013, the NDIS legislation was passed, the trial period finishing in July 2016 (136-138). Following this, the scheme began its Australia-wide roll out (136-138). The 2019-20 National Disability Insurance Agency (NDIA) report highlights that utilisation of the NDIS is negatively correlated with remoteness from metropolitan areas (139).

As demonstrated in this thesis, the children of the Fitzroy Valley have a high burden of acute and complex chronic health needs and disabilities. However, the process of applying for NDIS funding is complex and the funding is useless without access to relevant services. Currently, none of the 21 children from the Lililwan cohort, who were identified as having FASD, receive any financial or other benefits from the NDIS. The NDIS has the potential to improve the livelihood and long-term health outcomes of people living with disability in remote Australian settings and NDIS access is being addressed during the Bigiswun Kid project.

6.4.3. Changes to Closing the Gap Targets

During this thesis few improvements have been made nationally towards the Council of Australian Governments (CoAG) Closing the Gap targets (140). The Prime Minister’s 2019 Closing the Gap report highlighted that only two of the key targets were on track to be met and declared a need to reform the way these targets were addressed by developing more meaningful partnerships between federal, state and territory governments and Aboriginal and Torres Strait Islander (ATSI) Australians (140). In particular, the report highlighted the need for changes in how governments approach implementation of policy and delivery of services (140). It acknowledged that forming genuine partnerships with ATSI peoples is central for progression towards Closing the Gap targets (140).

The new 2020-30 National Partnership Agreement on Closing the Gap between Indigenous and non-Indigenous health outcomes includes many goals that are aligned with the findings and recommendations of this thesis. Many focus on improving the social determinants of health through increasing rates of educational attainment and employment and decreasing youth incarceration, but there are several health-related targets (141).

Target one is to close the life expectancy gap within a generation, by 2031 (141). Target Two focuses on increasing the proportion of babies born with a healthy birth weight to 91% by targeting maternal health, through decreasing prenatal alcohol and cigarette exposure, increasing antenatal support, and decreasing maternal morbidity (e.g., from diabetes mellitus and hypertension) (141). This goal is supported by the Marulu FASD prevention program. Target Four aims to increase to 55% the proportion of children deemed to be on track with all five domains of development (number one being physical health and wellbeing) assessed in the Australian Early Development Census (AEDC) (141). The need to address physical health is supported by my data and is being addressed by current projects in the Fitzroy Valley.

Additional targets align with overall wellbeing. Target Nine, which is supported by my data, is to increase the proportion of people living in non-overcrowded houses to 88%. Target 14, to reduce suicide rates, is highly relevant to the Fitzroy Valley as is improved cultural wellbeing through sustaining first languages (Target 16) (141).

6.4.4. The positive impact of public health campaigns in remote Australia

The year 2020 was disrupted by the global pandemic of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), more commonly known as coronavirus-19 (COVID-19). Fears about its implications for remote Indigenous Australian communities were paramount (142). Indigenous Australians were predicted to experience higher morbidity and mortality associated with COVID-19 (due to pre-disposing conditions e.g., obesity, diabetes, hypertension and less access to healthcare services) and the challenges regarding control of the spread of this highly infectious virus in remote communities seemed insurmountable. Social distancing and self-solation strategies were deemed unrealistic due to the mobile population and high rates of overcrowding in inadequate housing (41.4% in remote Aboriginal Australia compared to 1.9% non-Indigenous peoples) (142, 143).

In response, the National Aboriginal Community Controlled Health Organisation (NACCHO) called for a closure of rural and remote Australian communities to minimise risk of disease spread from non-residents (142, 144). The power of effective public health campaigns was demonstrated in response to COVID-19 in remote Australian communities. Campaigns and infographics to 'Protect your mob and stop the spread' encouraged handwashing; coughing or sneezing into your elbow; disposing of used tissues; avoiding touching your face, hugging and handshaking; frequent cleaning of household surfaces; and remaining distant from others when unwell (144). These simple, widely applicable controls of communicable disease spread were adopted throughout Fitzroy Valley communities and no cases of COVID-19 were reported in 2020 (personal communication with Maureen Carter, CEO Nindilingarri Cultural Health Services).

The vulnerable Indigenous Australian population experienced additional challenges due to COVID-19. Significant shifts in health care use were demonstrated across Australia and although we do not have data from the Fitzroy Valley, data from NSW are available. In four months in NSW (March to June 2020), in-person primary care consults decreased by 22.1%, emergency department visits by 13.9% and hospital admissions by 14.3% compared to the same time frame in 2019 (143). Missed or delayed health care for children may have occurred in the Fitzroy Valley during the pandemic and may result in increased long-term adverse health outcomes. Coincidently there has been a significant increase in uptake of Telehealth throughout Australia, including in urban settings, although it is not clear whether the same uptake was seen in remote communities (145).

Many public health campaigns run across the Fitzroy Valley have had a positive impact on child health over the last decade. This includes, but is not limited to, the Telethon Institute's Wet Cough campaign: which aims to detect and treat childhood bronchiectasis; KAMS Look out for Strep campaign: to reduce rates of rheumatic heart disease; NACCHO's "no school, no pool" campaign: that improved rates of skin infections and scabies as well as school attendance.

Our data support the need for increased Telehealth services for both capacity-building for local health professionals and multi-disciplinary care for children with chronic disorders.

6.5. Implications and recommendations for future research

6.5.1. Implications

The research in this thesis has implications for the development of child health services in remote Australia and for future research.

My literature review highlights the lack of a centralised, regularly updated and easily accessible schedule of visit timings for child health services in the Fitzroy Valley and the challenges of not having shared electronic health records. Access to these electronic resources would improve coordination, collaboration and communication between services and minimise duplication. We showed that clinical time is wasted in travel time (which could be minimised by the provision of accommodation for visiting professionals in remote towns) and performance of administrative tasks (which could be outsourced).

There is also a need to address the economic barriers to health service access for patients (e.g., access to NDIS, affordable public transport). Increasing funding support for training of AHWs and removing barriers to uptake of certification (e.g., by providing training in remote towns to avoid the need for prolonged separation from family or increasing access through use of current technologies such as videoconferencing and mobile phones) would provide huge benefits for local health services. We must also continue to strengthen and encourage Aboriginal students studying in the health professions and to promote non-Indigenous health workforce to commit to rural and remote living, working in Aboriginal Medical Services, and upskilling in cultural competency.

Multi-disciplinary child health teams improve coordination, communication, and collaboration between services, resulting in better health outcomes. They also provide health professionals with professional development and support, and deliver management strategies that target multiple health and development domains. In the absence of child health specialists living and working in remote communities Telehealth can be used by external teams for training and support of local staff as well as for child health assessment and treatment. For example, despite high rates of developmental disorders and mental ill-health identified in the Lililwan cohort, there is no resident child psychologist or child psychiatrist in the whole of the Kimberley, let alone the Fitzroy Valley. To address this Marninwarntikura Women's Resource Centre in Fitzroy Crossing, in partnership with Royal Far West and the University of Sydney, is developing a model of trauma-informed, wrap-around care that incorporates face-to-face and telecare by a multi-disciplinary team working closely with local practitioners including the Marulu Unit (Marurra-U project).

Key areas for improving remote child health services include but are not limited to: removing barriers to service delivery (distance, transport, staffing, resources, IT capabilities, cost); improving coordination of and collaboration between existing services; increasing numbers of AHWs; increasing support (financial, emotional and educational) for health professionals working in remote locations; enabling access to long-term funding for successful programs; and focusing on primary prevention. Although many of these barriers have been previously identified, and significant attention and government funding has been provided, there have been few gains in health outcomes. This suggests the need to do things differently. We must focus on how best to effect the required changes and involve Indigenous people in every aspect of service planning. We must also develop meaningful measures of service delivery. The National Framework for Universal Child and Family Health Services needs updating with an applied focus towards Indigenous maternal and child health care and services, as a model for best practice (146). This would provide children with a strong start to life through improved antenatal care, prevention of illness in the perinatal period, and access to good nutrition, health and education in early childhood.

The health service audit showed that theoretical barriers to service provision and access identified in the literature translate into reality in the remote Fitzroy Crossing. The complexities of service provision there are caused by significant physical and invisible barriers including health workforce recruitment and high turnover, piecemeal funding across multiple levels of government and NGOs, and lack of integration and coordination of services. Furthermore, it highlighted the barriers to access of health services.

Future research should explore how child health services have changed since the audit in 2014 and how the NDIS funding will impact funding and delivery of services. As discussed, none of the children identified with a FASD diagnosis in 2010-12 have yet received any NDIS support, which is being addressed by the Bigiswun Kid project. The Lililwan Project demonstrated the effectiveness of multi-disciplinary teams in service provision for children with complex needs in remote settings. The benefits included the capacity to efficiently assess, diagnose, and intervene for a range of complex physical, developmental and mental health problems and provide immediate feedback to families and support to local health professionals and educators. In addition, a team promotes increased communication and collaboration across disciplines, minimisation of duplication, collegiality, and professional support from co-workers. The Bigiswun Kid project will provide insight into the trajectory of health and wellbeing of the Lililwan cohort from childhood to adolescence and identify predictors of positive and adverse outcomes.

Improvements in technology and infrastructure were identified as core areas of future need. This could include improved telephone and internet coverage; development of an electronic health record shared between services; a regularly updated online health service calendar; increased capacity for telehealth service provision; a more efficient and effective system for notifying patients of upcoming appointments; and provision of transport to health appointments. Urgent attention is required to develop key infrastructure including increased, affordable accommodation for visiting practitioners and patients, in towns such as Fitzroy Crossing and in satellite communities. Accommodation is key because unsealed roads, climate factors including the annual ‘wet’ season, and the inability to drive at night due to cattle and other animals on roads, limit community access and duration of visits in the current model of ‘fly/drive-in-fly/drive-out’ service provision. The use of telehealth services in remote settings during the COVID-19 pandemic should be examined to determine its availability, uptake and acceptability.

My data on the Lililwan cohort’s hospitalisations and ED presentations shows the importance of documenting and reporting health outcomes in population-based and community level studies. The work of the Lililwan project has been used by the local community to source further funding for specific programs to address community concerns regarding child health and wellbeing. My work demonstrates the specific needs of the Fitzroy Valley community, which would be lost in state-wide or national datasets.

These data were unable to determine whether co-morbidities associated with PAE, social circumstances of families, or both, contributed to high rates of ED presentation and this should be explored in future research.

The high rates of potentially preventable common infections and the persistence of rare medical conditions noted in my health service utilisation data reflect poverty and illustrate the need for culturally appropriate preventative health programs, better health literacy, improved primary health care access, and better strategies to address the social determinants of health in remote Australia. My data will inform development of educational resources and preventative health campaigns for communicable and non-communicable diseases in children in the remote Fitzroy Valley.

We documented key modifiable determinants of ill-health including inadequacies in housing, sanitation and clean water supplies, as well as low levels of parental education and health literacy. Key prevention programs should target community education regarding how to decrease communicable disease transmission through hygiene practices (e.g., covering the mouth when coughing, coughing into the elbow, washing hands, and regular bathing), building on the work done during the pandemic. Other targets should include vaccination; improved nutrition; regular deworming; programs for treating early skin infection; and wound management such as the Kimberley Aboriginal Medical Service SToP Program (see, treat and prevent skin sores and scabies) (147). The benefits of regular use of the chlorinated town swimming pool should be promoted; and improved understanding of environmental safety could reduce the rates of injury including burns and bites. Resources should be allocated to improve increased training opportunities for AHWs and to the infrastructure underlying some of the social determinants of health. This includes improved health hardware including improved housing, better waste disposal, access to clean drinking water and sanitation (148); and vocational training to increase opportunities for employment and affordable healthy food.

Many of the common causes of gastroenteritis and upper and lower respiratory tract infections are preventable with vaccination (124, 149). A number of free immunisation programs have been rolled out nationally over the last two decades. These include *Rotavirus* (2007), *Haemophilus influenzae* type B (2000), *streptococcus pneumoniae* (7vPCV and 23vPPV, 2001), *Bordetella pertussis* (DTPa-IPV, 2005), Influenza (2008) (124). Although we did not have data on the immunisation rates of the Lililwan cohort, in 2014, it was estimated that 90% of children living in WA had full immunisation coverage (150). Ensuring high vaccination targets are met is essential to increase infectious disease prevention in cohorts like the Lililwan children.

The Kimberley population is a fluctuating population group in WA, that was predicted to expand (averaging 2.7% per annum until 2013), however has since stabilised (151). Also, the population pyramid is disproportionately skewed towards young people 0-24 years (151), which will place pressures on existing Kimberley child health services (151). This highlights the need to improve the infrastructure of the remote Australian child health care system that already struggles to meet demands in many remote communities. My work demonstrates the need for improved access to GP clinics in community settings to alleviate the pressure of high volumes of low acuity presentations to ED (152). Currently all GP services are located in the hospital, apart from outreach GP services provided intermittently by the RFDS.

The gaps in prevention and clinical service delivery identified in this thesis provide a template for future planning of health services. Ideally this will be needs driven by local populations, facilitated with extensive community consultation, and will provide vulnerable population groups with long-term child health and wellbeing programs.

6.5.2. Recommendations

Following the work in this thesis I have developed 10 core recommendations, supported by my work, to inform planning and delivery of child health services in the remote Kimberley region of Australia. These constitute a gold standard model of care and align with government, Aboriginal-controlled health organisation and community targets.

Recommendation One: All new services should be developed in close consultation with Aboriginal leaders and Aboriginal-controlled organisations. Governments should form genuine partnerships with local populations, to develop and implement programs that augment Aboriginal-controlled community health services and focus on health promotion, prevention, and early intervention.

Recommendation Two: Future priorities in Aboriginal communities should be aligned with the new 2020 Closing the Gap Partnership Agreement targets for child health and wellbeing.

Recommendation Three: A formal prospective audit of Kimberley based child health services should be undertaken to identify ongoing service gaps and inform responsive development of services. This should be done in close consultation with community and existing services. Assessment of the quality and effectiveness of services, as well as access to NDIS support, should be included.

Recommendation Four: New models of child health services should be multi-disciplinary, trauma-informed, capable of providing for acute and chronic needs, culturally appropriate, and inclusive of Aboriginal Health Workers. Efforts should be made to better co-ordinate services to improve integration, maximise efficiency and minimise duplication. Services must align with and augment services provided by local Aboriginal-controlled services (for example in the Fitzroy Valley the Marulu Unit for wrap-around support of families, Baya Gawiy Buga Yani Child and Parent program, Jandu Yanu U positive parenting program, and Women’s Shelter provided by Marninwarntikura Women’s Resource centre), Nindilingarri Cultural Health Services, WA government services (Kimberley Aboriginal Health Services and Child and Adolescent Mental Health services) and non-government organisations (e.g. Royal Far West, Royal Flying Doctor Service, Boab Health).

Recommendation Five: Preventative public health strategies and primary health care services should be prioritised. The specific focus should be the first 1000 days of life, including antenatal care, healthy pregnancy campaigns (addressing smoking, alcohol, gunja and healthy lifestyle), and prevention of injury and communicable diseases.

Recommendation Six: Improvements to IT capabilities and other key infrastructure are required. A centralised electronic health scheduling platform would improve the transparency of health service visits to Fitzroy Crossing and surrounding communities. This platform should be online, allowing health organisations to register their planned visit times, and updated regularly. This would allow coordination and increase efficiency of services to provide patients and families with certainty, enabling planning for transport etc. Use of a centralised electronic health record (e.g., My eHealth Record) would improve communication and collaboration between health services, limit duplication of services and improve patient care. Increasing the capabilities of telehealth and videoconferencing services should be investigated and implemented both for clinical settings and to increase capacity for online training and professional development. Despite geography and distance between homes and services, and the lack of public and private transport, we argue that the access gap can be bridged by 1) providing further funding for clinical teams to visit communities, (e.g., Healthy Kids Bus Stop run by Royal Far West), 2) improving availability of transport (e.g., by providing a free daily bus service that collects patients from communities, takes them to appointments, and returns them in the evening), and 3) training and employing more AHWs to facilitate transport to services.

Recommendation Seven: Evidence in this thesis confirms the need for annual auditing and assessment of the effectiveness of primary health care models. We need to develop standardised tools to measure health service access and the effectiveness of service delivery in remote Australia. Attention is required to standardise child health care across Australia. An Indigenous focus should be applied to the National Framework for Universal Child and Family Health Services, to include disease prevention and address the quality of and access to antenatal care and child health services throughout remote communities (146). Furthermore, we need to prescribe optimal staffing levels for the remote Australian workforce. These measures will ensure best practice delivery of remote child health care services.

Recommendation Eight: An ongoing focus is required to address the social determinants of child health and wellbeing. Many strategies have been suggested in the literature however, disadvantage persists and requires further attention. This should incorporate improvements to the health hardware, education programs and further funding. Programs of import include those that improve sanitisation (clean water and washing people, clothing and bedding), appropriate waste and sewage disposal, housing to reduce overcrowding, nutrition and reduce the impact of disease vectors (e.g., dogs, mosquitoes etc.). Further benefits could arise from development of culturally appropriate, school-based education programs on food sustainability, agriculture and food supply, including lessons in sourcing traditional foods.

Furthermore, it is imperative that we increase access to affordable healthy food in remote communities by subsidising the cost of fruit and vegetables available at remote stores.

Recommendation Nine: Resourcing is required to enable better integration of health and education services in remote communities e.g., screening, health checks, health education, allied health support and vaccination in schools and preschools.

Recommendation Ten: Increased funding and access to training is required to increase the Aboriginal health workforce in remote communities. Cultural awareness and cultural safety programs tailored to the community context must be available for non-Indigenous health professionals and researchers working in Aboriginal communities.

6.6. Final Statements

This thesis provides new and unique data on two whole birth-cohorts in a population-based study of predominantly Aboriginal children living in remote Australia, many with PAE and FASD. We are the first to document the range of health and allied health services – inpatient, outpatient and outreach – for an entire paediatric, predominantly Aboriginal, cohort. This thesis demonstrates the significant burden of health problems, service usage and needs in a remote setting throughout childhood (0-9 years). This is the first work to demonstrate the impact that PAE has on the rates of engagement with health services and health service requirements of children with PAE and FASD.

Children in remote Australia have high health needs, related in part to their social disadvantage. Many of these health problems are complex but potentially preventable. Despite vast expenditure, little progress has been made over the last decade to meet the Closing the Gap targets. Remote-dwelling children are disadvantaged by a lack of health services, and a lack of access to existing services. Many factors contribute to this. The lack of integration, coordination and communication between agencies exacerbates this. This work has significant implications for informing future health service planning and workforce recruitment in remote Australia, which must be done in partnership with Aboriginal people.

This new information increases understanding of the typical pattern of childhood health problems, the complexity of health issues and developmental disorders in remote Australian communities, and the role of health professionals and health services in remote communities. This demonstrates the extraordinary challenges faced by children with complex health needs

– both acute and chronic – and the inability, in the current landscape, of services to meet their needs.

Work in disadvantaged remote communities is logistically challenging and emotionally tough, however it is essential that we maintain resilience and continue to work in genuine partnership with Aboriginal people to address their priorities and ensure that the health and wellbeing of this particularly vulnerable group is addressed. We have a wider responsibility for creating healthy societies with equitable access to health care opportunities and by offering all children a beginning in life that is compatible with longevity, health and happiness and ensures the standards established by the United Nations Convention for the Rights of the Child are met for all Australian children.

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Appendix

Foreword for Appendix 1: Lililwan Health feedback for research partners

Community feedback of results is an essential component of research partnerships with Aboriginal communities. At the request of our partner organization, Marninwarntikura Women's Resource Centre, I have developed a ***Lililwan Health*** pamphlet that summarises the research results from this thesis (***The Health Service Use and Needs of the Lililwan Project***) in a format similar to what has previously been requested.

The organization, in turn, will feed these results back to community members, e.g., through work of the Marulu Unit, Baya Gawiy Child and Family Centre and at bush meetings and other appropriate forums. The pamphlet will also be distributed to other community-led organisations in the Fitzroy Valley.

This ***Lililwan Health*** pamphlet includes accessible language, infographics and graphs that could be adapted by our partners when providing feedback to parents and families in community.

LILILWAN HEALTH

Feedback for research partners

Findings from the community led project on child health services in the Fitzroy Valley

PROJECT REPORT – EXECUTIVE SUMMARY

MAY 2021

FUNDED BY THE NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL 2009-2021,
AUSTRALIAN NATIONAL UNIVERSITY, POCHE CENTRE FOR INDIGENOUS HEALTH,
AVANT DIT

In a nutshell

- In 2007, the Fitzroy Valley Community successfully lobbied for restrictions on takeaway alcohol.
- In 2008, The Marulu Strategy was initiated by Aboriginal leaders to address their concerns about the effects of prenatal alcohol exposure (PAE), fetal alcohol spectrum disorders (FASD) and early life trauma (ELT) on children in the community.
- The Lililwan ('all the little ones') Project (2009-2020) found that early life trauma was almost universal and that 55% of primary school children had PAE and 19% of had FASD, with associated complex needs and challenging behaviours.
- In 2012, the National Health and Medical Research Council (NHMRC) funded the Lililwan team for the Health Services Project.
- Childhood services were mapped. The need and use of these services in the Fitzroy Valley were evaluated.
- We showed that service access for patients is challenging and there are many barriers to delivery including: retention and accommodation of health professionals, and duplication and dis-cohesion of services.
- Priority should be given to training and employment of more Aboriginal Health Workers (AHW) to meet the gold standard of 1 AHW per 100 Aboriginal people (currently there are 1 for 1500 people).
- The Lililwan cohort's use of Fitzroy Crossing Hospital from birth (2002-3) until 2011 was examined. There was high hospitalisation and usage of the emergency department. Many conditions were potentially preventable infections and injuries reflecting a lack of primary health services and disadvantage.

We hope this research will be useful and promote positive outcomes for parents, family members and children in the Fitzroy Valley.

A fictitious case illustrating challenges to health service access

An 8-year old living 150 km from town is suspected to have a Fetal Alcohol Spectrum Disorder (FASD). Problems with learning, academic achievement, oppositional behaviour, attention and hyperactivity (ADHD), writing and growth are identified. Current skin infections (scabies and impetigo), ear infections (suppurative otitis media), severe tooth decay (dental caries) and asthma are also diagnosed. The child requires ongoing management by many services: paediatric, allied health, community health, dental, Child and Adolescent Mental Health services (CAMHS) and assessment by the school psychologist.

The paediatrician visits the community every two months and the allied health team monthly. These health professionals drive from Derby or Broome to Fitzroy Crossing (~4.5 hours) and from Fitzroy Crossing to the community (~1.5 hours). Because of cattle on the roads, driving after dark is dangerous and forbidden, so they must stay overnight in Fitzroy Crossing (the only available accommodation). Accounting for travel time, they have 6 useful hours at most in one day in the community. The paediatrician investigates and manages problems with growth, ADHD and asthma and provides a review 2 months later. Initial and follow-up treatment for skin and ear infections is provided by the remote area nurse (visits the community 4 days/week) the ENT/audiology team (visits Fitzroy Crossing 4 times/year but rarely visits remote communities). Thus, this child has to travel with their family to Fitzroy Crossing to see the ENT/audiology team.

A visiting occupational therapist liaises with the school to advise on activities to improve fine motor skills and provides follow up monthly. A formal cognitive assessment is required so the school can apply for extra funding to support children with developmental delay. This is carried out by the Education Department's school psychologist, who visits remote schools on demand, however there is a long wait for assessments. Following assessment, the school psychologist provides advice to the school as to how best support the child's learning and academic endeavours. The school applied for funding to employ a local Education Assistant – a family member - to work alongside the child in the classroom. Additional assessment of behaviour and ongoing psychological support is requested from the CAMHS worker, who visits the community every month.

The paediatric nurse practitioner, remote area nurses and specialist coordinator at the Fitzroy Crossing hospital all help to ensure attendance by this child at specialist clinics. His parents do not have a landline telephone or computer access. His father does have a mobile phone through which he can access social media, but the health services still use community noticeboards or post letters – to a communal 'mailbox' - to alert people of clinic appointments, both of which are notoriously unreliable methods of notification.

The Regional Ear Coordinator for the Kimberley, employed by Kimberley Aboriginal Medical Services Council (KAMSC) and based in Broome, is alerted to this child and liaises between specialists and the community. Ideally a child like this with complex, chronic needs would have a multi-disciplinary team case coordinator, with funding supplied by The National Disability Insurance Scheme (NDIS).

There is no public transport available between this remote community and the service town of Fitzroy Crossing. Aboriginal liaison officers who work in town will only travel to communities within a 30km radius, but beyond that, there is no transport support. Few people, including this family own a family car. In this community of 165 people there were only 4 licensed vehicles in 2013 (41 people per vehicle) and an unregistered community bus.

Key findings: Lifetime Fitzroy Crossing Hospital Admissions

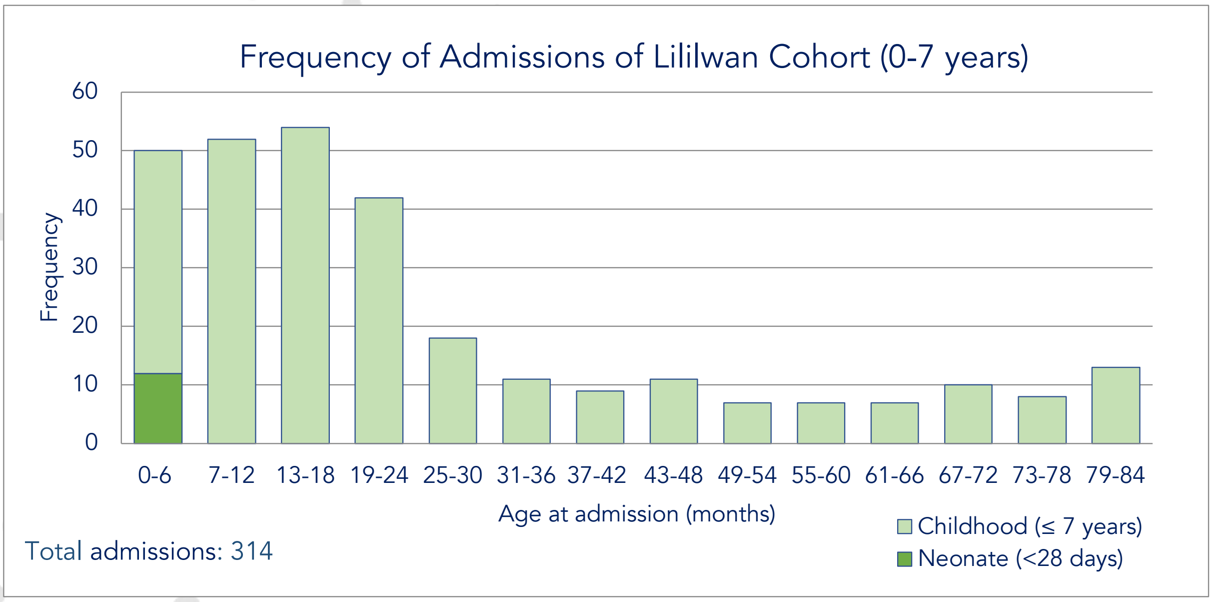
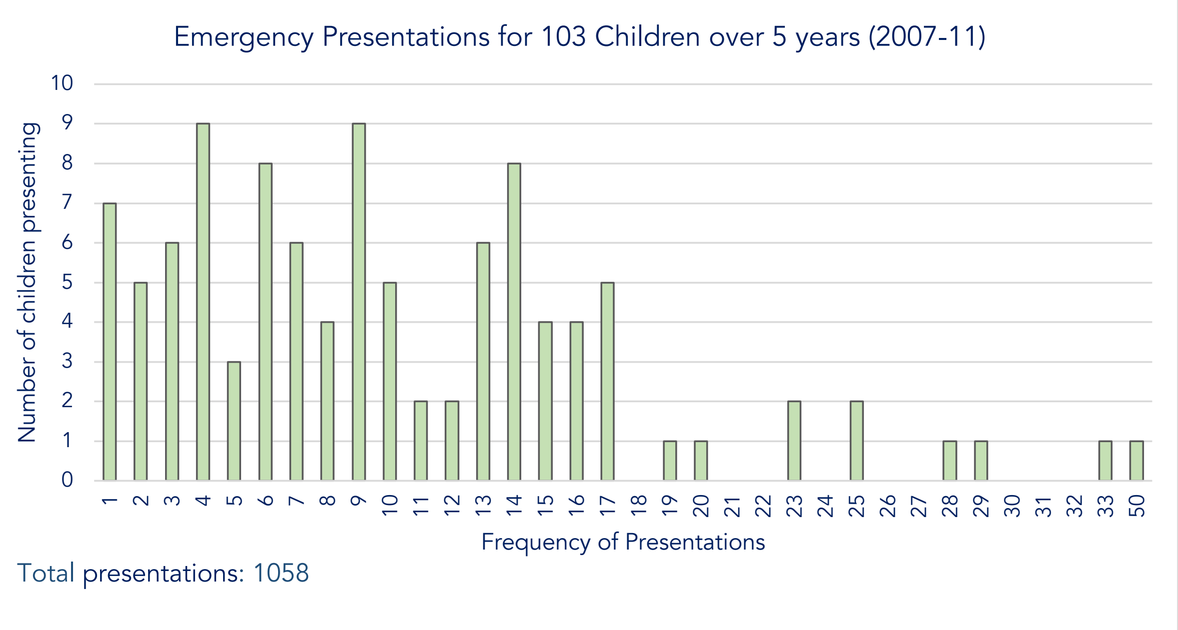


Figure 1. Frequency and age of admissions in children (0-7 years) and neonates (<28 days) (dark blue)

- Of the 127 Lililwan children, 89 were admitted to hospital 314 times before the age of 7 years (range 1-12 admissions).
- 38.6% of admissions occurred in infants (babies < 1 year old)
- Infections were the most common reason for admission
  - Lung infections
    - lower respiratory tract (27.4%)
    - upper respiratory tract (11.4%)
  - Gut infections - gastrointestinal system (22.7%)
  - Skin infections (5.6%)
- Other reasons for admission included injuries (7.0%) and failure to thrive/poor growth (5.4%).
- Many of these conditions and hence admissions were potentially preventable

Key findings: Fitzroy Crossing Emergency Department Use


Emergency Presentations for 103 Children over 5 years (2007-11)

Total presentations: 1058

Figure 2. Distribution of ED presentations from 2007-11 for 103 children in Fitzroy Crossing, excluding those with no presentations

- 102 of the 127 Lililwan children used the emergency department (ED) between 2007-11
- Some children used the ED up to 50 times over 5 years
- Patterns of use were the same in the wet and dry seasons
- Over half the presentations were for infections
- Common presentations included: screening/follow-up/social reasons (16.0%); injury (15.1%); diseases of the ear (14.9%); skin (13.8%); respiratory tract (13.4%); and other infectious and parasitic diseases (9.8%).
- Injuries were common, including:
    - Wounds and wound care 48%
    - Fractures or dislocations of bones 12%
    - Head injuries 9%
- Children who had alcohol exposure during pregnancy had more presentations, than those without.
- Many ED presentations are preventable and could be managed by the GP.

Recommendations for Lililwan Health and Fitzroy Services

Recommendation One: All new services should be developed in close consultation with Aboriginal leaders and Aboriginal-controlled organisations. Governments should form genuine partnerships with local populations, to develop and implement programs that augment Aboriginal-controlled community health services and focus on health promotion, prevention, and early intervention.

Recommendation Two: Future priorities in Aboriginal communities should be aligned with the new 2020 Closing the Gap Partnership Agreement targets for child health and wellbeing.

Recommendation Three: A formal prospective audit of Kimberley based child health services should be undertaken to identify ongoing service gaps and inform responsive development of services. This should be done in close consultation with community and existing services. Assessment of the quality and effectiveness of services, as well as access to NDIS support, should be included.

Recommendation Four: New models of child health services should be multi-disciplinary, trauma-informed, capable of providing for acute and chronic needs, culturally appropriate, and inclusive of Aboriginal Health Workers. Efforts should be made to better co-ordinate services to improve integration, maximise efficiency and minimise duplication. Services must align with and augment services provided by local Aboriginal-controlled services (for example in the Fitzroy Valley the Marulu Unit for wrap-around support of families, Baya Gawiy Buga Yani Child and Parent program, Jandu Yanu U positive parenting program, and Women's Shelter provided by Marninwarntikura Women's Resource centre), Nindilingarri Cultural Health Services, WA government services (Kimberley Aboriginal Health Services and Child and Adolescent Mental Health services) and non-government organisations (e.g. Royal Far West, Royal Flying Doctor Service, Boab Health).

Recommendation Five: Preventative public health strategies and primary health care services should be prioritised. The specific focus should be the first 1000 days of life, including antenatal care, healthy pregnancy campaigns (addressing smoking, alcohol, gunja and healthy lifestyle), and prevention of injury and communicable diseases.

Recommendation Six: Improvements to IT capabilities and other key infrastructure are required. A centralised electronic health scheduling platform would improve the transparency of health service visits to Fitzroy Crossing and surrounding communities. This platform should be online, allowing health organisations to register their planned visit times, and updated regularly. This would allow coordination and increase efficiency of services to provide patients and families with certainty, enabling planning for transport etc. Use of a centralised electronic health record (e.g., My eHealth Record) would improve communication and collaboration between health services, limit duplication of services and improve patient care. Increasing the capabilities of telehealth and videoconferencing services should be investigated and implemented both for clinical settings and to increase capacity for online training and professional development. Despite geography and distance between homes and services, and the lack of public and private transport, we argue that the access gap can be bridged by 1) providing further funding for clinical teams to visit communities, (e.g., Healthy Kids Bus Stop run by Royal Far West), 2) improving availability of transport (e.g., by providing a free daily bus service that collects patients from communities, takes them to appointments, and returns them in the evening), and 3) training and employing more AHWs to facilitate transport to services.

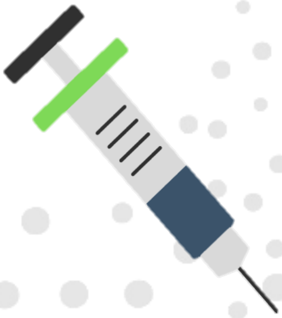
Recommendation Seven: Evidence in this thesis confirms the need for annual auditing and assessment of the effectiveness of primary health care models. We need to develop standardised tools to measure health service access and the effectiveness of service delivery in remote Australia. Attention is required to standardise child health care across Australia. An Indigenous focus should be applied to the National Framework for Universal Child and Family Health Services, to include disease prevention and address the quality of and access to antenatal care and child health services throughout remote communities (146). Furthermore, we need to prescribe optimal staffing levels for the remote Australian workforce. These measures will ensure best practice delivery of remote child health care services.

Recommendation Eight: An ongoing focus is required to address the social determinants of child health and wellbeing. Many strategies have been suggested in the literature however, disadvantage persists and requires further attention. This should incorporate improvements to the health hardware, education programs and further funding. Programs of import include those that improve sanitisation (clean water and washing people, clothing and bedding), appropriate waste and sewage disposal, housing to reduce overcrowding, nutrition and reduce the impact of disease vectors (e.g., dogs, mosquitoes etc.). Further benefits could arise from development of culturally appropriate, school-based education programs on food sustainability, agriculture and food supply, including lessons in sourcing traditional foods. Furthermore, it is imperative that we increase access to affordable healthy food in remote communities by subsidising the cost of fruit and vegetables available at remote stores.

Recommendation Nine: Resourcing is required to enable better integration of health and education services in remote communities e.g., screening, health checks, health education, allied health support and vaccination in schools and preschools.

Recommendation Ten: Increased funding and access to training is required to increase the Aboriginal health workforce in remote communities. Cultural awareness and cultural safety programs tailored to the community context must be available for non-Indigenous health professionals and researchers working in Aboriginal communities.

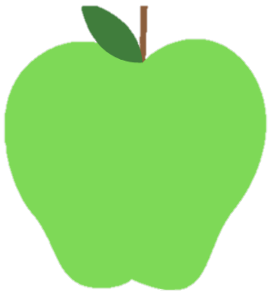
Stay healthy:



Get Vaccinated!

See the doc!

Take your
medicines!

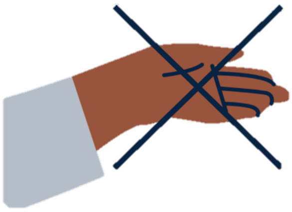


Eat well!

When you’re sick, stop others getting sick too:

Cover your mouth!

Wash your hands!



Don’t shake hands!

Clean dirty surfaces!

Stay healthy in pregnancy:

No smoking or gunja!

Health checks for mums and bubs!

No grog!

Australian National University

Marulu FASD Strategy — Making FASD History

Marninwarntikura Women's Resource Centre

The University of Sydney

The research partnership includes Marninwarntikura Women's Research Committee, Nindilingarri Cultural Health Services, The University of Sydney and The Australian National University.

The research team comprised Philippa Jane Dossetor, Emily Fitzpatrick, Kathryn Glass, Kirsty Douglas, Rochelle Watkins, June Oscar, Maureen Carter, David Harley, Heather Jeffery, Elizabeth Elliott and Alexandra Martiniuk.

The Lililwan Project team who contributed to this work included Dr James Fitzpatrick, Professor John Boulton, Professor Carol Bower, Sharon Eadie, Robyn Doney, Barbara Lucas, Jane Latimer, Olive Knight, Juliette O'Brien, Dr Melanie Olding, and Charlie Schmidt.