

Decolonising Public Health: Applying epidemiology and Indigenous worldview to how health and well-being is considered by Aboriginal and Torres Strait Islander people

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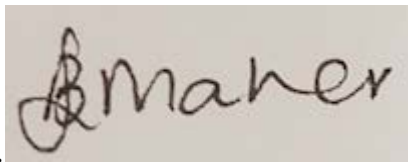


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Originality statement

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

A rectangular box containing a handwritten signature in dark ink. The signature appears to be 'Amner' with a stylized initial 'A'.

Signed.....

Date.....8/11/2018.....

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Abstract

This thesis presents a collection of applied epidemiological studies within an Aboriginal and Torres Strait Islander social, health and wellbeing context. I have applied mixed method approaches to epidemiological knowledge and methods to meet the required Masters of Philosophy in Applied Epidemiology competencies. A sociocultural determinants of health framing was applied to the evaluation of a social health program, an epidemiological study and data analysis studies. Field work with two Aboriginal communities were undertaken in the outbreak investigation and the evaluation and epidemiological study. Community based participatory research models underpinned these studies. The studies included:

- A cross-sectional analysis of data from the *Footprints in Time*: the Longitudinal Study of Indigenous Children (LSIC). The study explores the prevalence of community leadership aspirations and other future aspirations for children aged 9 to 12 years participating in Wave 8 of the LSIC study. Descriptive and regression analyses were included to examine the association between leadership aspirations and key demographic factors: age, sex and remoteness. Additionally, I explored other self-reported aspirations for children in relation to community leadership aspirations to further unpack leadership from a holistic perspective. I applied qualitative inquiry with LSIC key informants to contextualise the findings. An important feature of the study is the focus on internal comparisons within an Aboriginal and Torres Strait Islander cohort, as opposed to the standard comparisons of Indigenous people to non-Indigenous people.
- An outbreak investigation of mumps in Yarrabah, an Aboriginal community in Queensland. The outbreak investigation took place in March 2018 and was conducted in partnership with Gurriny Yealamucka Health Service Aboriginal Corporation (Gurriny). The study included field epidemiology, advocacy and community engagement models of practice. Building relationships with the Aboriginal Health Workers (AHWs) was key to the study. The AHWs facilitated cultural brokerage between me and the community and contributed to adaptation of

a public health questionnaire. I identified gaps in communication between public health and primary health care practice and recommended practical strategies to help strengthen the relationship.

- A process evaluation of a Commonwealth funded program, Stronger Communities for Children, undertaken in a remote community in the Northern Territory, January to June 2018. A partnership between the Australian National University, Palngun Wurnangat Aboriginal Corporation, the Kardu Lurruth Ngala Purrungime committee and community members guided the study. An epidemiological study was a component of the evaluation and included developing and administering an adapted survey instrument to collect data on cultural participation, a key program outcome. Building community relationships was key and required a number of field visits to the community, where I facilitated workshops with the main stakeholders to ensure community voice remained at the center of the study. Community input directed the study design, adaptation of the survey instrument, and development of the logic model and community researcher manual. The evaluation design was constrained by political factors and resourcing.

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Abbreviations and acronyms

ACCHS	Aboriginal Community Controlled Health Service
ACT	Australian Capital Territory
AHW	Aboriginal Health Worker
ANU	Australian National University
CBPR	Community-based participatory research
CDC	Centers for Disease Control and Prevention
CI	Confidence Interval
DSS	Department of Social Services
ED	Emergency Department
Gurriny	Gurriny Yealamucka Aboriginal Health Service Corporation
HPF	Health Performance Framework
IAS	Indigenous Advancement Strategy
KLNP	Kardu Lurruth Ngala Purrungime
LFF	Lessons from the Field
LSIC	Longitudinal Study of Indigenous Children
MAE	Masters of Philosophy in Applied Epidemiology
MK	Mayi Kawayu
MMR	measles-mumps-rubella
NATSISS	National Aboriginal and Torres Strait Islander Social Survey and Australian Health Survey
NNDSS	National Notifiable Diseases Surveillance System
NOCS	Notifiable Conditions System
NT	Northern Territory
OR	Odds ratio
P1	Primary caregiver
PMC	Prime Minister and Cabinet
PWAC	Palngun Wurnangat Aboriginal Corporation
RAO	Research administration officers
RCT	Randomised controlled trials
SC	Study child
SCfC	Stronger Communities for Children
TPHSC	Tropical Public Health Services Cairns
WA	Western Australia

Chapter 1

Introduction

The production, analysis and presentation of Indigenous data are not neutral interpretations of numerical counts. Institutionally positioned within a portrayal of Australian national social trends, the data's ubiquity belies their discursive power. By virtue of the racialised terrain in which they are conceived, collected, analysed and interpreted the data are politicised in ways mostly invisible to their producers and users (1 p.45).

1.1 Introduction

Much of the dialogue about Aboriginal and Torres Strait Islander health depicts inequality and inequity in health and wellbeing (2). Often this dialogue is captured through a deficits lens highlighting disadvantage, illness and disease, problematising Aboriginal and Torres Strait Islander people (3). Decolonising practice in public health reorientates towards a focus on strengths, resilience and capacity, and includes trust and the building of relationships (4). Decolonising frameworks acknowledge the historical layers of knowledge production about Aboriginal and Torres Strait Islander people and are an important consideration in the collection, analysis, reporting and dissemination of data. Additionally, decolonising public health practice acknowledges the importance of social justice and aims to address power relations between non-Indigenous and Indigenous peoples in the knowledge production processes (5). Social justice in public health is necessary for ensuring that racism and discrimination are addressed and are recognised as barriers to Aboriginal and Torres Strait Islander people accessing appropriate and safe health care and management (2, 6-8). The National Aboriginal and Torres Strait Islander Health Plan (8) has made efforts to raise awareness of this at a national policy level. More efforts are required across public health.

My thesis provides an outline of decolonising practices useful to public health practice that privileges the perspectives of Aboriginal and Torres Strait Islander people. I have integrated Indigenous knowledge systems and western knowledge systems, to provide a deeper understanding of how Aboriginal and Torres Strait Islander people view health and wellbeing (9). This approach also recognises the important role of the sociocultural determinants of health in public health and social policy. Applying epidemiological skills and knowledge that consider Indigenous worldviews and the sociocultural determinants of health can complement strength-based approaches and build a narrative that focuses on positive levers aligning with health and wellbeing, such as leadership and culture.

Population data collection and analysis is important in understanding the state of health and wellbeing for a population. It is also central to informing policy decisions and

program design, and guiding the allocation of resources. Realigning statistical approaches to include the assets of Aboriginal and Torres Strait Islander people and their contributions to health and wellbeing is important (10). Much of the Aboriginal and Torres Strait Islander health and social policy narrative has been created through the power of statistical representation (3). The interpretation of statistical evidence can at times create a simplistic view by separating individual statistics from the families, communities, kinship system, social factors and historical layers in which they are embedded (11). As Maggie Walter explained:

The numerical format of these statistics and their seemingly neutral presentation, however, elide their social, cultural and racial dimensions. In a seemingly unbroken circle, dominant social norms, values and racial understandings determine statistical construction and interpretations, which then shape perceptions of data needs and purpose, which then determine statistical construction and interpretation, and so on (3 p.3).

Community engagement and community-based participatory research (CBPR) play an important role in public health. Community engagement is imperative to building trust and ensures cultural safety when working with Aboriginal and Torres Strait Islander communities (11). CBPR promotes the research partnership with Aboriginal and Torres Strait Islander people and considers the research benefiting the community (11, 12). Further, these essential approaches acknowledge the contributions of Aboriginal and Torres Strait Islander knowledge systems in public health practice and research.

1.2 Framing

My position and standpoint are an important component of the thesis; they provide a framing to how I have undertaken the studies. I am a Yamatji woman from Western Australia (WA). I grew up on Wiilman country of the Noongar nations and my ancestral roots lie in the northern regions of WA, the Pilbara and East Kimberley. The concept of improving health, wellbeing and quality of life for our mob resonates with me and has influenced the university studies and the public policy and research roles I have

undertaken. I am attracted to the idea that there will always be an important role for researchers and public health professionals to improve health and wellbeing. Long-term knowledge, experience and better understanding of interdisciplinary and cross-cultural challenges in research is, as I see it, one way to make a difference.

My primary motivation in pursuing the Masters of Philosophy in Applied Epidemiology (MAE) is derived from my ongoing dedication to making a difference and improving Aboriginal and Torres Strait Islander health and wellbeing outcomes. Throughout the MAE I have gained an impression of the challenging but rewarding nature of undertaking research in public health. I also have extensive experience working in Commonwealth Aboriginal and Torres Strait Islander health and social policy, and experience in sexual health education in remote and urban Aboriginal settings. Framing Aboriginal and Torres Strait Islander health and wellbeing to include the sociocultural determinants of health, Indigenous worldviews, community engagement and the application of strengths-based approaches with applied epidemiological skills and knowledge guided the studies in this thesis.

1.3 Field Placement

My scholarship placement for the MAE was within the Department of the Prime Minister and Cabinet (PMC) Indigenous Affairs Group Policy Analysis and Evaluation Branch. This is the first time PMC has hosted an MAE scholar. The branch leads the development of the Annual Evaluation Work Plan, is responsible for strategic evaluations and provides guidance and support for program evaluations, evaluations capability and capacity building. Additionally, it has ownership of the Aboriginal and Torres Strait Islander Evaluation Framework under the Indigenous Advancement Strategy (IAS). The framework aims to guide and recommend ethical approaches to be undertaken with Aboriginal and Torres Strait Islander communities and people to evaluate PMC-funded programs under the IAS. The policy direction within my placement informed my focus on leadership, which was a key element of the National Aboriginal and Torres Strait Islander Health Performance Framework, and the evaluation study was based on a PMC-funded program.

1.4 Thesis Structure and Competencies

This thesis meets the core competencies of the MAE. Reviewing relevant literature and synthesising the information has been applied in chapters two to four.

For chapter two, I undertook data analysis using *The Footprints in Time: Longitudinal Study of Indigenous Children (LSIC)* to explore children's community leadership aspirations and their relationship to demographic factors and other aspirations. A mixed methods approach was applied to the study. I sought approval to access the LSIC data from the Commonwealth Department of Social Services and obtained ethics approval to undertake quantitative and qualitative inquiry. I developed a data analysis plan to guide the analyses based on the study type. I applied both descriptive and analytical methods (logistic regression), and qualitative inquiry to contextualise the findings of the analyses with Aboriginal and Torres Strait Islander key informants.

Chapter three presents a descriptive analysis of a mumps outbreak in an Aboriginal community, Yarrabah, in Queensland. This involved data extraction, developing an epidemiological curve, and adapting and administering a public health mumps case follow up questionnaire. Community engagement was pivotal to the project and included working closely with the Aboriginal Health Workers (AHWs) in the local Aboriginal Community Controlled Health Service (ACCHS). A report was provided to the ACCHS and the public health unit and an advance draft of a paper for the *Medical Journal of Australia* for peer review has been prepared (Appendix 1). I also presented to a scientific and lay audience on the outbreak investigation to meet the MAE competencies. This included presenting at the Australian Partnership for Preparedness Research on Infectious Disease Emergencies (APPRISE) annual meeting, the target audience being experts involved in medical, scientific, public health and ethics research. The lay audience presentation was to clinicians and Aboriginal health workers at the local ACCHS.

Chapter four combines an evaluation and an epidemiology study. The chapter outlines the process undertaken for an evaluation of a program in a remote Northern Territory

Aboriginal community. The study included developing a program logic model, co-designing the evaluation, obtaining ethics approval to undertake the study, adapting a survey instrument, testing the survey, training community researchers to administer the survey, conducting a pilot study, undertaking group interviews, managing the study team and writing a report with recommendations to the community organisation. Mixed methods were applied to this study.

Chapter five presents two teaching exercises: ‘Lessons from the field’ (LFF), and teaching to the first-year MAE cohort on a skill acquired. Both teaching sessions were focused on the role of program logic models in evaluations and involved developing a logic model. The LFF included teaching to my MAE peers. They were provided with a case study, learning objectives, relevant reading and tutorial material and a series of questions to be answered. I collated their answers and chaired a teleconference session to discuss the responses. The learnings were synthesised and distributed to my peers. The teaching session for the first-year cohort was undertaken during a course block at the ANU and was co-facilitated with two fellow students. We provided learning objectives, a case study of health intervention evaluation, an overview of logic model designs and a group activity. The group activity involved developing a logic model for the case study.

These projects are discussed in detail in the following chapters and are outlined in Table 1 below. In addition to the core competency projects, I also engaged in the following activities:

- Presenting at the MAE journal club. In semester two, I established the journal club with another MAE scholar. The aim of the journal club was to enhance skills in critically reviewing scientific papers. Unfortunately, due to increased commitments for the scholars, we only had two presentations.
- Contributing to qualitative analyses for the study “‘Telling our story... creating our own history’”: caregivers’ reasons for participating in the Australian Longitudinal Study of Indigenous Children’ (Appendix 2) and was a co-author for the publication; and

- I was a guest lecturer for an undergraduate sociology lecture on qualitative research methods at the ANU.

Table 1. Overview of the MAE course requirements

Table 1. Overview of the MAE course requirements	Chapter 2: Analyse a public health dataset	Chapter 3: Investigate an outbreak	Chapter 4: Program evaluation and epidemiology study	Chapter 5: Lessons from the field teaching
Analyse a public health dataset	X			
Epidemiology study			X	
Evaluate public health program			X	
Literature review	X	X	X	
Oral conference presentation		X		
Draft scientific article for a peer-review journal		X		
Summary for a lay audience		X		
Lessons from the field and teaching				X

1.5 Summary of public health impact

The application of the studies undertaken during the MAE highlighted the importance of community engagement and community-based participatory research (CBPR)

approaches with Aboriginal communities in public health practice. The outbreak investigation and evaluation/epidemiology studies embedded community engagement at the beginning and throughout the duration of the studies. This approach also aligns with the core values for undertaking ethical research with Aboriginal and Torres Strait Islander people, National Health and Medicine Research Council, 2018 (13):

- Spirit and integrity
- Cultural continuity
- Equity
- Reciprocity
- Respect
- Responsibility

The outbreak investigation included a collaborative partnership with the ACCHS, AHWs and community members. Building the capacity and skills of AHWs in field epidemiology training provides an opportunity for the workforce to contribute to a public health response during outbreak events. Further, strengthening working relationships between public health units and ACCHSs is essential to addressing discrimination and racism, and building trust and partnerships with Aboriginal communities.

The data analysis and evaluation/epidemiology studies focussed on the role that the sociocultural determinants play in Aboriginal health and wellbeing. Incorporating the sociocultural determinants of health into epidemiological research provides an opportunity to better understand what attributes are important to Aboriginal and Torres Strait Islander people and their health and wellbeing. Examining children's aspirations to community leadership, social cohesion and community pride through cultural knowledge and practice contribute to the body of evidence in the Indigenous Affairs social policy arena. Additionally, these studies demonstrate strengths-based practice and inform the policy dialogue about how Aboriginal and Torres Strait Islander people view health and wellbeing.

Reflecting on my field work experience with Aboriginal communities and my impressions of the MAE, I finish with critical thinking questions that I consider important to public health practice and applied epidemiology within an Aboriginal and Torres Strait Islander context.

Table 2. Critical thinking questions for people working in public health

<i>Questions to consider</i>
Who are the traditional custodians on the land where you currently live and work?
Who are the other traditional groups connected to this region?
What are their priorities, perspectives and understandings of health and wellbeing and what are their perspectives of enhancing it?
What are the Indigenous/non-Indigenous socioeconomic and health status disparities in your region?
How does your day-to-day life and work impact on these disparities?

Adapted from Smylie J, Firestone M (14).

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Chapter 2

Aboriginal and Torres Strait Islander children's leadership aspirations

Masters of Applied Epidemiology: course requirements

- Analysis of a public health dataset

Prologue

I acknowledge all the traditional custodians of the lands and pay respect to elders past, present and future. I acknowledge the generosity of the Aboriginal and Torres Strait Islander families who participated in Footprints in Time: the Longitudinal Study of Indigenous Children, and the elders of their communities. I also acknowledge the children - they are our future leaders.

My role

The study examines leadership aspirations within a community context of Aboriginal and Torres Strait Islander children. I analysed data from *Footprints in Time: the Longitudinal Study of Indigenous Children (LSIC)* to explore children's future aspirations, focusing on community leadership as the outcome. I was required to apply for access to data from the LSIC, Wave 8, through the Commonwealth Department of Social Services (DSS).

The study design included mixed methods and I obtained ethics approval through the Australian National University Human Research Ethics Committee, through an amendment to Protocol 2016/534, to undertake quantitative analysis of data on leadership, and qualitative inquiry with key LSIC informants. This included drafting an information sheet and consent form, and developing a presentation for the focus group.

I developed a data analysis plan to guide the study and undertook descriptive and analytical analyses. The aim of the study was to determine community leadership aspirations among Aboriginal and Torres Strait Islander children, and the relationship with age, sex and remoteness.

I reviewed the literature to assess the existing evidence specific to Indigenous youth leadership; I was required to extend my search outside of leadership to include other

sociocultural characteristics due to the paucity of relevant literature. After undertaking my initial analyses and seeking qualitative feedback from the Indigenous LSIC interviewers (Research Administration Officers (RAOs)) on the findings, I proceeded to extend the analyses to explore other future aspirations of those children who had selected community leadership aspirations, to understand how leadership aspirations co-occurred with other aspirations. Pursuing this approach allowed a holistic framing of leadership aspirations and confirmed the complexities in measuring leadership.

Lessons Learned

Aboriginal and Torres Strait Islander cohort studies have an important role in collecting data that is meaningful and aligns with how Aboriginal and Torres Strait Islander people view wellbeing. Undertaking analyses to conduct internal comparisons within an Aboriginal and Torres Strait Islander cohort can remove the deficit lens that is produced when comparisons are made with non-Indigenous populations. Applying a mixed methods approach to the study enhanced the analysis of data by contextualising what community leadership could look like for Aboriginal and Torres Strait Islander children in their community setting. For example, the RAOs illuminated that the meaning of leadership might vary across different contexts, i.e. between urban and remote settings. Learnings from the focus group directly informed further quantitative analysis. The RAOs are an important component of the LSIC data collection process; they collect the data through face-to-face interviews with the participants in the LSIC annually and have a good understanding of the children, their families and the community context, as well as a trusting relationship with families. This approach demonstrated reciprocal knowledge exchange; I was able to disseminate early findings, and the RAOs' knowledge was critical to contextualising findings. Further, a richer story than the numerical format was produced through engaging with the RAOs, and when translated to the policy setting, can provide a useful contribution. I acknowledge limitations in applying cross-sectional analysis, recognising that there are difficulties in identifying causal links between outcomes and exposures.

Public health implications

The Aboriginal and Torres Strait Islander Health Performance (HPF) Report 2017 states that supporting the development of Aboriginal leadership contributes to improving community functioning. However, we currently lack any agreed indicators on leadership and we lack large-scale data on leadership. The findings demonstrate that youth leadership is a difficult construct to measure and highlight the importance of considering the meaning of leadership in different settings (i.e. a single measure of leadership might not be meaningful – different measures might need to be used in different contexts). Aboriginal and Torres Strait Islander cohort studies provide opportunities to undertake analysis using strengths-based approaches to identify health and wellbeing assets. The LSIC applies a strengths-based methodology to better understand what makes Aboriginal and Torres Strait Islander children grow up strong. Future analysis using these data provides an opportunity to understand how sociocultural characteristics, such as leadership and culture, enhance health and wellbeing for children across the life course. This is important both to public health practice and policy and to inform the development of preventative health programs, particularly as children’s health behaviours and health outcomes track into adulthood.

Study acknowledgements

Footprints in time: the Longitudinal Study of Indigenous Children (LSIC), would never have been possible without the support and trust of the Aboriginal and Torres Strait Islander families who opened their doors to the researchers and generously gave their time to talk openly about their lives. My gratitude goes to them and to the leaders and elders of their communities who are active guardians of their people’s wellbeing.

I would like to thank the *Footprints in Time* RAOs for sharing their views during the focus group discussion and LSIC staff at DSS, particularly Fiona Skelton for their support and assistance.

This chapter uses unit record data from LSIC, which has been initiated, funded and managed by the Australian Government. The findings and views reported in this

chapter, however, are those of the author and should not be attributed to DSS or the Indigenous people and their communities involved in the study.

The study also acknowledges the contributions of Aunty Debra Reid and Dr Ruth Nicholls and their guidance with providing policy context to the *Community Functioning* measure in the HPF.

Abstract

Background: Leadership can be viewed as a positive contributor to Aboriginal and Torres Strait Islander health and wellbeing outcomes; however, there are challenges in measuring leadership. There is a significant gap in knowledge relating to Aboriginal and Torres Strait Islander children's leadership. This work aimed to provide evidence on Aboriginal and Torres Strait Islander children's perspectives on their future leadership aspirations, to contribute to informing policy and program development.

Method: Cross-sectional data from Wave 8 of *Footprints in Time*: the Longitudinal Study of Indigenous Children were analysed to explore the prevalence of leadership aspirations and their relation to key sociodemographic factors and other aspirations. A focus group was conducted with Aboriginal and Torres Strait Islander key informants to contextualise findings.

Results: Overall, 15% (n=72/474) of children aged 9 to 12 years reported aspirations to become a community leader. The odds of community leadership aspirations were 49% lower for children in remote areas versus urban areas (OR = 0.51, 95% CI: 0.27, 0.98); there was not a significant difference by sex or age group. After adjusting for remoteness, the odds of reporting leadership aspirations were triple for those aspiring to undertake more education compared to those who did not report further education aspirations (OR=3.26, 95% CI: 1.28,8.30), double for those who wanted to stay living in their current area compared to those who wanted to move (OR=2.05, 95% CI: 1.19,3.52), and six-fold for those desiring to maintain good health compared to those without an aspiration to health (OR=6.19, 95% CI: 2.77,13.84). The focus group identified that there were diverse meanings of leadership across contexts (urban versus remote), and that leadership aspirations were linked to other constructs beyond education, consistent with the quantitative findings.

Conclusion: Leadership is often generalised and simplified; however, application of a holistic perspective and mixed methods approach identifies that measurement of

leadership is complex. To my knowledge, this is the first evidence on differences in Aboriginal children's community leadership aspirations between urban and remote settings, and the first evidence on the link between leadership aspirations and other future aspirations. Future research in this area that includes holistic frameworks and draws on Aboriginal and Torres Strait Islander cohort studies can inform policymakers about the contributions leadership makes across the life course to improve children's health and wellbeing outcomes.

Key words: Leadership, aspirations, Aboriginal and Torres Strait Islander, children, wellbeing, strengths-based, life course

I'm telling you and I'm telling anybody else, this report of the Aboriginal health stats that....every bureaucrat sends out every time, it doesn't make us feel any better and I'm sure it doesn't make any other people around the country feel any better when the report belongs to Australia. It's not Puggy Hunter's report or NACCHO's report, it's an Australian report on the lack of outcomes for our people and to think that we live in this so-called Lucky Country. – The late Dr Puggy Hunter, 6th National Rural Health Conference, Keynote Address, Canberra, March 2001

2.1 Introduction

Dr Puggy Hunter's words quoted above are a reflection of the deficits narrative in policy reporting on the health and wellbeing outcomes of Australia's First Nations people. Health statistics are loaded with power and persuasion, and have directed the shaping of policy and practice in Australia (1, 2). Further, 'as systematically collected numerical facts, they do much more than summarise reality in numbers. They also interpret reality and influence the way we understand society' (2 p.7). Nationally, the discussion of Aboriginal and Torres Strait Islander health and wellbeing is shifting to strengths-based narratives to better reflect the gains being made (1). This has been captured in the National Aboriginal and Torres Strait Islander Health Performance Framework (HPF) (3) and the National Aboriginal and Torres Strait Islander Health Plan (4).

The HPF has been developed to provide guidance in policy analysis, program planning and implementation relating to health and social outcomes for Aboriginal and Torres Strait Islander people (3, 5). It draws key evidence from national administrative data and population-based surveys such as the National Aboriginal and Torres Strait Islander Health Survey, National Aboriginal and Torres Strait Islander Social Survey and Australian Health Survey (NATSISS). A component of the HPF's contribution to strengths-based narrative includes the measure on *Community Functioning*, drawing on Aboriginal and Torres Strait Islander people's strengths and resilience to better

understand human functioning (6). *Community Functioning* is underpinned by frameworks of functioning (7) and capabilities (8) to include Aboriginal and Torres Strait Islander people's core values and their context as a vehicle enabling their participation in society. Leadership is one of the six key themes within community functioning, developed with Aboriginal and Torres Strait Islander input. While leadership is identified as a key asset of and potential positive influence for individuals and communities (3, 9), there is not a clear understanding of what leadership means across contexts, or how to measure it.

Leadership within First Nations settings is an under-researched area both nationally and internationally and relies heavily on the contribution of qualitative studies (9-13). Leadership is complex as a concept. It is often expressed as a western construct within a homogenous model where a 'one size fits all' approach is applied (9, 14). Within a First Nations arena, leadership has links to diverse cultural characteristics that have identified formal and informal functions that are viewed as a collective arrangement, embedded in a governance structure of cultural responsibility and determined by elders in some settings (9, 15-17). Analysis of data from a national Australian study found that for Aboriginal and Torres Strait Islander people aged 15 years and over, leadership is associated with: strong elders in family and community, both female and male; role models, both male and female; strong direction, vision; and having a 'rock' - that is, someone who has the time to listen and advise (3 p.64). This study did not explore leadership aspirations among youth (<15 years).

Aboriginal and Torres Strait Islander children aged 5–14 years represent 24% of the total Aboriginal and Torres Strait Islander population (3). Children's health behaviours and health outcomes track into adulthood; focusing on efforts to improve health in these mid-years could have a positive impact over the long term, beyond setting adolescents up well at the time they enter adulthood. Therefore it is particularly important to understand leadership, a potential health asset, among young Aboriginal and Torres Strait Islander people. The literature acknowledges the importance of including Aboriginal and Torres Strait Islander young people in the leadership arena to create a

shared platform that brings past, present and future together. It is not without its challenges. A contemporary leadership framework is a continuum, including constructs in an evolving cultural world and the interweaving of traditional and contemporary factors, which varies across geographical settings (9, 10, 15). However, children's leadership aspirations and their relationship to health and wellbeing have received limited study. These findings are limited to a small body of evidence and reveal challenges in quantifying leadership. For example, the NATSISS collects data from adolescents and youth (15–24 years) (3), and we are unable to assess how leadership is situated in children's lives, including how leadership might be influenced by external factors such as parents, community, teachers and peers. Additionally, quantitative and comparative studies may capture smaller sample sizes of Aboriginal and Torres Strait Islander people that do not reflect the diversity within the population, potentially resulting in analysis that generalises and simplifies leadership (9).

An opportunity exists to draw on data from *Footprints in Time: the Longitudinal Study of Indigenous Children (LSIC)* to address the gap in evidence about leadership for Aboriginal and Torres Strait Islander children. The aim of this study was to explore leadership as a potential asset supporting health and wellbeing for Aboriginal and Torres Strait Islander children. I quantified the prevalence of self-reported community leadership aspirations among children aged 9 to 12 years participating in the LSIC and quantified the association between leadership aspirations and key demographic factors: age, sex and remoteness. Additionally, I explored how leadership aspirations related to children's other aspirations to further unpack leadership from a holistic perspective.

2.2 Methods

2.2.1 Study design

This study employed a mixed methods approach, using a sequential explanatory design (18) to support a holistic exploration of leadership aspirations for Aboriginal and Torres Strait Islander children. The quantitative component sought to quantify children's leadership aspirations and association with demographic characteristics. The qualitative

component sought to contextualise ‘leadership’ within participants’ community contexts. Findings from this focus group informed the interpretation of results and are described in the Results section.

2.2.2 Ethics approval

LSIC has ethical approval from the Departmental Ethics Committee of the Australian Commonwealth Department of Health. The current analysis using LSIC data (including the focus group) was conducted with ethics approval from the Australian National University Human Research Ethics Committee, Protocol 2016/534.

2.2.3 Study population

This analysis is based on data from LSIC. LSIC arose from a strong interest in collecting longitudinal evidence on children’s growth, development and wellbeing (19). It is a national cohort study that used a multi-stage clustered purposive sampling design to recruit families of Aboriginal and Torres Strait Islander children from 11 broad sites (20). These sites were based on the Steering Committee recommendations and information provided by Centrelink and Medicare Australia, and capture diverse geographical, cultural and socioeconomic characteristics (20, 21). The study includes children from two age cohorts: a cohort aged 0.5 to 2 years (B cohort) and a cohort aged 3.5 to 5 years (K cohort) at baseline (2008).

The Australian Commonwealth Department of Social Services (DSS) funds and manages the study and promotes the dataset as a shared resource for policymakers and researchers. The study has an Indigenous majority Steering Committee comprising members from backgrounds in academia and the community sector (20, 22). LSIC is designed to capture information relating to how Aboriginal and Torres Strait Islander children grow up strong, drawing from the lived experiences of families and children.

Underpinning the LSIC study design is a methodological framework that places Indigenous people, values and priorities at the center of the study and the research approach (23). The design includes a strong community development approach that

includes consultation and engagement with Aboriginal and Torres Strait Islander communities, placing community priorities at the forefront (22).

Data collection is carried out by Indigenous Research Administration Officers (RAOs). The RAOs undertake the face-to-face interviews annually with the families, including the study children (SC) and at least one of their caregivers. The primary caregiver for the study child (P1) completes the most comprehensive survey; the P1 can be the child's mother, their father or another guardian (24). The study collects data on a broad range of factors including social, emotional, educational and developmental outcomes (25).

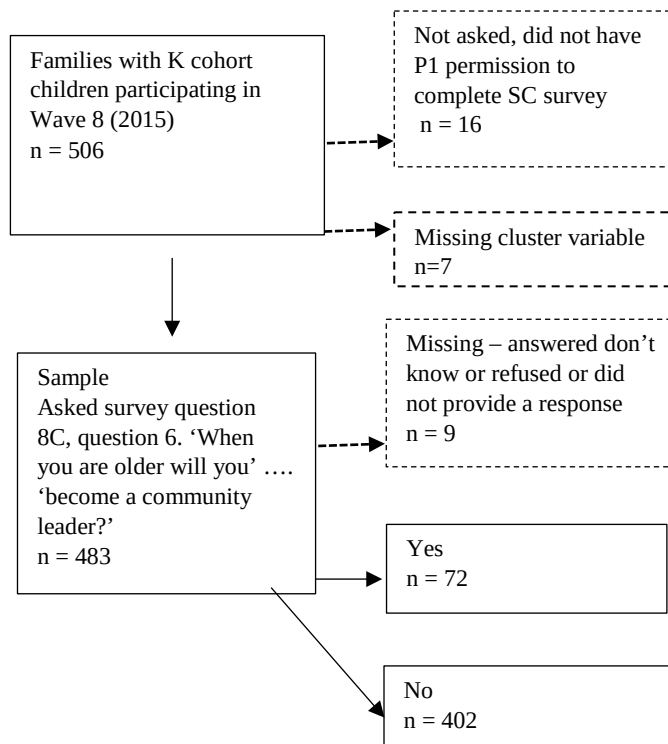
The current study is a cross-sectional analysis of data from the K cohort (9.5 to 12 years of age) from Wave 8 of LSIC, which was conducted in 2015.

2.2.4 Sample

Families of 506 children in the K cohort participated in LSIC Wave 8. The current study is restricted to children whose P1 gave permission for their child to complete the study child survey (n=16/506 excluded), and to children who had valid data on their geographic area (n=7/506 excluded), as this variable is required to adjust for the study's clustered design. This left a total of 483 children in the sample.

2.2.5 Study variables

To explore leadership, I used a proxy measure of *aspirations to become a community leader* in this study. Participating children were asked: '*When you are older will you ... become a community leader?*' If the study child selected either *yes* or *no* to this they were included in the sample. Children who selected *don't know* or *refused* or did not provide a response were coded as missing (Figure 1).

Figure 1. Flow chart of study sample

Exposure variables included age, sex and remoteness. Sex was defined as male or female. Age was defined as the age of the child at interview. Age was recorded in months, and recoded into age group categories of 9-10 (113-131 months) and 11-12 (132-152 months) years of age. Remoteness was determined based on postcode, and defined according to the Australian Statistical Geography Classification remoteness areas (2006). Remoteness was categorised as major cities, inner regional, outer regional, remote and very remote. Due to small numbers, remoteness was recoded to make a binary variable: major cities and inner regional (defined as urban), versus outer regional, remote and very remote (defined as remote). These definitions were influenced by the distribution of the sample.

Further, to understand what aspirations co-occurred with leadership aspiration, I also explored the other aspirations that children reported. Children were also asked, '*When you are older will you ...*' '*do year 12?*', '*go to university?*', '*do more study or training*

(e.g. TAFE)?', 'get a job?', 'get married?', 'be a mum/dad?', 'stay living in this area?', 'move away from this area?', 'live in the bush?', 'live in the city?', 'become a community leader?' and/or 'be healthy?' The responses were examined individually to reflect what other aspirations they had for their future, and also grouped into five categories: education (responded yes to 'do year 12', 'go to university' or 'do more study or training'); job (responded yes to 'get a job'); relationship (responded yes to 'get married' or 'be a mum or dad'); stay living in the area (responded yes to 'stay living in the area' or 'move away from this area'); and health (responded yes to 'be healthy'). Responses were coded as no if they did not select those aspirations, and were coded as missing if they selected *don't know* or *refused* or did not provide any response.

2.2.6 Statistical analysis

A descriptive analysis was undertaken to explore demographic characteristics (age, sex and remoteness) of children in the sample, the prevalence of other aspirations and their association with aspirations to become a community leader. Participants were excluded from the descriptive and regression analyses if they were missing data on the outcome.

Univariate and multivariable logistic regression was used to test for an association between children's aspiration to become a community leader and the demographic characteristics, estimating odds ratios (ORs), p-values and 95% confidence intervals (CI). I first conducted univariate analyses to individually explore the relationship between each demographic factor and the outcome. I then conducted a multivariable analysis including all three demographic factors together to assess their independent effects.

Children living within the same cluster may be more similar to each other than children living in different clusters (for example in characteristics such as income, employment, education and child care). Therefore, analysis may underestimate standard errors if the clustered sampling approach is not taken into account (26). To overcome this, multilevel analysis has been conducted to account for the clustered nature of the LSIC

survey: all models include the cluster variable. This approach is used to account for the correlation between individuals who live in close geographic proximity (19, 26).

I also wanted to investigate if leadership aspirations for children related to any other aspirations. That is, I wanted to know if children who had leadership aspirations were likely to also report other aspirations. First, I needed to test if the demographic factors might be confounding the relationship between other aspirations (exposure) and leadership aspirations (outcome). The chi-square test was used to test if each of the other aspirations were associated with the demographic factors: age, sex and remoteness. Next, univariate and multivariable multilevel logistic regression models were used to test for associations between other aspirations and leadership aspirations. I first conducted unadjusted models, and then conducted models adjusted for remoteness, because remoteness was identified as a potential confounder of the exposure-outcome relationship.

Additionally, a sensitivity analysis was undertaken to explore the possibility if those data coded missing (responded ‘*don’t know*’) could be included as an appropriate response. I repeated the regression analyses to include those with missing responses together with those who had responded no, to examine the potential impact of these missing data on the results.

2.2.7 Qualitative analysis

In July 2017, I conducted a semi-structured focus group with the RAOs (n=7/12). The RAOs were considered key informants, based on their connection to the communities where they undertake the LSIC interviews. Many of the RAOs live in the sites and have a continuing relationship with the communities and families that participate in the LSIC study.

I presented preliminary findings from the statistical analysis to the RAOs in PowerPoint presentation and posed the following questions for the group to provide depth and focus to the discussion of topics:

- What qualities do you think make up community leadership?
- What do you think about children in urban settings being more likely to have community leadership aspirations?
- What things do you think can influence why children want to become a community leader?
- What can you tell me about the characteristics of children who are strong in their cultural identity? Do you think this is different between those that are living in urban settings to those that are in remote settings?

The discussion was captured on butcher's paper. Manual coding was undertaken to identify themes that were subsequently provided back to the RAOs for confirmation. Manual coding was deemed appropriate as a method, due to the small sample (27). Data were coded and grouped into common topics arising from the data captured on the butcher's paper (21), I was able to then draw out relevant themes that also aligned with the literature. This method provided more insight and context to the quantitative findings.

2.3 Results

Of the sample, 15% (n=72/474) reported that they aspired to be a community leader when they become older (see Table 1). Similar percentages of male and female children reported aspiring to be a community leader at 14.6% (n=35/240) and 15.8% (n=37/234) respectively. In age categories, 16.2% (n=41/253) of children aged 9-10 years and 14.0% (n=31/221) of children aged 11 to 12 years reported community leadership aspirations. In remoteness categories, 18.0% (n=48/267) of children from urban areas and 11.6% (n=24/207) of children from remote areas reported aspirations to community leadership.

Table 3. Demographic characteristics of LSIC children's aspirations to become a community leader

	Total (N)	Has aspiration to become a community leader % (n)
Overall	474	15.2 (72)
Sex		
<i>Male</i>	240	14.6 (35)
<i>Female</i>	234	15.8 (37)
Age group		
<i>9-10</i>	253	16.2 (41)
<i>11-12</i>	221	14.0 (31)
Remoteness		
<i>Urban</i>	267	18.0 (48)
<i>Remote</i>	207	11.6 (24)

In the univariate analyses, I did not identify a significant association between community leadership aspiration and age (OR=0.85, 95% CI:0.50,1.43, p-value=0.53) or sex (OR=1.15, 95% CI:0.68,1.94, p-value=0.61). Remoteness was significantly associated with community leadership aspiration, with odds of aspirations to become a community leader 49% lower for children in remote areas versus urban areas (OR = 0.51, 95% CI: 0.27, 0.98; p= 0.04) (see Table 2).

When mutually adjusted for remoteness, age and sex, the association between remoteness and leadership aspirations was not materially changed, and remained significant (OR=0.51, 95% CI: 0.26, 0.99; p=0.045). The odds of aspiration to become a community leader continued to be half for children in remote areas compared to children living in urban areas. There was not an observed association between leadership aspirations and age (OR=0.88, 95% CI:0.52,1.50, p-value=0.64) or sex (OR= 1.17, 95% CI:0.69,1.99, p-value=0.56) in the multivariate model.

Table 4. Association of demographic factors with LSIC children's aspirations to become a community leader (n=474)

Variables	Univariate model			Multivariable model		
	OR	(95% CI)	P value	OR	95% CI	P value
Aspirations to become a community leader						
Sex						
Male	1					
Female	1.15	0.68 – 1.94	0.608	1.17	0.69 -1.99	0.559
Age (years)						
9-10	1					
11-12	0.85	0.50 – 1.43	0.531	0.88	0.52 -1.50	0.644
Remoteness						
Urban	1					
Remote	0.51	0.27 – 0.98	0.043	0.51	0.26 -0.99	0.045

Using the chi-square test, I identified an association between remoteness and children's education, relationship and health aspirations. I also identified an association between sex and university aspirations (54% of males reported university aspirations compared to 37% of females); however, I did not identify an association between sex and other education related aspirations, including the composite 'any education aspirations' variable (see Table 3). I did not identify any significant associations between aspirations and age group.

Table 5. Self-reported aspirations of Aboriginal and Torres Strait Islander children's and association with sex, age and remoteness

Aspiration	Total, % (n)	Sex, % (n)		Age, % (n)		Remoteness, % (n)	
		Female	Male	9-10 years	11-12 years	Urban	Remote
Overall	474	234	240	253	221	267	207
<i>Leadership</i>							
No	84.8 (402)	85.4 (205)	84.2 (197)	83.8 (212)	86.0 (190)	82.0 (219)	88.4 (183)
Yes	15.2 (72)	14.6 (35)	15.8 (37)	16.2 (41)	14.0 (31)	18.0 (48)	11.6 (24)
<i>Education</i>							
Will do year 12 ‡	68.9 (327)	68.3 (164)	69.7 (163)	68.8 (174)	69.2 (153)	73.4 (196)	63.3 (131)
Will go to university * ‡	45.3 (215)	37.1 (89)	53.9 (126)	45.5 (115)	45.3 (100)	57.7 (154)	29.5 (61)
Do more study	20.9 (99)	18.3 (44)	23.5 (55)	17.4 (44)	24.9 (55)	22.9 (61)	18.4 (38)
Any education aspirations ‡	81.0 (384)	78.3 (188)	83.8 (196)	80.6 (204)	81.5 (180)	86.9 (232)	73.4 (152)
<i>Job</i>							
Get a job (No)	21.0 (100)	20.0 (48)	22.2 (52)	19.0 (48)	23.5 (52)	14.2 (38)	30.0 (62)
Yes ‡	78.9 (374)	80.0 (192)	77.8 (182)	81.0 (205)	76.5 (169)	85.8 (229)	70.1 (145)
<i>Relationships</i>							
Get married ‡	31.9 (151)	35.8 (86)	27.8 (65)	28.5 (72)	35.8 (79)	44.2 (118)	15.9 (33)
Be a parent ‡	38.0 (180)	40.8 (98)	35.0 (82)	37.6 (95)	38.5 (85)	51.7 (138)	20.3 (42)
Any relationship aspiration ‡	43.5 (206)	46.3 (111)	40.6 (95)	41.9 (106)	45.3 (100)	58.1 (155)	24.6 (51)
<i>Stay living in this area</i>							
No	69.0 (327)	69.2 (166)	68.8 (161)	65.6 (166)	72.9 (161)	67.0 (179)	71.5 (148)
Yes	31.0 (147)	30.8 (74)	31.2 (73)	34.4 (87)	27.2 (60)	33.0 (88)	28.5 (59)
<i>Health ‡</i>							
No	38.8 (184)	40.4 (97)	37.2 (87)	39.1 (99)	38.5 (85)	29.6 (79)	50.7 (105)
Yes	61.2 (290)	59.6 (143)	62.8 (147)	60.87 (154)	61.5 (136)	70.4 (188)	49.3 (102)

*Significant association between aspiration and sex (p-value for chi-square <0.05).

†Significant association between aspiration and age group (p-value for chi-square <0.05).

‡Significant association between aspiration and remoteness (p-value for chi-square <0.05).

Multivariable analyses were undertaken to examine the link between children's leadership aspirations and other future aspirations. In the unadjusted analysis I identified a significant association between children's leadership aspirations and aspirations to education (OR=3.56, 95% CI: 1.14,4.97), relationships (OR=1.79, 95% CI: 1.05,3.04), to stay living in their current area (OR=2.08, 95% CI: 1.21,3.57), and to stay healthy (OR=6.59, 95% CI: 2.96,14.66) (Table 4). After adjusting for remoteness, the association between leadership aspiration and relationship aspiration was no longer significant (OR=1.57, 95% CI: 0.90, 2.74). After adjusting for remoteness, the odds of reporting leadership aspirations remained triple for those aspiring to undertake more education compared to those who did not report further education aspirations (OR=3.26, 95% CI: 1.28,8.30), double for those who wanted to stay living in their current area compared to those who wanted to move (OR=2.05, 95% CI: 1.19,3.52), and six-fold for those desiring to maintain good health compared to those without an aspiration to health (OR=6.19, 95% CI: 2.77,13.84).

Table 6. Association between leadership aspirations and other aspirations, unadjusted and adjusted for remoteness (n=474)

Aspirations	Community leadership % (n/N)	Unadjusted for remoteness OR (95% CI)	Adjusted for remoteness OR (95% CI)
Education			
No (ref)	6.7 (6/90)	1 (ref)	1 (ref)
Yes	17.2/66/384	3.56 (1.41-8.97) *	3.26 (1.28-8.30) *
Job			
No (ref)	11.0/11/100	1 (ref)	1 (ref)
Yes	16.3/61/374	1.62 (0.79-3.31)	1.45 (0.70-3.00)
Relationship			
No (ref)	11.9/32/268	1 (ref)	1 (ref)
Yes	19.4/40/206	1.79 (1.05-3.04) *	1.57 (0.90-2.74)
Stay in current area			
No (ref)	12.2/40/327	1 (ref)	1 (ref)
Yes	21.8/32/147	2.08 (1.21 – 3.57)*	2.05 (1.19– 3.52) *
Health			
No (ref)	4.9/9/184	1 (ref)	1 (ref)
Yes	21.7/63/290	6.59 (2.96-14.66) *	6.19 (2.77-13.84) *

* P-value less than 0.05.

Additionally, a sensitivity analysis was undertaken. I repeated the regression analyses including those with missing responses together with those who had responded no ($n=402 + 8$). The OR and 95% CI results were not materially changed by the inclusion of missing responses within the 'no' category.

2.3.1 Qualitative results - Leadership in the community context

The RAO focus group revealed that leadership is a complex issue as it might mean different things in different contexts. The RAOs discussed children spending time with elders being an important lever to leadership aspirations. Their recollection of field work was that the LSIC children in urban spaces spoke about interaction with elders more than their remote counterparts; however, the children in Wave 8 were not asked questions about how much time they spend with elders, so this could not be explored in the quantitative data. The discussion also identified that children in urban settings are more likely than children in remote settings to be exposed to leadership programs within an education context, and have opportunities to develop their leadership skills in settings such as camps locally, nationally and internationally. In urban settings, leadership was also represented by children's roles as school captains, and having a job or 'being a worker'.

The focus group discussion also identified that leadership is not always reflected through a positive lens. Leadership can often be linked to governance, such as involvement on community boards. The RAOs identified that community boards at times produce nepotism, bullying and violence to varying degrees, which tends to be more obvious in remote settings. In remote settings, children may interpret these constructs as qualities of leaders.

2.4 Discussion

2.4.1 *Leadership aspirations*

I found that 15% of Aboriginal and Torres Strait Islander children aged 9 to 12 years in the LSIC reported aspirations to become a community leader, noting that this result is not meant to be representative of the prevalence nationally. The study revealed that the odds of community leadership aspiration were close to double for children living in urban compared to remote areas. To my knowledge, this is the first evidence on differences in Aboriginal children's community leadership aspirations between urban and remote settings. I did not detect a difference between males and females, or between younger and older children, in the desire to become a community leader. Additionally, I identified strong links between children's community leadership aspirations and future aspirations to education, staying where they are currently living and being healthy.

Differences between settings are notable; Children in urban settings appear to have more exposure to formal leadership opportunities through their school institution. This was confirmed in the focus group, where the RAOs viewed leadership programs as being more accessible in urban settings and an achievement such as becoming a school captain was seen as an individual achievement. In remote settings, leadership has been explained with a collective framing, particularly in younger years. Women in the remote Northern Territory place value on young people being involved in leadership pathways through passing on knowledge of kinship structures and cultural traditional practices. This is seen as integral to integrating with western systems, a way of being able to 'walk in two worlds' (28). Children in remote settings therefore may not view becoming a community leader as an individualistic concept, and potentially their perception of leadership is as a responsibility that is already determined, rather than an aspiration.

Studies in urban settings have challenged the stereotypical view of there being limited connectedness to culture in comparison to more remote locations (29). They reveal strong links to identity and culture through the interaction of elders and leaders in the community and enhanced social networks (28, 30, 31). Around 45% of the LSIC

children in Wave 6 in urban settings reported spending time each week with elders and leaders. Further, these high levels of interactions can positively relate to social capital binding within an Aboriginal and Torres Strait Islander context (32).

The role of leadership can be linked to governance structures in community boards. Within community boards, factors in the quality and capability of governance range from leadership, resourcing and stable structures to other factors that relate to nepotism, corruption and favoritism and contribute to community violence (33). Coffin et al 2010 identify that bullying is linked with exposures to community and lateral violence experienced by children and adults, with these factors being more prevalent in remote settings. Bullying in rural settings was linked to Aboriginal children being bullied by other Aboriginal children, not by non-Indigenous children. Further, bullying was linked to identity, lower self-esteem and feuding among families in the community (34) and ‘something that Aboriginal people do’ (35 p.157). These characteristics have been linked to lateral violence, and can result in certain families benefiting from particular services or roles in leadership positions (36). Leadership therefore may not always be perceived in a positive framing, which could deter children from aspiring to be a leader in the future. This also supports the findings from the discussion with the RAOs.

2.4.2 Stay living in the area

Children who wanted to stay living in the area had higher odds of reporting leadership aspirations, compared to children who wanted to move. A study in the Kimberley region of Western Australia found that young people’s future aspirations were influenced by their families, where leaving the community and family is not encouraged (37). This related to communities wanting their cultural practices and knowledge to be retained by the younger generations (38). Attending ceremonies can be challenging if children are living away from the community. For example, children in remote settings may need to move away for secondary education in regional or urban settings. Pressure may be placed on children to return to their community to participate in ceremonies and may lead to them dropping out of school to fulfill their cultural obligations. Additionally, if children want to contribute to their community in roles such as teachers, gardeners,

mechanics and nurses, they may not have any desire to leave their current setting. Family and community play an important role in their lived experience prior to tracking into adolescence, and is also linked to their identity and culture (31). Leadership has also been linked to staying connected to community and culture (38), thus staying within their community and close to family would support this. On the flip side, if there are no positive role models or if there is a large number of unemployed family members, this could have a negative impact on children's future aspirations (37, 39).

2.4.3 *Being healthy and educational aspirations*

Odds of leadership aspirations were three times higher for children reporting versus not reporting education aspirations. These findings are consistent with a holistic view of leadership. The focus group discussion with the RAOs identified leadership being linked with education, and that leadership programs were accessed through the education setting. A previous study of adolescents aged 15+ years found those who were engaged in education reported strong leadership in their community and included community leaders and elders having time to listen and give advice (38), compared to those who were not studying. As children develop and move through the life course, and remain engaged in education, the notion of leadership is familiar and supported within the education setting.

Children who reported aspirations to be healthy had six times the odds of leadership aspirations than those who did not have aspirations to be healthy. This may suggest that children view being healthy as linked to being a community leader. The findings demonstrate that it is valuable to consider aspirations holistically, rather than focusing on one aspiration in isolation. Children are also influenced by the views of their parents, caregivers, extended family members, peers and teachers (37, 40) and parents who want their children to have an education and to be healthy may be contributing to how children view being healthy and having an education in the future. Staying connected with community and culture, and being healthy also contribute to how leadership is viewed by children, and is more than education alone.

2.4.4 *Strengths and limitations*

Understanding leadership aspirations within an Aboriginal and Torres Strait Islander setting requires a more holistic view in which leadership does not sit in isolation, but is embedded in culture, identity and connectedness to family and communities (9, 38). Children often learn through their peers and their family members, and culture is also a contributor to leadership (2). When culture and identity is strong within family and community settings, culture is seen as an enabler of leadership capabilities and aspirations for children. Studies in urban settings have found there is a connection (29, 31, 41). These factors also support Aboriginal children to remain strong and resilient, particularly when they are exposed to other challenges such as racism and discrimination (29, 42). Cultural continuity has been linked to improved social and emotional wellbeing outcomes for First Nations youth in Canada and is captured in the literature relating to suicide prevention and social and emotional wellbeing for Aboriginal and Torres Strait Islander children and adolescents (42, 43). Further, other studies on resilience in Aboriginal children capture sociocultural factors as levers supporting their pathways to wellbeing, encouraging self-belief, knowledge and positive decision making (44). These factors were important contributors to how I framed the analysis for the study: the intention was not simply to generalise leadership, but also to draw out how the concept of leadership is understood within the context of the LSIC children.

This study has several potential limitations. Like most cohort studies, the LSIC dataset is not intended to be a representative sample of the overall Aboriginal and Torres Strait Islander youth population (21, 22); therefore the prevalence of community leadership in this sample should not be interpreted as the prevalence among all Aboriginal and Torres Strait Islander children nationally. These data are designed for use in internal comparisons, such as examining the association between leadership aspirations and other factors within the cohort. Therefore, the findings are likely to be generalisable beyond the cohort to the broader Aboriginal and Torres Strait Islander population.

The aim of cohort studies is usually to capture heterogeneity in exposures and in outcomes. Further, other studies (45-47) have demonstrated that representativeness is not necessary for reliable quantification of exposure-outcome relationships. For example, Mealing et al. found that patterns of exposure-outcome associations were similar in two studies of very different response rates within the same population: a cohort study (the 45 and Up Study) and a cross-sectional study (NSW Population Health Survey) (47).

The study uses a clustered sampling approach and does not include children living across all areas of Australia. However, the design is intended to capture a diversity of environments in which Aboriginal and Torres Strait Islander children live (22). Given the small sample size, I collapsed remoteness categories into a binary variable. This combines children living in quite diverse settings, such as outer regional, remote and very remote, within a single category. Between these three remoteness categories there are notable differences in characteristics associated with socioeconomic status, population context and cultural context (48) which may impact on how community leadership aspirations are viewed by the children in the study. The combination of these groups into a single 'remote' category may disguise important differences between these groups. This could be explored in further mixed methods research, using the LSIC data and the same sample in their adolescent years to gain further understanding of their aspirations across the life course. Potentially, using another data source, such as *Mayi Kuwayu* (45) to capture aspirations in adolescent years could also contribute to a more rounded understanding of leadership and other aspirations.

2.5 Conclusion

The middle years are formative to health behaviours and development prior to children and adolescents' pathway to adulthood; for example, there is evidence of the onset of chronic diseases and other non-communicable diseases among Aboriginal and Torres Strait Islander people at this age (49). Epidemiology that applies a life course approach and accounts for social factors provides an opportunity for greater insights into children

and adolescents during their developmental stages, and highlights enablers such as leadership aspirations and culture; that support their journey (50).

Undertaking an alternative method to a biomedical approach of wellbeing opens the narrative to understand social factors as mechanisms that support and improve health and wellbeing for Aboriginal and Torres Strait Islander children and adolescents. The notion of First Nations' leadership embodies cultural values that move away from the constructs of individual, single-led participation, as seen in western frameworks, to collective participation (9). Leadership qualities can be embedded within children's social structures and relationships from an early age, and the interconnectedness of these relationships is informed by the community context (28). Additionally, aspiration to community leadership not necessarily viewed in isolation; it entails a holistic view to include aspirations relating to education, being healthy and staying in one's community. Children who are engaged in education are able to access leadership programs and, as they transition into adolescence, associate leadership characteristics with the interaction of elders. Family, community and culture are external factors that impact on children's decision-making, and aspiring to become a community leader means staying where they are and having access to these supportive factors. Further, it is more than just education that directs leadership aspirations, being healthy is an important component.

The translation of leadership in health policy is currently framed through a community functioning lens and is recognised as an important contributor to Aboriginal and Torres Strait Islander wellbeing (3). The national dialogue on Aboriginal and Torres Strait Islander health and wellbeing extends to include Aboriginal and Torres Strait Islander young people and culture as a determinant of health (4). There is recognition that a gap in knowledge about this population group exists, and that in the past little engagement has occurred to include their voices in policy discussions (50). Given the young age of the Aboriginal and Torres Strait Islander population, more attention is required to better understand how this population navigate and participate in society (3, 49, 50).

Aboriginal and Torres Strait Islander youth are the leaders of tomorrow. They are being supported to be positive role models and

participate in decisions that affect them, their future and their communities. Leadership among Aboriginal and Torres Strait Islander youth is enhanced by a strong sense of identity and connection to culture (4).

Furthermore, exposure to culture and cultural identity may underlie the association between remoteness and leadership aspirations observed among Aboriginal and Torres Strait Islander children in this sample. This study is an important contribution to the current body of knowledge and evidence relevant to Aboriginal and Torres Strait Islander children and adolescents' wellbeing and leadership. Further analysis exploring the association between cultural identity and Aboriginal and Torres Strait Islander children's community leadership aspirations and other aspirations is important to inform policy for this age group.

The context in which Aboriginal and Torres Strait Islander children live daily is important to leadership aspirations and wellbeing. Supportive environments assist in children's ability to believe in themselves and to remain persistent and resilient (51). Additionally, community leaders, parents and teachers can play a positive role in supporting students' engagement with education, and assist children in their decision making abilities relating to their future aspirations. Undertaking mixed methods analyses of data from an Aboriginal and Torres Strait Islander children's cohort study offers a strengths-based narrative to highlight the positive future aspirations of Aboriginal and Torres Strait Islander children, rather than a dialogue of deficits.

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Chapter 3

Community mumps outbreak

Masters of Applied Epidemiology: course requirements

- Investigation of an acute public health problem
- Oral presentation to a scientific audience
- Preparation of a draft paper for publication
- A report to a non-scientific audience

Prologue

I acknowledge the traditional owners, the Gunggandji people, of whose lands I undertook this outbreak investigation. I acknowledge their continuing connection to land, sea and community. I pay my respects to them, their cultures and their elders, past, present and emerging.

My role

The mumps outbreak in Yarrabah, Queensland began in December 2017. I undertook and led the investigation, supported by the local Aboriginal Community Controlled Health Service (ACCHS), Gurriny Yealamucka Aboriginal Health Service Corporation (Gurriny). My role as a trainee epidemiologist relied heavily on the partnership with the staff at Gurriny, including the Aboriginal Health Workers (AHWs), and building respectful relationships with the community. My time was limited to 12 days in the field, travelling from Cairns each day. Establishing trust and building rapport was vital. There was little support and guidance from Tropical Public Health Services Cairns (TPHSC) and I relied heavily on the support of my supervisors during the field work. Access to Queensland Health data was restricted compared to other outbreak investigations which have been conducted by external MAE scholars (1, 2). The bureaucratic nature of Queensland Health, including internal processes and approvals, and limited resources, impacted on what was achievable. Additionally, the outbreak was viewed as a low priority. These elements affected the study design and my field epidemiological learning in this outbreak event. My role also entailed a small advocacy contribution, focused on relationship building and bridging gaps in communication

between TPHSC and Gurriny. I provided an opportunity to share information between the two stakeholders and offered to share any further information during a presentation to the staff at Gurriny on my final day. Additionally, I developed a situation report for TPHSC and Gurriny.

Lessons learned

Balancing bureaucratic environments within public health units and undertaking an outbreak investigation in a primary health care setting was challenging. As an Aboriginal trainee epidemiologist, and an outsider to the Yarrabah community, working within the community setting required reflexivity, cultural appropriateness and cultural awareness in my practice. Community engagement is essential in such events, and establishing relationships in a short time frame is a skill that is an important component of field epidemiology training. The MAE coursework prepares candidates with the steps to undertake during outbreak investigations and has a strong focus on low-resource overseas settings. Usually these investigations are supported within a team of skilled public health professionals. There are, however, gaps in translating knowledge and practice in settings involving Aboriginal and Torres Strait Islander communities. The reality of undertaking this outbreak investigation resulted in a number of the ‘steps to an outbreak investigation’ not being applicable, due to particular barriers. As a trainee epidemiologist, the best that I could do for the local health service and the community was to describe the investigation by person, place and time. I also collated data into a visual format for the clinicians and AHWS. Further, working with the AHWs and engaging with the community through the case follow up process, allowed me to provide additional public health information to community members and to capture their experiences as contributors to the investigation. The investigation provided a great learning experience for me, although it did leave me questioning ‘have I done enough?’

Public health implications

Primary health care settings do not have the resourcing, skills or capacity to manage outbreak investigations, nor is this their responsibility. Community engagement is a

core component of any outbreak event. While some events do not result in high morbidity and mortality outcomes, any outbreak provides an opportunity to reflect, learn and evaluate preparedness and responsiveness. Past outbreak events in Aboriginal community settings have been met with delayed public health responses, which can be a reflection of poor relationships and coordination between public health units and communities. Investing in building relationships between public health, primary health care and Aboriginal communities is essential in establishing a foundation for future events requiring a higher level of urgency and resourcing. Further, it is important that these relationships are strengthened outside of outbreak events.

Additionally, there is an opportunity for public health to support building the capacity of the AHW workforce in field epidemiology training. AHWs are embedded within the communities they work in and have local knowledge relating to cultural practices. They are able to broker relationships between external practitioners and community members that ensure cultural appropriateness and safety.

Study acknowledgements

This study included contributions from Gurriny staff members, AHWs and community members. I would like to acknowledge the support of Ruth Fagan, Dr Jason Agostino, Dr Kingsley Pearson, Dr Andrew Baade, AHWs Lynn Yeatman, Savanna Bulmer and Lynese Hari. Thanks also to the local community members who participated in the follow up questionnaires.

Lastly, thanks to TPHSC for their contributions in providing aggregate Queensland Health data, particularly Sally Rubenach and Alister Keyser.

Abstract

Background: There is growing awareness nationally that building local community capacity is important in outbreak responses. A recent mumps outbreak in an Aboriginal community, Yarrabah, Queensland, provides valuable insights into the benefits of a partnership with the local Aboriginal Community Controlled Health Service's workforce to undertake an outbreak investigation. Yarrabah's vaccination coverage is high, yet the community experienced a rise in mumps cases between December 2017 and March 2018.

Method: Case notifications were extracted from the *Communicare* patient information and recall system at Gurriny Yealamucka Health Service. I co-designed and administered a questionnaire with Aboriginal Health Workers (AHWs) to follow up cases, establishing severity of symptoms, knowledge about mumps, and contacts and overcrowding.

Results: There were 36 confirmed cases and 25 probable cases from December 2017 to March 2018; the index case presented in December 2017. Over half of all cases were aged 5 to 19 years ($n=41/61$), and 62% ($n=38/61$) were males. The AHWs were instrumental in facilitating a pathway between me and community members, assisting in additional data collection, locating cases in the community and enabling culturally respectful and safe data collection. Adapting the follow up questionnaire to include the social determinants of health provided further insight into barriers to reducing transmission. Collecting local level information provided further insight into those barriers. Further, the AHWs could transfer their current skill set of contact management and clinical engagement to an outbreak investigation setting.

Conclusion: The public health importance of outbreak investigations in Aboriginal communities has implications beyond the outbreak. Epidemiologists working in these settings are required to have skills in building working relationships. Establishing trust and respect with the community, clinic and government health service is paramount. Engaging with the community and working in partnership, primary health care settings

and public health units could develop infection control strategies that consider the local community and social context. AHWs were vital in the follow up of cases. There is an opportunity to build and utilise the capacity of this workforce to assist in responsiveness to outbreaks in communities where resources are limited. Further, outbreak investigations also prompt us to evaluate and question ‘How can we do this better next time?’

Key words: mumps, Aboriginal, vaccination, Aboriginal Health Workers, community outbreak, Aboriginal Community Controlled Health Service, community engagement

3.1 Introduction

Yarrabah is an Aboriginal community located 50 kilometres east of Cairns in the far northern Queensland region. The community's primary health care service, Gurriny Yealamucka Health Service Aboriginal Corporation (Gurriny), is an Aboriginal Community Controlled Health Service (ACCHS) and was the first in Queensland to transition from a state run clinic in 2014. Gurriny provides culturally appropriate primary health care to the community and extended family from Cairns and the surrounding region who travel to the community for health services (3). A state run Emergency Department (ED), serviced by Queensland Health, provides after hours services and shares the same building as Gurriny. Gurriny adheres to the National Immunisation Program Schedule (4) and data from the *My Healthy Communities immunisation reports* for the South Cairns region (which includes Yarrabah) report high immunisation rates (5). Gurriny also manage and implement immunisation campaigns within the capacity of the ACCHS and includes a multidisciplinary workforce of clinicians, nurses and Aboriginal Health Workers (AHWs).

Yarrabah, a former Anglican mission, is on the lands of the Gunggandji people with a high proportion of the population being descendants of the Stolen Generations (6, 7). The 2016 census recorded the population of Yarrabah as being around 2,600 people (may be underestimated) and 97% identified as Aboriginal and/or Torres Strait Islander (8). Yarrabah is considered a close-knit community and features sole services (such as a single shop, pharmacy, school and health care clinic) that serve the entire community. Characteristics that define 'close-knit' relate to members being closely connected through kinship or other cultural networks and having shared aspects such as culture, spirituality, history, identity and position in society (9, 10). Close connectedness to family, and cultural ties and practices linking to other communities is also common and can result in regular movement between communities. A community is generally defined by the physical environment, noting that many Aboriginal communities were formed through the assimilation policies resulting in missions and 'it was geographic

and demographic considerations, rather than social ones that determined the definition of communities' (9 p.5).

In December 2017, an index case of mumps was reported in Yarrabah. Cases of mumps continued to be identified in the clinic and the ED through to March 2018; 61 cases were recorded by early March. At the time of the investigation in March, there was no public health vaccine related intervention in place as a control measure to reduce further transmission within Yarrabah. There was no consensus within Queensland health that a third dose of measles-mumps-rubella (MMR) vaccine could be used as a means to manage or control the outbreak. The current guidelines do not support administering a third dose, noting that the guidelines are intended to change in December 2018 to support a third dose in an outbreak event. TPHSC followed up with a letter to Gurriny in February 2018, from the Director of Tropical Public Health in Townsville. The letter dated February 2017, stated that North West Queensland were seeing a resurgence of mumps and there were suspected and confirmed cases in Indigenous adults and children. The NT were experiencing a mumps outbreak, which started in 2015, and several areas bordering Queensland had been effected. The letter recommended exclusion from work or school for 5 days after the onset of parotitis and administering a dose of the MMR vaccination if immunisation status was unknown. For cases presenting with clinical symptoms, laboratory testing for the virus was recommended (11). A Queensland Health mumps fact sheet was also provided as a reference point for clinicians (Appendix 3). In past outbreak events, Gurriny has received advice and updates from TPHSC on a regular and ongoing basis (GP 2018, not named for confidentiality purposes, oral communication, June). However, when there was a significant increase in mumps cases in Yarrabah, Gurriny could not initiate an outbreak response, as this is the function of the TPHSC and the managing public health medical officer (PHMO). The increase in mumps cases was not notified by Gurriny, but via the laboratories (from buccal swabs) through the Notifiable Conditions System (NOCS). These cases were then identified by the TPHSC.

Gurriny raised concerns with TPHSC that the local school and parents would need to be informed about the outbreak. In response, TPHSC sent a letter out to the school informing parents, and therefore the community, of the outbreak in Yarrabah. Advice included ensuring that students were up to date with MMR vaccinations and recommending those who were ill to stay away from the general school population as a mechanism to limit further transmission within the school setting. This standard public health advice may not be effective where there is increased mobility between schools and communities and overcrowded housing conditions, and the possible impacts these factors potentially had on the outbreak. At this time, there was community concern about the increasing number of cases, and concern that existing public health actions were insufficient to reduce transmission. This resulted in Gurriny initiating further examination of the outbreak (2018 community and organisational staff, personal communication, March).

3.2 Background

3.2.1 *Mumps*

Mumps is a vaccine preventable infectious disease caused by the paramyxovirus (12, 13). Characteristics of mumps include swelling of the salivary glands, or parotitis, affecting one or more glands. Transmission occurs through direct contact and the incubation period is between 12 and 25 days. The most infectious time is from 7 days prior to any onset of parotid swelling to 9 days after; asymptomatic features are common during this time and transmission can occur unknowingly (12, 14). Though mortality and morbidity outcomes are low overall, a number of rare complications can result such as encephalitis, orchitis and meningitis. These complications can have serious implications, including negative affect on fertility, and require hospitalisation.

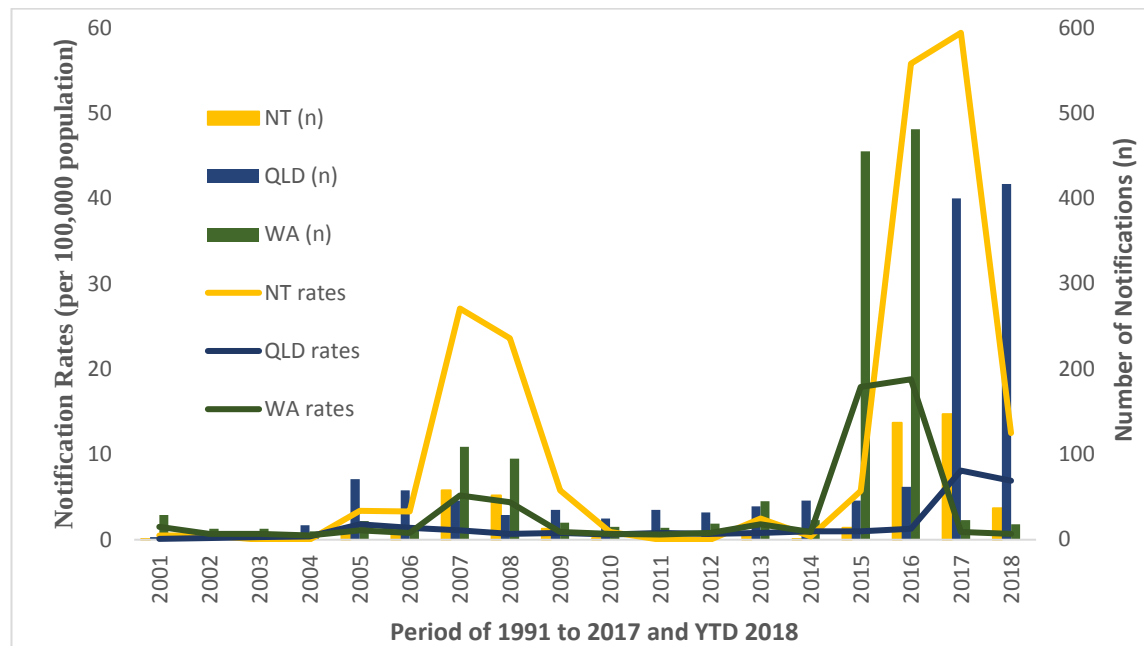
The mumps vaccine was first introduced in Australia into the National Immunisation Program in 1980 and a second dose was added in 1992 (15). The vaccine is referred to as the MMR vaccine. A first dose is recommended for children at 12 months and a

second dose at 18 months (4). The MMR vaccine contains the genotype A Jeryl Lynn strain, a live attenuated strain of the mumps virus (16).

Standard public health control measures can include: home isolation of cases from settings with high social interaction, such as schools and workplaces; increasing community awareness and education; and administering a third dose of the MMR vaccine to protect against further infection by the disease (13). In the past there was conflicting evidence regarding the efficacy of administering a third dose of the MMR (13, 17-19). The US Department of Health and Human Services Centers for Disease Control and Prevention (CDC) have since reviewed the evidence and undertake stakeholder consultations with students and parents. Students and parents placed high value on the prevention of mumps, including complications and other harms associated with loss of productivity that can occur with the disease (20). For people who are at increased risk of mumps, the CDC now recommend a third dose to improve protection against the disease and related complications (20). This study is based on a single study from a different setting to that of Aboriginal community settings. It is important to consider these studies and possibly make adjustments to current practice, for example having access to resources that are readily available and opportunities to follow up individuals to confirm vaccination status and symptom severity.

Australia is experiencing a resurgence in mumps virus outbreaks. Data from the National Notifiable Diseases Surveillance System (NNDSS) show rising numbers of notifications in the total population, predominantly in the Northern Territory (NT), Western Australia (WA) and Queensland from 2006 to 2010 and 2014 to 2018 (Figure 2). The NNDSS notification data, indicate a rise in notification rates in WA from 2014 to 2015. A similar pattern is seen in the NT from 2015 to 2017. An increase in Queensland notification rates is indicated in 2016 to 2018 and potential links associated to cases in the NT outbreak. The total number of notifications is higher in WA and Queensland, compared to the NT where the population size is smaller than the other jurisdictions.

Figure 2. Mumps notification rate and total number of notifications, 2001 to 2018 in Northern Territory, Western Australia and Queensland.



Source National Notifiable Disease Surveillance System (21)

In 2007–2008 the Kimberly region in northern WA experienced a prolonged outbreak of mumps and 92.2% ($n=141/153$) of cases were Aboriginal people (16). The NT also experienced increased numbers of mumps notifications around this time, and epidemiological links were made to the WA outbreak (22). Later, in 2015–2017, there was a mumps outbreak in the NT in which 92.2% ($n=261/283$) of reported cases were Aboriginal people (13). The majority of cases in these outbreaks were in people between the ages of 10 and 19 years (13, 16, 22). The rise in numbers of mumps cases has occurred recently in other first world countries (22, 23). Characteristics common among mumps outbreaks globally and nationally include associations with institutional settings, such as high schools and universities, and with close-knit communities (18, 19, 24). The US experienced large outbreaks in university settings where vaccination coverage was high, affecting university students, staff, and community members. Social mixing, close contacts and shared housing are likely to have contributed to the propagation of the outbreak (16, 19). Similar social contexts have also been recorded in Israel, Guam, New Zealand, and Australia (13, 16, 24–29).

3.2.2 *Objective*

The objective of the investigation was to describe the outbreak, identify the number of cases within the community, and identify public health interventions that were culturally appropriate within the context of the community. A participatory approach, that included community engagement at the centre, was undertaken. This was determined by the interest from Gurriny to better understand why affected children and adolescents were getting the mumps virus, particularly as Yarrabah has high rates of immunisation. A formal outbreak investigation could also provide useful information, including:

- incomplete vaccination
- poor cold chain
- primary vaccine failures
- waning immunity
- a virus strain poorly targeted by the live vaccine strain
- social factors leading to lowered immunity and heightened transmission, including crowded and poor living conditions.

3.3 **Methods**

3.3.1 *Ethics*

Ethics approval from the Australian National University (ANU) Human Research Ethics Committee (Protocol: 2017/909) was granted to undertake the outbreak investigation.

Permission was also sought from Gurriny to undertake the local investigation. The investigation occurred in partnership with Gurriny. I was required to sign a confidentiality form to access patient information from the *Communicare* patient information system.

3.3.2 Study design

A case series design was implemented for the outbreak investigation. My intentions were to access the health service and immunisation data to determine immunisation rates in the community. Follow up questionnaires were administered to collate information from cases relating to symptom severity, understanding of public health advice, social and environmental factors and immunisation status.

3.3.3 Case definition

The Australian national notifiable diseases case definition was applied to this outbreak: a confirmed case included a laboratory confirmation and clinical symptoms, or clinical symptoms and an epidemiological link to a confirmed case with laboratory confirmation. Probable cases were cases with clinical symptoms without laboratory confirmation, this case definition was applied retrospectively in line with TPHSC decision to update current guidelines.

3.4 Methodology

3.4.1 Community engagement and outbreak steps

As an Aboriginal trainee epidemiologist and an outsider to the Yarrabah community, a community development approach was applied to the outbreak investigation to maintain cultural appropriateness and integrity. Community engagement remained at the forefront and was implemented at the clinical and community level. Bridging together the community development framework with public health practice was an important element of this particular outbreak, placing the community, AHWs at the centre. The AHWs provided cultural brokerage between me and community members during the outbreak investigation. This involved AHWs taking me to the households of follow up cases, seeking verbal permission from the members of the household before any engagement between me and the person whose case was being followed up explaining the purpose of the questionnaire, introducing me and explaining why I was in the community. AHWs never enter a community member's household without being

invited in; this is an important component of their cultural protocols with case finding practice. They will call out to the household from the driveway or fence until somebody comes out of the house. Harnessing this model of practice enabled a culturally safe practice, supported the contribution of Aboriginal people in responding to an outbreak affecting their community and provided input into public health practice at the local level.

Figure 3. Engagement model



Outbreak field investigations follow a basic step outline to assist in responding to the outbreak and implementing control and prevention measures (30). We drew on these steps, noting that not all steps are relevant to this investigation (30, 31).

Table 7. Steps into an outbreak investigation

Steps	Steps undertaken in Yarrabah outbreak
1. Verify that an outbreak is occurring	Established in early February when the numbers of cases of mumps increased above what is normally expected in the population in the area.
2. Confirm the diagnosis	Established after the index case had positive pathology diagnosis for mumps. Laboratory testing continued until February 2018.
3. Assemble an investigation team	The team for the investigation included a trainee epidemiologist from ANU, AHWs and clinicians.
4. Create a tentative case definition	The national case definition for mumps was applied to the investigation, according to advice from the public health unit.

Steps	Steps undertaken in Yarrabah outbreak
	Suspected cases were those cases with clinical symptoms, later defined as a probable case and in line with TPHSC advice.
5. Count cases	The trainee epidemiologist counted cases from the data extracted from the <i>Communicare</i> system.
6. Perform epidemiological analysis	A descriptive analysis was undertaken with the data extracted and an epidemiological curve developed with the data. The trainee epidemiologist and AHWs adapted an Australian Capital Territory (ACT) public health mumps follow up questionnaire for the community context. Follow up questionnaires were administered to cases by the AHWs and the trainee epidemiologist to understand symptom severity, contact management and housing conditions such as overcrowding and faulty taps.
7. Perform supplemental laboratory or environmental investigation (if indicated)	Not applicable.
8. Develop a hypothesis	Not applicable.
9. Introduce preliminary control measures	This was not possible at the time of the investigation due to time and resourcing constraints. A poster had been developed and placed at the ACCHS alerting patients to the mumps outbreak in the community, advising them to present to the clinic if experiencing any symptoms, and recommending the MMR vaccine if immunisation status was unknown.
10. Decide whether observation or additional studies are indicated	I was not able to access public health data or immunisation data; therefore there were limitations on any further research. A follow up questionnaire was adapted and administered to cases to capture additional information.
11. Perform additional analyses or plan and perform additional study	Not applicable.
12. Perform new (investigation-derived) control measures, and/or ensure the compliance of existing control measures	Not applicable.
13. Communicate prevention information and findings	A presentation was provided to the clinicians and AHWs at Gurriny with an update on person, time and place of cases during the investigation period. Two reports were provided to Gurriny and TPHSC – a situation report and a summary report outlining the investigation, findings and recommendations for Gurriny.
14. Monitor surveillance data	There was no systematic process regarding monitoring and recording cases at Gurriny to be reflected on the Queensland Health Notifiable Conditions System (NOCS). Communication from TPHSC was not clear at the time of the investigation.

3.4.2 Health service data

I extracted data from the health service's *Communicare* system. The data were included in an epidemiological curve and used as an education tool for the clinicians and AHWs at Gurriny.

3.4.3 Questionnaire

The AHWs and I adapted the mumps case follow up form (sourced from the ACT public health unit), into a questionnaire that was more appropriate for the cultural context and literacy levels in the community. The AHWs identified that the clinical terminology might not be understood by community members and required adapting to more lay language. For example, 'bilateral' and 'unilateral' in relation to swelling were changed to 'both sides L & R' or 'one side L or R' and 'parotitis' was changed to 'face swelling'. Adapted questions related to the person's duration of illness, level of understanding of public health information provided, contact history, immunisation and travel history. Additionally, social environment questions were included, identifying the number of bedrooms in the house, the number of people in each bedroom and whether the household had any faulty taps. Facial diagrams were also included for cases to identify the area where symptoms of swelling were experienced (see Appendix 4 for the original and modified versions). Given the time and resourcing constraints of undertaking the investigation within a primary health care setting, we could only follow up with a small sample of the cases. I consulted the epidemiological curve to capture more recent cases, as memory recall would be better. I was also interested in following up cases at the beginning of the outbreak to establish what control measures were put in place, travel information, contact management and if overcrowding contributed to increased number of cases in the household (see Table 8 for questionnaire results).

3.4.4 Queensland Health notifiable conditions system

Queensland Health guidelines require that notifiable diseases are laboratory confirmed. These notifications are then reflected on the NOCS. The ACCHS took throat swabs

from cases for the period 15 December 2017 to mid-February 2018. After this time, cases presenting at the health service with clinical symptoms and an epidemiological link were considered confirmed cases, as per public health advice. The ACCHS did not notify these cases to the NOCS, as Queensland positive pathology is automatically notified to the NOCS, to reduce the burden on primary health care staff.

3.4.5 Data analysis

The outbreak investigation was undertaken over a two week period. I analysed de-identified data from *Communicare* at the ACCHS. These data were the primary source as access to the NOCS data was not available due to restrictions with Queensland Health approval processes. Immunisation status was not included in the analysis due to incomplete records on *Communicare* and not having access to the NOCS data, where immunisation status is automatically recorded with positive pathology results. We were not able to cross check cases with information from the Australian Immunisation Registry or the Vaccination Administration System in Queensland as the ethics protocol that was in place did not support access and a separate ethics protocol would be required.

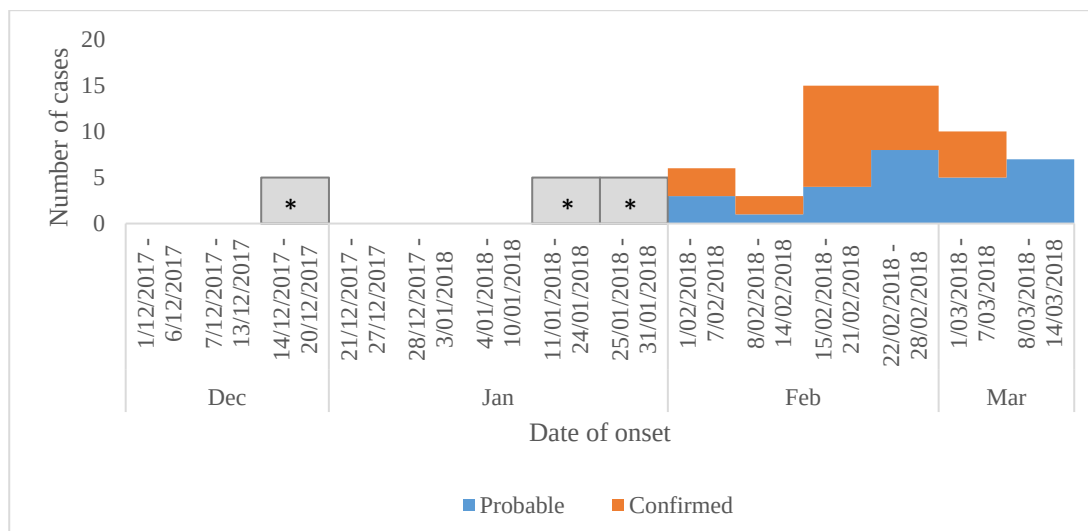
The data were analysed using Microsoft Excel. I undertook a descriptive analysis to explore the distribution of cases (confirmed and probable) by age and sex. I also explored the distribution of symptoms experienced, including bilateral and unilateral swelling, and any complications such as hospitalisations, to understand severity of the mumps within the sample. Additionally, descriptive analysis of questionnaire data explored the distribution of social and environmental characteristics, as well as age and clinical factors, to conceptualise and describe the outbreak features within the community context.

3.5 Findings

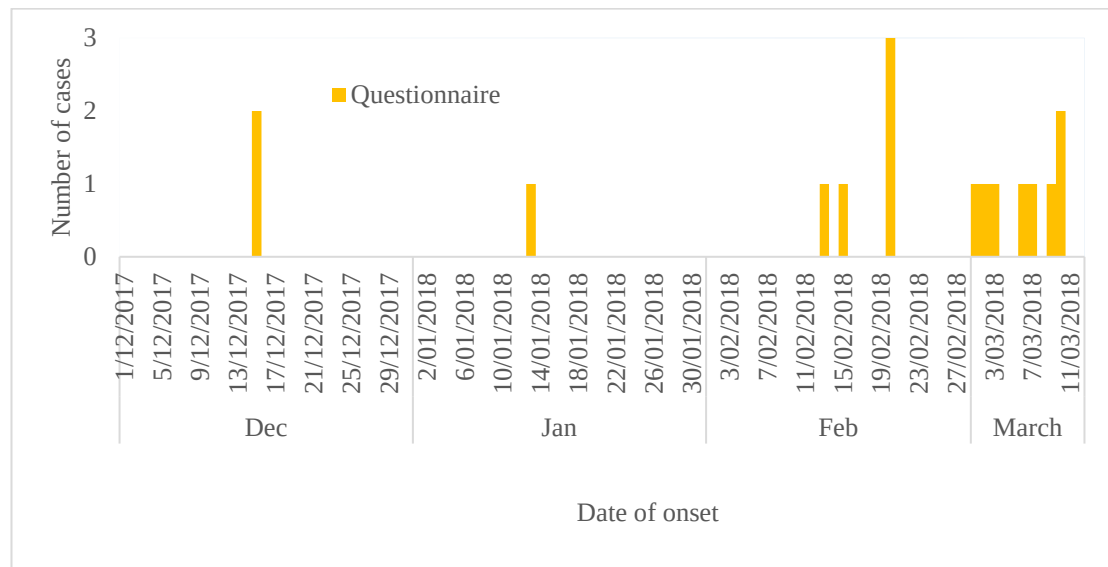
An index case was identified in the community in December 2017 and cases continued to present beyond this study (12 March 2018) at the local ACCHS. Overall, there were 61 cases for the study period 1 December 2017 to 12 March 2018 including 36 confirmed and 25 probable cases. Over half of all cases were aged 5 to 19 years ($n=41/61$), and 62% ($n=38/61$) were males. Symptoms included bilateral swelling in 34% of cases ($n=21/61$) and unilateral swelling in 66% of cases ($n=40/61$).

Retrospective notification data provided by TPHSC after the study period confirmed there were 222 mumps notifications in the Cairns and Hinterland and Torres and Cape from July 2017 to June 2018 (Table 8). From December 2017 through February 2018, Yarrabah notifications represent the majority of the notifications (ranging from $n=5$ to $n=39$). We were only able to capture notifications of mumps cases up to 12 March ($n=17$), which represented 39% of the total notifications in the region for the whole month of March. It is likely that many (if not all) of the remaining 27 notifications in March in the region are also from Yarrabah. Gurriny confirmed that cases continued to present to the clinic past June 2018.

Figure 4. Epidemiology curve of mumps cases in Yarrabah, December 2017 to March 2018



**small cells ($n \leq 5$) are confidentialised to protect patients' privacy*

Figure 5. Follow up questionnaires administered to cases in Yarrabah December 2017 to March 2018**Table 8.** Monthly notifications of mumps among usual residents of the Cairns and Hinterland and Torres and Cape hospital and health service areas, 1 July 2017 to 30 June 2018, and in Yarrabah, 1 December 2017 to 12 March 2018

Year of onset	Month of onset	Total number of notifications in the region	Number of notifications in Yarrabah	% of total notifications in Yarrabah
2017	Jul	14	*	--
	Aug	5	*	--
	Oct	≤5†	*	--
	Nov	≤5†	*	--
	Dec	≤5†	<5†	100%
2018	Jan	≤5†	<5†	100%
	Feb	39	39	100%
	Mar	44	17‡	39%*
	Apr	61	*	--
	May	40	*	--
	Jun	10	*	--
Total		222	*	--

*No data available. † Small cells ($n \leq 5$) are confidentialised to protect participants' privacy. ‡Yarrabah data were only available up until 12 March. It is likely that many of the 27 remaining notifications in March occurred in Yarrabah.

Source: Queensland Health Notifiable Conditions Database, extracted 30 August 2018.

The AHWs and I collected questionnaire responses from 24.5% of cases (n=15/61) during the outbreak period (Figure 5). The median duration of illness was 8.3 days. The questionnaire also captured that overcrowding was prevalent in a majority of the cases (n=9/15) and that many of the cases had been fully immunised (n=10/15). Swabs had been taken for pathology testing for the disease (n=13/15) however two cases had not received confirmation of the results. There were also a small number of cases who reported a lack of understanding of health information relating to the disease, including transmission and isolation (n=2/15). Table 9 presents a summary of the questionnaire results.

Table 9. Results from the follow up questionnaire

Age range	# of surveyed cases (n=15)	% of surveyed cases
<i>5-19 years</i>	10	67
<i>20-29 years</i>	2	13
<i>30+ years</i>	3	20
Social characteristics		
<i>Overcrowding – more than two people in one bedroom</i>	9	60
<i>Travel – had travelled outside of Yarrabah or had visitors to Yarrabah</i>	5	33
Environmental factors		
<i>Faulty taps</i>	5	33
<i>Smoking in the home</i>	1	7
Clinical characteristics		
<i>Hospitalisation</i>	*	7
<i>Immunisation status – were fully immunised</i>	10	67
<i>Had contact with an infected case</i>	7	47
Laboratory testing information		
<i>Swab taken</i>	13	87
<i>Results confirmed</i>	11	73
Knowledge		
<i>Type of information received</i>		
• <i>Pamphlet</i>	6	40

• <i>Verbal</i>	5	33
• <i>Self-research</i>	1	7
• <i>Missing information</i>	3	20
<i>Understood the information relating to mumps, transmission and isolation</i>		
• <i>Yes</i>	13	87
• <i>No</i>	2	13

**small cells ($n \leq 5$) are confidentialised to protect patients' privacy*

I used the epidemiological curve (Figure 4) as an educational tool for clinicians and AHWs to understand the local context of the outbreak and the impact on the community. I shared the information at a feedback meeting with clinicians and AHWs (Appendix 5, presentation slides) at Gurriny. This generated some discussion regarding the increase in numbers of cases in February, potentially linked with the start of the school year. A high proportion of children from Yarrabah travel daily to Gordonvale and other regions of Cairns to their primary and secondary schools.

There was also discussion regarding consistency of clinical information being recorded on the patient file in the *Communicare* system, noting that information recorded varied between clinicians. For data to be extracted, the clinician needs to select mumps from a drop-down list of conditions. Staff who are less familiar with the *Communicare* system, such as locums, are less likely to enter data correctly for extraction.

A situation report collated the information from the data analysis and collection processes, and was provided to TPHSC and Gurriny. A summary report of the investigation has also been provided to Gurriny.

3.6 Discussion - marrying the system and the setting

Usual public health practice requires public health units to monitor notifications and manage outbreak events, including communication and raising community awareness, active case finding and introducing control measures to reduce case numbers (32). Access to notifiable disease data during an outbreak event provides insight into the frequency of notifications within a population and can assist in understanding the severity and impact at the local level. These data are easily accessible within public

health units; however, they are more challenging to access for those working in a primary health clinical setting. Primary health clinics are not designed to lead outbreak investigations as they generally do not have the health hardware or workforce with epidemiological skills and public health practice. Two of the people whose case we followed up reported not understanding the information provided by clinicians. This could reflect the extra demand of increased number of cases presenting to the clinic on top of their usual primary health care core business and quality of service delivery being compromised. *Communicare* system is a patient information system and has the ability to run reports on particular diseases and infections; however, there are limitations in how clinical notes are recorded, varying between practitioners. Consistent data collection requires consistency in staff training on the *Communicare* system, and can be challenging with staff turnover and temporary locum staff.

The current *Communicable Disease Control Guidance* provides advice, information and guidance relating to mumps and managing transmission in outbreak events. The management section recommends exclusion from school or the workplace for 5 days after the onset of parotitis if susceptible contacts are present (11). This presents challenges when social factors such as poor living environments, including household overcrowding, means that the person in 'quarantine' may infect others who share a bedroom or home.

In the instance of this outbreak, in my capacity of a trainee epidemiologist, I was supported by the ACCHS to undertake the investigation. The ACCHS saw this as an opportunity to respond to heightened community concern about the notable increase in numbers of cases. However, there were limitations on resources and capacity to follow all of the steps to an investigation (Table 7). The team were able to undertake steps 1 to 5 and 13, and we adjusted these steps to the community context.

Bridging together a community development framework with public health practice was an important element of this particular outbreak. The approach placed the community, the ACCHS and AHWs at the centre and contributed to the study design and methods used in the investigation. The AHWs' role as cultural brokers facilitated engagement

between me and community members. The AHWs and I adapted standardised collection tools, such as the follow up case questionnaires, to address health literacy levels and frame questions to align with the context of the community. Health service data were extracted at the service level from the ACCHS *Communicare* patient management system; this was the primary source of data used to describe the outbreak.

A partnership between the ACCHS, AHWs and me assisted in raising community awareness and building the capacity of AHWs in components of field epidemiology outbreak response. We were successful in following up a small series of cases within a short timeframe to develop a picture of the local evidence and enhance the description of the outbreak. AHWs' role in health care varies between different primary health care settings (33). They are a valuable asset to their primary health care setting, and bring clinical and cultural brokerage skills that can add value to outbreak investigations (34, 35). Epidemiological information, particularly the epi curve, was used as an educational tool for clinicians and AHWs to understand the local context of the outbreak and the impact on the community.

3.7 Lessons Learned

Infectious disease outbreak events provide an opportunity to evaluate and reflect on lessons learned. Special considerations are necessary in Aboriginal community settings that consider the local and cultural context and consideration of social and environmental factors such as overcrowding, mobility and close social interactions. Establishing relationships with the local ACCHS and community members are an important element of working in partnership, and including the local needs and perspectives of community members is essential. My reflections on the community mumps outbreak in Yarrabah include the following.

3.7.1 Workforce

The AHWs involved in this outbreak investigation were paramount in helping forge a pathway and building partnerships with community members, locating cases in the community and enabling the collection of data in a culturally respectful and safe way.

The process was seen as a two-way learning and contributed to increasing AHWs' own knowledge of infectious diseases, contributing to raising community awareness and local knowledge of people who completed the questionnaire. They were able to build on their current skill set of contact management and clinical engagement.

3.7.2 Adaptation of public health tools

Public health tools may have limitations in their current form when used in Aboriginal community settings. Adjusting the language and clinical concepts in case follow up forms to assist in cultural appropriateness for the community context was helpful. I added to and revised existing survey instruments to better understand patterns within the community relating to symptom severity, health literacy and knowledge, and social factors. The questionnaire also served as an educational tool to answer questions from community members and raise awareness relating to symptoms, complications and transmission. Gurriny is currently using a New South Wales mumps fact sheet and there is an opportunity to develop a fact sheet in partnership with the ANU, Gurriny, the community and TPHSC. The fact sheet could be specifically targeted to the Yarrabah community and take into account local health literacy, using wording and diagrams that are meaningful to community members and ensuring that all information is clearly understood.

3.7.3 Strengthening relationships between public health and primary health care

Forging a working relationship between public health units and primary health care clinics offers an opportunity to inform better public health response and preparedness strategies in outbreak settings. Bringing public health knowledge into the primary health care setting enables AHWs to be involved in field epidemiology practice and assist in strengthening communication and awareness at the local level. Investing in relationship building is important and requires an ongoing effort beyond outbreak events. This would allow public health units to be better placed in responding to outbreaks in a manner most relevant and appropriate to the local context.

3.7.4 *Community engagement opportunities*

There were a number of environmental (overcrowding) and social (high levels of social interaction) factors that require careful consideration in the Indigenous context and for recommending control measures. Sole services that serve the whole community, kinship structures, and housing designs that do not account for large family structures and increased social interaction. In this context, isolation is challenging as a control measure to implement when there are upwards of 15 people in a home. It is also hard to implement isolation when cultural obligations require a high degree of social interaction. Provision of health promotion and education about the need for vaccination and delivery of vaccination is required. Working closely with communities and ACCHSs to develop infection control and communication strategies is required. This could include increasing community education and health promotion relating to reducing transmission through the use of tissues, soap, hand gels and sanitising products. Engaging with the local shop and pharmacy to ensure they have adequate stock for the increased demand and that the products are offered at a price that is affordable for the community would contribute to preparedness.

3.7.5 *The role of advocacy in outbreaks investigations*

This outbreak investigation highlights the role of advocacy in community initiated outbreak investigations. The ability for a community organisation to undertake or even ask for an investigation to be initiated is highlighted here. The community organisation central to the provision of health care was unable to access government held information to determine the breadth of the outbreak, effectively limiting the control measures and response. Instead the community had to rely on data and a process that was constrained, as their systems are not designed for these purposes. This outbreak also highlights the apparently limited ability or agency for communities and community organisations to initiate or seek to initiate an investigation due to their concerns, despite these concerns being raised with public health authorities.

3.8 Recommendations

1. A stakeholder workshop has been recommended to include Gurriny, community members and public health officers as a next step to assist in reducing transmission. The intention of the workshop is to engage with these major stakeholders to develop an infection control and communication strategy that is culturally appropriate to the community setting. The workshop would be useful not only in addressing the ongoing mumps outbreak, but also in relation to infections with similar transmission modes. Community approval has been granted for me to co-facilitate the workshop with a Health Promotion Officer from Gurriny (Appendix 6). To date the workshop has not occurred due to other community priorities.
2. The current Queensland *Communicable Disease Control Guidance management section* relating to mumps requires updating to take into account factors such as overcrowding, noting that the last full revision of the guidelines was in February 2012. Working in partnership with Gurriny and the community, TPHSC could support this process and provide recommendations to the Executive Director of Queensland Health. Further, developing other communication resources such as fact sheets and posters could also be addressed through the partnership and assist in raising community awareness.
3. Engagement between Gurriny and TPHSC could be strengthened. Potential opportunities for public health officers to attend clinical meetings at Gurriny could help to build rapport and trusting relationships. This forum would be an opportunity to support knowledge sharing through building public health knowledge with clinical staff, including AHWs, and for community awareness and engagement practice to be shared with the public health officers. Building cultural awareness and safety into public health practice is essential.
4. Work should be done in partnership to address issues relating to gaps in real-time data in the *Communicare* system and notifications to the public health unit. This could include creating a system that is practical and not too burdensome on

clinical staff at Gurriny. Training all staff, including locum staff, in using the *Communicare* system and reporting systems would help ensure consistency and continuity in reporting.

3.9 Conclusion

Outbreak events in Aboriginal communities require efforts to be focused on effective communication, collaboration and coordination between public health units and ACCHSs. Relationship building with ACCHSs is a core component of public health practice within Aboriginal community settings and requires investment beyond outbreak events. Lesson learned from any outbreak provide a platform to assess and refine practice, and opportunities to strengthen community engagement. Enhancing the skills of the AHW workforce in field epidemiology and supporting placements of MAE scholars can prove helpful where resourcing and capacity are challenging for public health units.

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Chapter 4

A process evaluation of the *Stronger Communities for Children* program

You've got to start at the beginning where you're made. Your belonging, you know. Where you're from. Where you're connected through not only country, but also how you fit in with family members in that area. Regrouping or grouping each other in cultural, but it starts off with ceremonies to know where you stand as a person for being involved in culture.

If you're not involved with ceremony or anything you should be able to learn by elders to go through the culture. But the main thing is just through ceremonies.

– participant of Mayi Kuwayu focus group

Masters of Applied Epidemiology: course requirements

- Evaluate a health program
- Design and conduct an epidemiology study

Prologue

I acknowledge the Kardu Yek Diminin people as the traditional owners of the land on which Wadeye is situated and where this study took place. I acknowledge their continuing connection to land, sea and community. I pay my respects to them, other clans, their cultures and their elders, past, present and emerging.

My role

A large component of the study involved project management of the study. I coordinated and designed the study in partnership with the Palngun Wurnangat Aboriginal Corporation (PWAC), the Kardu Lurruth Ngala Purrungime (KLNP) committee and the Stronger Communities for Children (SCfC) program coordinators. During the 6-month study period, I also facilitated three community workshops with community members and the program coordinators of the SCfC program. This included co-facilitating training for community researchers and developing a community researcher manual.

An Aboriginal-led research team, which comprised Aboriginal researchers from the Australian National University (ANU) Research School of Population Health Aboriginal and Torres Strait Islander programs and local community researchers who were trained in administering the quantitative survey, undertook the study in Wadeye, a remote Aboriginal community in the Northern Territory. Over the 6 months, there were three field visits. Community engagement was essential for the implementation of the study, particularly as the research team were based in Canberra.

I contributed to this evaluation through two key domains of evaluator competency (1):

1. Co-designing a program logic model with community members during the workshops and drawing on the literature to inform the model and study design
2. Leading the development and completion of the study ethics application, which included the work of the ANU team to implement an epidemiological study; and managed liaison with the program coordinator to ensure the ethical processes were adhered to and clear communication was maintained with the field site SCfC program coordinator.

Lessons learned

Undertaking research in remote Aboriginal communities requires reflexivity (2, 3), flexibility and ethical approaches embedded in the study design. Training community researchers is a core component of community-based participatory research and contributes to building the capacity of community members in research. However, distance, timing constraints and the concept of research not being well understood within remote communities is challenging (4). English is a second or third language, and numeracy and literacy capabilities can create barriers for community researchers administering surveys. The effort and commitment required by program coordinators to support community researchers was impacted by delays in funding decisions, resulting in workforce changes and a loss of momentum to promote the study and recruit participants.

Situating social justice at the center of the research assisted with framing how the research was conducted and supported a transformative mixed methods approach (3, 5). Drawing on mixed methods approaches maintained community input into the survey design and prioritised data items that were meaningful to the community context. Including a qualitative component to the study design involved reflexive approaches to critically assess how I was positioned in the research, including maintaining a balance in power relations between me and the participants. For example, participants may have seen me as being in a place of dominance due to factors such as being educated, the way

I was dressed and the language I used. Noticing participants' body language, such as having their head down, was a cue that they were uncomfortable. I also sat on the ground with participants when I was talking to them (5).

A cohort study design best supported the study's aim of measuring change and assessing the impact of community-identified priorities such as cultural participation and corroborree. Initially, the cohort study would aim to achieve a baseline sample and to then follow up with the cohort at different points in time (i.e. 6-month, 12-month intervals) to assess impact and measure change. However, this was not viable due to decreased efforts in participant recruitment and in the promotion of the study within the community. The study design changed to a case series. A baseline sample of the SCfC participants could be established. The analyses of the baseline data was undertaken by another colleague in the research team, and I undertook the qualitative data collection and analysis. A case series study design is not a favored hierarchy of design for evaluations and is open to bias; however, employing a mixed methods approach attempted to mitigate this. The qualitative component strengthened the study to include participant's perspectives and contextualise how the SCfC program supports access to culture. Further, the study places the SCfC program to be ready for future evaluations.

Public health implications

Randomised controlled trials (RCTs) are regarded as the gold standard in evidence and the favored hierarchy of design for evaluating causal relations of social and health programs (6, 7). Implementing RCTs to evaluate complex community-based programs within Aboriginal and Torres Strait Islander settings has been viewed as inappropriate and unacceptable (8). Further, complex study protocols, limited community engagement and compromised methodology design due to smaller sampling size contribute to the challenges of effective implementation of RCTs in these settings (8). Community engagement is essential to all stages of evidence-based studies and evaluations. Community input and contribution are important to the co-design of surveys and logic models, data collection and privileging local voices in program evaluations.

Additionally, cohort study designs offer an opportunity to measure change and assess the impact of community identified priorities such as culture and corroboree.

Government funding cycles and uncertainty in funding arrangements have implications beyond the contracted organisation: program momentum is altered as a consequence, competitiveness between existing organisations in the community increases and the ability of studies to collect quality evidence is compromised. This study provides an important contribution to the policy setting, revealing the layers of complexity in program implementation at the community level and the different perspectives on how a program is perceived to work.

Study acknowledgement

I acknowledge the contributions of and partnership with PWAC, the KLNP committee, SCfC program participants and SCfC program coordinators.

Thanks to Bill Ivory for providing me with a historical and cultural account of the Thamarrurr region, and to Linda Ivatts from the Women, Families and Children Branch, Indigenous Affairs Group, Department of the Prime Minister and Cabinet for providing the policy context of the SCfC program.

A big thanks to Jan Chapman, Mayi Kuwayu study coordinator, who assisted in training the community members and the SCfC program coordinators to administer the adapted survey. This thanks is extended to Ray Lovett and Roxy Jones for their contributions in the field to help undertake focus groups and assist with administering surveys.

Special thanks to Erin Walsh and her creative talent to co-develop the models in the chapter. This assisted to visually capture my observations and synthesis of the evaluation components within the community content.

Abstract

Background: Community engagement and community-based participatory research (CBPR) with Aboriginal communities ensures ethical research practice and trust building is harnessed. A process evaluation was undertaken in Wadeye, Northern Territory, to examine how the *Stronger Communities for Children* (SCfC) program is addressing community priorities. The SCfC program is a community-led social change program, funded by the Commonwealth. It aims to provide children with a better start in life and ensure supportive and safe environments are in place to meet this outcome. Additionally, community priorities are committed to harnessing sociocultural factors as the foundations for addressing these outcomes. This study provides an example of the contested spaces in which government funded programs are situated in Aboriginal communities and the impact of funding uncertainty.

Method: A mixed methods study was embedded in a process evaluation of the SCfC program. The study design included developing a program logic model to guide the study and was underpinned by a partnership engagement model for ethical research and privileging local community input. A quantitative survey was adapted and piloted with the community and community researchers were trained to administer the survey instrument. Qualitative interviews were also undertaken with participants in the SCfC program.

Results: Community engagement was an essential contribution to the study processes. Culture and the way it is articulated through expression and practices is a key component of the lives of Aboriginal people in Wadeye. Qualitative interviews revealed that the SCfC program provides a platform for community members to access culture and support corroboree. Corroboree is viewed as an essential characteristic to support social and community harmony, and wellbeing. Baseline data was also collected for ongoing monitoring and evaluation but has not been included in this study.

Conclusion: Undertaking Indigenous-led evaluations that harness CBPR and community engagement is essential to ensuring that ethical practice is administered and

community voices are privileged. This includes community priorities and contributions being included in the design and implementation of social change programs and as a necessary component to address the complex layers of programs and the context in which they are situated. Community input into appropriate survey design and data collection is an important factor in collecting meaningful data to measure change. Uncertainty in funding decisions, however, has unintended consequences impacting on the stability of program governance, the workforce and program activities. Additionally, these impacts pose the question ‘Is more harm being done than good?’ by Indigenous Affairs social policy and programs.

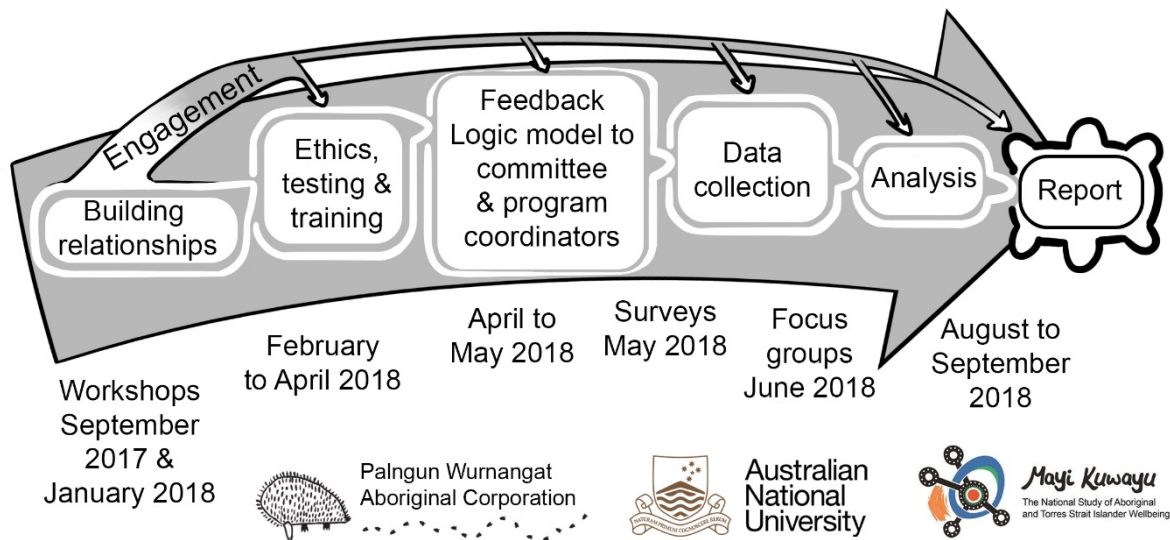
Key words: Community-based participatory research, community engagement, Aboriginal, remote community, culture, evaluation, program logic model

4.1 Introduction

Aboriginal and Torres Strait Islander peoples and communities have experienced disconnection from culture and country, and ongoing intergenerational trauma as a result of colonisation and subsequent government policies (9). Recognising the critical importance of culture for wellbeing, several community programs have been developed to support connection to culture as a way to improve wellbeing. For example, in Wadeye, Northern Territory (NT), the *Stronger Communities for Children* (SCfC) program provides a mechanism to promote cultural revitalisation and support community-led social change through the program activities.

Palngun Wurnangat Aboriginal Corporation (PWAC), the facilitating partner implementing the SCfC program, and the Kardu Lurruth Ngala Purrungime (KLNP) committee (which includes community representatives), which provides a community voice and input into the activities implemented under the program, invited the Australian National University (ANU) to co-develop and co-deliver an evaluation of the SCfC program. The objective was to co-develop a program logic model and evaluation approach for the SCfC program, and establish an ongoing, community-owned data resource and monitoring and evaluation framework. This involved qualitative inquiry as well as a community-administered survey.

The timeline below (Figure 6) provides a visual representation of the processes undertaken in the study and is intended as a guide. It covers the main components of the study, which was undertaken between January 2018 and June 2018. The ‘Methodology’ section discusses the frameworks included in the study to ensure cultural appropriateness and safety. In particular, two models underpinned the study design: a partnership model for ethical research (Figure 8) and a program logic model to enable the evaluation (Figure 10). A site description has also been included to provide context to the study. Following this section, the study design and methods have been combined to establish the approach undertaken to collect data. The findings, discussion, and recommendations are combined and are followed by the conclusion.

Figure 6. Timeline of the Stronger Communities for Children study

4.2 Context

4.2.1 Setting

The Thamarrurr region includes Wadeye, formerly known as Port Keats, which is located south-west of Darwin (NT) and has a population of approximately 3,000 (10). Wadeye became a site for a mission, which brought a number of different clan groups into one geographical location (11). There are nine language groups in Wadeye - Murrinhpatha, Marri Thieyel, Jaminjung, MalakMalak, Matngele, Marri Amu, Marri Ngarr, Magati Ke, and Marri Tjevin. Within each language group there are several clans; the local people identify 25 clan groups (12). Wadeye has been heavily impacted by the Northern Territory Emergency Response intervention, resulting in restructures of local governance arrangements, fiscal and program implications, and overall community disempowerment. This exacerbated a range of social issues relating to community disharmony, disempowerment, substance misuse, unemployment and cycles of welfare reform (13). As a result, the SCfC program was initiated. Its main focus was to support communities to develop program activities that placed children in a safe community environment to support social and health outcomes.

- Build community capacity to lead, plan and prioritise services that children and families need
- Build the capacity of Indigenous organisations to deliver these services.

The SCfC is currently implemented in the following communities: Ngukurr, Galiwin'ku, Wadeye, Ntarta, Santa Teresa, Gunbalanya, Maningrida, Utopia Homelands, Atitjere (encompassing Engawala and Bonya) and Lajamanu (Appendix 7, SCfC fact sheet).

Since its inception in Wadeye in 2013, there have been a number of changes relating to organisation structures, staffing and governance. Implementation of program activities has been heavily impacted by these changes and community disruption, in particular the transfer of the program from Thamarrurr Development Corporation to PWAC in 2015; delays with the program establishment and contractual arrangements with partnering organisations being delayed, only commencing during 2017 to early 2018.

4.2.3 PWAC

PWAC is an independent women's organisation in Wadeye. Palngun Wurnangat (PW) means 'women together here' in Murrinhpatha, the main shared language of the Thamarrurr region (10). The women of Wadeye contribute to the town's economic, social and cultural development. Through PWAC initiatives, the women in Wadeye own a number of enterprises that provide essential services to the community:

- Mi Patha Catering includes a takeaway store and bakery, supplying healthy food options and fresh bread to the community, along with a catering service, and a butcher providing fresh meat and seafood.
- The T-House complex houses a coffee shop, a laundromat, a retail space selling merchandise and second-hand clothing, and a gallery space for selling artwork.
- PW Plums provides seasonal harvesting employment to local people.

- The Art Centre is a workspace specialising in creating printed fabrics, featuring local women's contemporary and traditional designs, sewing, etching and paintings.

The profits generated from these businesses support PWAC to continue supporting families socially and economically.

The SCfC program in Wadeye is guided by the facilitating partner, PWAC, and collaborates with other organisations that have a shared interest and vision. The partnerships are listed in Table 10, along with the program activities they have responsibility for delivering to the community under the SCfC program. The program activities were negotiated with the KLNP committee.

Table 10. The SCfC program

Organisation	SCfC program activity
PWAC	• Women's cultural program • Early childhood program
Thamarrurr Development Corporation	• Men's shed program • Healthy homes program
Australian Football League Northern Territory	• AFL program
Thamarrurr Youth Indigenous Corporation	• Youth leadership program • After hours program

4.2.4 Previous SCfC evaluation

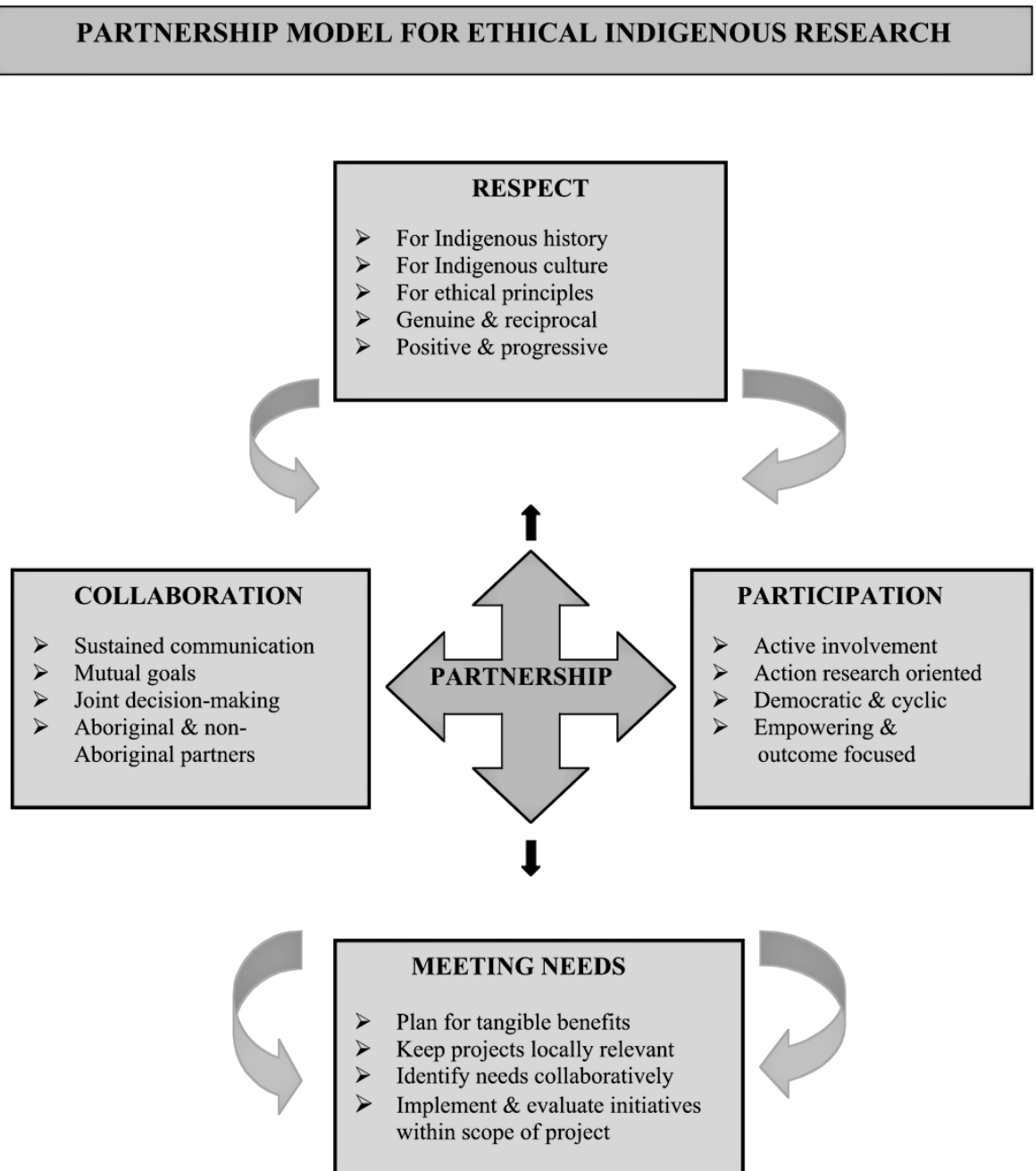
In 2017, a Winangali/Ipsos consortium was funded by PMC to undertake an evaluation of the SCfC program as a whole (14). A number of SCfC sites participated in the evaluation. The sites were at different stages of program implementation. The evaluation revealed that SCfC activities differed between the different community contexts. At the time of the evaluation, Wadeye had not fully implemented the intended program activities. Therefore, this evaluation is related to the Winangali/Ipsos one but

does not cover the same material, as this evaluation is specific to Wadeye and considers the context of the community and the stage or program maturity/implementation.

4.3 Methodology

4.3.1 *Partnership model for ethical Indigenous research*

The study was set in a remote NT Aboriginal community and underpinned by an Indigenous research methodological framework that centred on community engagement. The framework privileges local community voices in the study design, survey design, administration of surveys and logic model design. A partnership engagement model for ethical research (see Figure 8) underpinned the study and local community engagement was key to directing the evaluation. Adopting this model and its principles for the study involved considering a number of factors: the context and historical factors in which the study is undertaken; ethical considerations to do no harm to the community and participants; adopting flexibility to prioritise the needs of the community and participants needs; and ensuring that participatory inclusion is respectful and an empowering process (15). Additionally, ethical research principles such as respect, mutual agreement, collaboration, reciprocity, data use, storage and access, and reporting back to the community were factored into the study design (16). CBPR adopts these principles in practice and ensures the collective involvement of local people in research, enhancing their skills and privileging their voices (17). This was integrated into the study through training locally identified community researchers, including members of the KLNP committee, in co-developing the program logic model and refining the survey instrument. Additionally, adopting this framework involved Aboriginal community researchers undertaking research thus contributing to community capacity building as opposed to the benefits being granted to the researcher alone (18). Including the KLNP committee in the logic model design and adaptation of the survey contributed to building their knowledge in evaluation design including data collection. Additionally, training the community researchers in administering the survey assisted in building their research skills and knowledge.

Figure 8. Model of Engagement

Source: de Crespigny, Emden, Kowanko & Murray (2004) (15)

The research components undertaken included a program logic model and community engagement workshops. The process of co-developing the logic model for this study had multiple benefits, including identifying community priorities and including these in the evaluation design, using the logic model as a communication tool with stakeholders, and assisting in the adaptation of the survey instrument for data collection.

4.3.2 Evaluation design

The SCfC program aimed to build community and social cohesion through program activities that build pride and commitment to Thamarrurr culture. The intended evaluation design was a pre–post survey; however, this was not feasible due to time constraints and other contextual factors. Therefore, the quantitative survey (Appendix 8, SCfC survey) aimed to establish information on baseline levels of cultural participation and expression, and associations with health and wellbeing, to support ongoing monitoring and evaluation of the SCfC program. To achieve this, the quantitative survey collected information on cultural practices and expression, social factors and health and wellbeing from participants in the SCfC program. Qualitative inquiry with the SCfC participants assisted in contextualising these components. Bringing together these complementary data on the same topic provides a better understanding of the core components of the program (5).

This chapter focuses on the process of co-developing the evaluation (process evaluation). The study design was intended to capture a comprehensive picture of the program activities implemented under the SCfC program, including how these link to community priorities. This included the following processes:

- Developing a logic model
- Refining the survey instrument
- Implementing the survey
- Group questionnaires.

These processes are described in the ‘Results’ section.

A process evaluation was adopted and included mixed methods and CBPR approaches. A two-pronged approach (3) was adopted for the design: an epidemiological (epi) study collecting baseline information on culture and wellbeing from the participants in the SCfC program, and qualitative inquiry through group interviews with participants to establish how their participation in the SCfC program supports cultural participation. The study team included Aboriginal researchers.

4.4 Ethics

Ethics approval for the study was received from the Australian National University Human Research Ethics Committee (Protocol 2018/096).

4.5 Results

4.5.1 Community engagement workshops

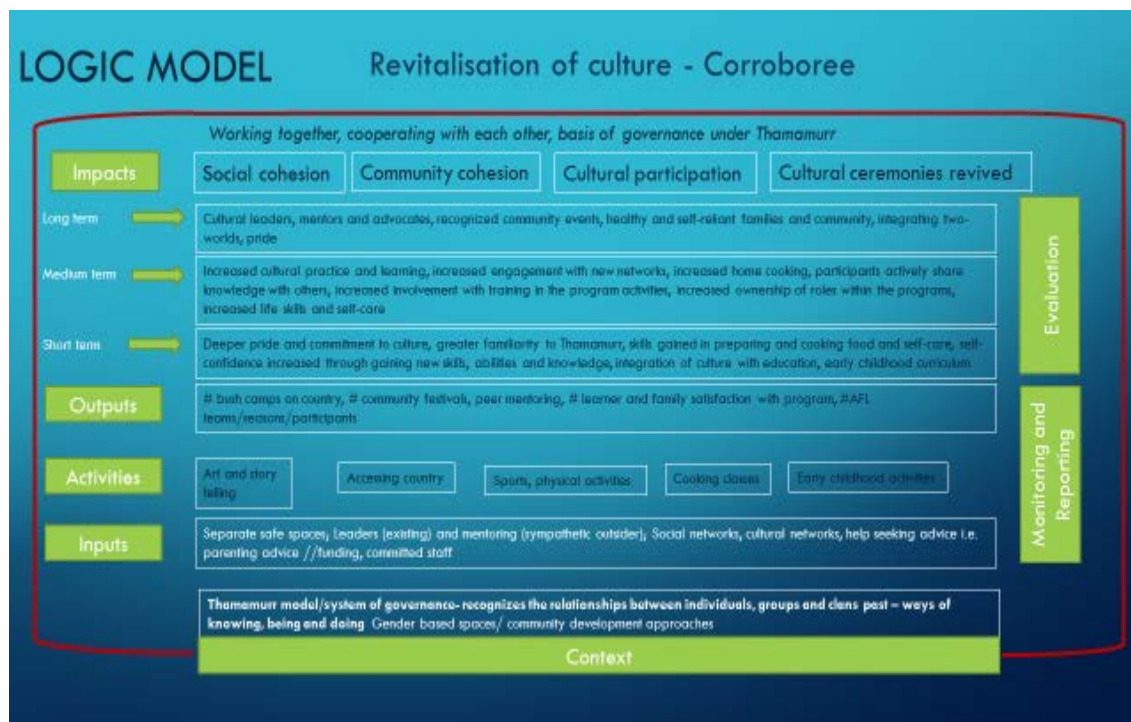
PWAC contacted the ANU to undertake a process evaluation of the SCfC program. An initial engagement workshop between ANU, PWAC and the KLNP committee was undertaken in September 2017. An ANU research colleague facilitated the workshop to determine the scope and foundation of the evaluation. Community engagement workshops took place in January 2018 between the ANU research team, the KLNP committee, community and the SCfC program coordinators. These were driven by CBPR principles that fostered partnership between the community and the ANU and facilitated knowledge co-production (19). Undertaking this process was paramount to establishing a respectful relationship, based on reciprocity and trust. As the ANU researchers were external to the community, the trust-building component was essential and supported the CBPR approach. Information from the workshops assisted in the development of the program logic model (see details below) and study design (see Figure 6, Timeline).

4.5.2 Co-developing a program logic model

Evaluating health and social programs to establish the drivers of change can be seen as complex and involves an element of ‘messiness’, meaning that the social realities in

which programs are implemented are influenced by social environments that affect participants in a program and staff of organisations implementing the program (20, 21). Program logic models are a common tool used in evaluations; they provide a visual representation of how the program is intended to work within a given setting and how the program is intended to achieve outcomes and other future changes or impacts for the participants in the program (22). The tool can be used to design a program, direct an evaluation or contribute to planning and monitoring the program at the service delivery level (23). Additionally, it is a practical tool that can remain a living document that can be updated to reflect changes affecting the program, such as changes to program activities, workforce, infrastructure or external factors such as funding arrangements (23, 24). I integrated Indigenous knowledge and worldview to design a culturally appropriate visual tool for the SCfC program in Wadeye (see Figure 9 and 10). The approach of integrating Indigenous worldviews into program logic model design has also been adopted in the Māori evaluation context (25).

Figure 9. Original SCfC program logic models



The program logic model was a key tool to guide the evaluation and was developed in partnership with the KLNP committee, PWAC and the SCfC program coordinators. Using the model assisted in dissecting the SCfC program to gain a deeper understanding of the community perspective on the program, thus creating a tool that is authentic to the context and embraces Aboriginal knowledge and systems. To achieve this, I undertook an initial workshop with the KLNP committee and program coordinators, to grasp a better understanding of the social realities and what they understood the program to be. I then followed up with further feedback sessions with the KLNP committee during field visits in May and June. Combining community perspectives with a review of contract templates and other grey literature about the program and community, such as community newsletters, and of government and evaluation reports, contributed to understanding the social layers of the community. I combined these various pieces of evidence and synthesised the information to create a visual picture of the SCfC program within the Wadeye context.

Additionally, a requirement of the logic model was to represent a design that could be translated to the KLNP committee and the program coordinators. We started with a standard model; however, we changed the flow to factor in the program's movement to impact and measurements of change. The model became very word heavy and needed further adaptation to account for the differences in language. A visual design with animation was the end result and captures the community context.

Figure 10. Revised logic model

4.5.3 Co-designing the quantitative data collection instrument

Outcomes from the initial engagement workshop in September 2017 confirmed that an Aboriginal research team would undertake the evaluation and that an adapted version of the validated survey instrument from the Mayi Kawayu (MK) study would be appropriate for the evaluation (26). Community input contributed to the adaptation of the survey instrument and I then tested the survey with the community. After receiving feedback I finalised the survey (Appendix 8, SCfC survey). The survey was intended to be administered by locally trained community researchers to collect baseline information for the SCfC program. I developed a Community Researcher Manual (Appendix 9, Community Researcher Manual) and co-facilitated the community

researcher training with an ANU colleague. The training workshop included the community researchers and program coordinators and explored administering the survey and ethical protocols such as participant information sheets and consent forms.

4.5.4 Qualitative inquiry

Two interviews were undertaken with participants from the women's cultural program and the men's shed program, providing their insights on the SCfC program. Yarning (27, 28) as a method was used in the interviews, and an interview guide helped to facilitate the discussion (see Appendix 10, Interview Guide, Consent Form and Participant Information Sheet). Notes from the interviews were taken by the researchers facilitating the session. To address gender protocols and ensure cultural appropriateness and safety, I facilitated a group interview with five of the women participants and a male colleague facilitated an interview with a male participant. I analysed the data thematically. The group interviews with the women revealed that their cultural program facilitated learning, passing on culture to children and coming together with different tribal groups. In the program they do weaving and other crafts. The PWAC Art Centre has a retail site in Wadeye, where the women can sell their art and craft through the shop and at festivals they attend outside Wadeye. Going out on to country and camping was seen as a way to connect with ancestors and do corroboree dancing. Comments included

*Day trips to collect the plants for weaving we call out to the ancestors
to let them know we are there.*

*Corroboree, peaceful way, dancing and connecting with ancestors,
feeling good.*

The women wanted the children to learn about culture and thought that the school should bring the kids to the art centre to learn more about culture from the old people.

The men's shed program participant discussed that the men had a place to come together, to do art and craft and to make furniture. It was a space to share stories and

culture and a place where they could learn from one another. Young men were coming to learn and ask questions from others who were in the program and when they wanted to avoid community fighting. The participant said:

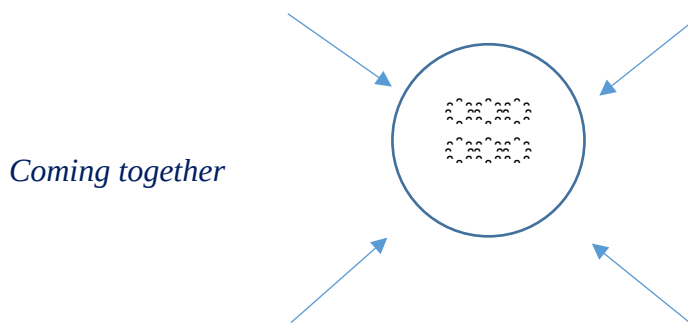
To keep out of mischief, violence and getting away.

He felt a lot of pride when making things, which could be tables, chairs, clap sticks, spears or a painting. He described the men's shed program as:

Just men getting together and talk good, bit sad

Men are happy to come and have health checks from the men's shed. The diagram below was developed in the interview by the researcher, to reflect what the participant was saying about 'coming together' being an important component of the Men's shed program.

Figure 11. Men's shed interpretation of 'coming together'



Findings and interpretations from the engagement process and qualitative inquiry show that there is a distinct understanding that the KLNPN committee and the female and the male participants see culture as an important factor of the SCfC program and the activities associated with the program. There were several major themes that came out of the two qualitative sessions:

- Pride
- Corroboree and culture
- Arts and crafts

- Coming together (social and community cohesion)
- Learning and teaching.

4.5.5 *Implementation of the survey*

Community researchers and program coordinators were trained and delivered the survey over two months, twenty one surveys were completed. We trained eight community researchers and six program coordinators to administer the surveys, including administering the research protocols such as consent forms and participant information sheets. These data will be used as a baseline for ongoing monitoring and evaluation (not included in this process evaluation).

4.6 Discussion

Culture and the way it is articulated through expression and practices is a key component of Aboriginal people's being, it is fundamental to their ways of knowing, being and doing (29). A main driver underpinning the Wadeye community is the thread of culture and, in particular, corroboree. Corroboree is recognised as a way of 'being, knowing and doing' for the local Aboriginal people in Wadeye, to connect with their ancestors and create a sense of harmony (29). The community has experienced many social changes over time such as access to the internet, people leaving the community to advance their education and employment opportunities, and people leaving the community as a result of interactions with the justice system (13, 30). These experiences have contributed to the changes seen within the traditional systems and cultural expression and people not practicing certain cultural ceremonies. Further, changes create a layer of contestation to the cultural structures and practices (11). The elders and community leaders in Wadeye want culture, particularly corroboree, to remain strong, and believe these practices need to be learned and practised by the younger generation. Boredom was identified as a contributor to the social disharmony experienced in the community and practising culture and corroboree was identified as a way to address social and community cohesion.

Connectedness to culture and country is also a key element for community functioning, where the things that people value, their ways of knowing, being and doing, translate to their freedom and choice of participation (31, 32). Having the freedom to articulate their understanding, knowledge and skills translates to capabilities and action to live a good life (33, 34). Capabilities are fundamental in providing a platform for people to make decisions that enhance their health and wellbeing and assist them to participate in mainstream functions such as education, employment, parenting and maintaining health and wellbeing. Evidence is growing in this space, connecting culture and wellbeing outcomes (35, 36). Concepts of connectedness to culture and wellbeing are often described as innate to Aboriginal people, and the role that caring for country plays in health and wellbeing outcomes is being captured in data collection through surveys that reflect the necessary and appropriate data items (26, 37). The MK study is an example of this where data items were developed through a community engagement process and validated through Indigenous worldviews, perspectives and lived experience (26).

There are differences between Aboriginal and western notions of wellbeing and social structures (38). An Aboriginal worldview on health and wellbeing is holistic and includes spirituality, connectedness to culture, community and traditional beliefs and values (38, 39). With the growing body of evidence exploring the association between culture and wellbeing, concepts and values that are important to Aboriginal and Torres Strait Islander peoples' wellbeing are being captured. These include being out on country, hunting, dancing and caring for country (37, 40). Further, these activities reflect how people participate in culture and knowledge sharing.

The power of connectedness to culture cannot be underestimated. Aboriginal people link their wellbeing to community, country and a sense of belonging (26, 31, 38). A recent study of a ranger program in Central Australia where the MK survey was administered to collect information on culture and wellbeing outcomes. The study found that exposure to participating in the program had two important wellbeing outcomes: very high life satisfaction, and high family wellbeing. It was hypothesised that increased

cultural engagement and expression through the ranger program could explain the associations with improved wellbeing outcomes (35).

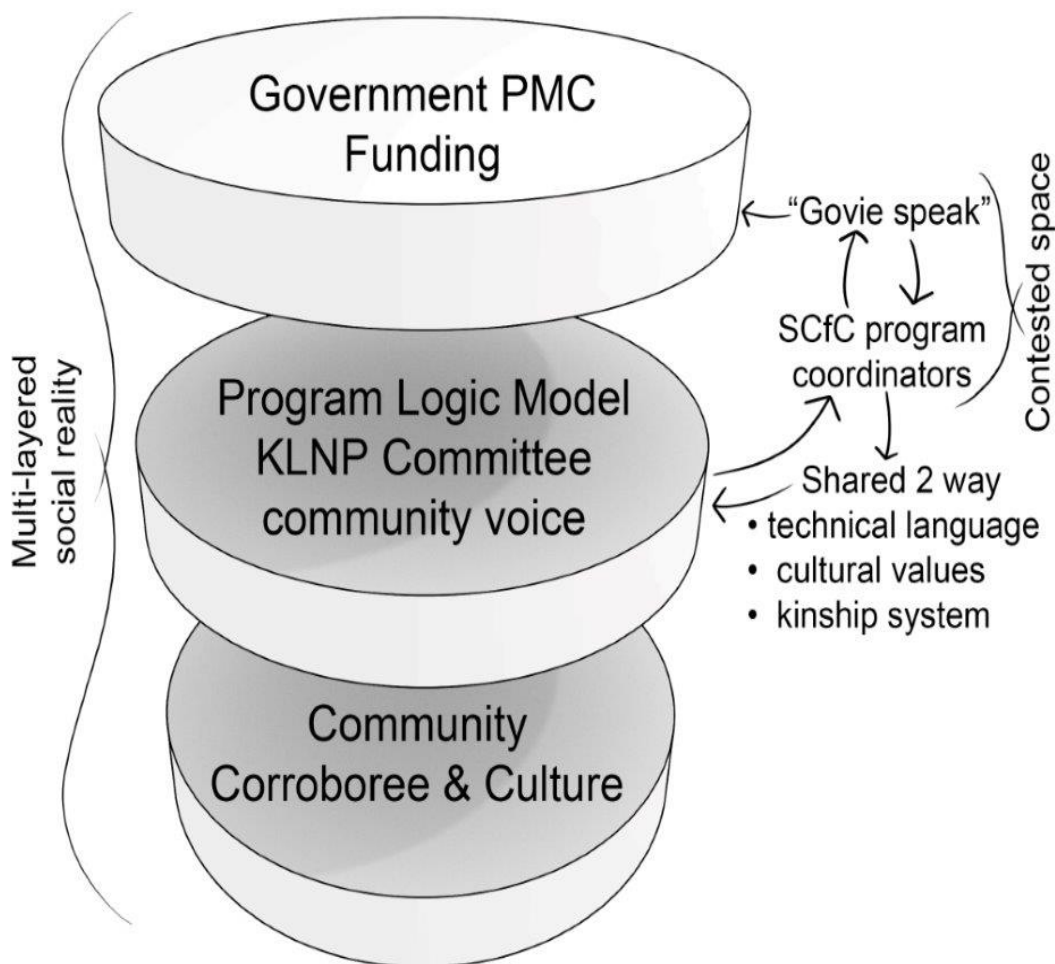
The *Interplay Wellbeing Framework* draws on local priorities and ownership to assist with improved community wellbeing. The study draws on validated measurement tools that have cultural validation and cultural indicators relating to health, community, education, culture, work and empowerment (41). Culture, empowerment and community were found to play a key role in education, employment and health. These findings also support a holistic and quantifiable approach to understanding wellbeing within an Aboriginal and Torres Strait Islander context. Together the *Interplay Wellbeing Framework* and survey provide a foundation that supports local priorities and community engagement to achieve better wellbeing outcomes at the local level (42).

A study with the Yawuru people in Broome, Western Australia, uses community participatory approaches to explore wellbeing, thus establishing a conceptual framework relevant to the Yawuru people's core values and how they aspire to achieve wellbeing. The major themes established were relationships, family and connection to country and culture. These were seen as assets and important measurement indicators for wellbeing in the Yawuru context (34). This study contributes to understanding how Aboriginal people within their community context understand what a good life means to them, highlighting meaningful wellbeing and cultural indicators that can be measured quantitatively at a community level.

The integration of the literature, engagement workshops and qualitative inquiry reveal that culture, including corroboree are fundamental contributors to wellbeing, social and community cohesion and are assets that are valued by the community. While these concepts are clear for the KLNP committee and PWAC in directing the SCfC program, there is a tension between the policy aspirations and predetermined outcomes for the program. This is not a new topic of debate in the Indigenous affairs space (32, 43, 44). Further, imposed performance indicators, unstable funding modalities and organisational competitiveness in acquiring funding contribute an added layer of tension and uncertainty for programs and their ability to change (43, 45). This also reveals a

‘contested space’ where the production of community evidence and scientific knowledge have differing agendas and contexts (46, 47). This is reflected in the model below.

Figure 12. Complexity model



The model depicts the intercultural space with ‘fuzzy boundaries’ (48 p.87) where the program coordinators are divided between addressing performance indicator reporting or ‘govie speak’, while adhering to the needs of the community. The model represents my interpretation of the SCfC program within the community context and has been informed by a combination of the grey literature and my observations in the field. The contested space in the model reflects the fuzziness in boundaries and reveals some of

the complexities of the SCfC program in Wadeye. Funding decisions remain the purview of the policy body, whose primary goal is to meet early childhood outcomes. The program logic model symbolises the community voice and Indigenous worldview of the participants and community. Further, the KLNPN committee view corroborates, culture and building the capacity of community members, particularly the younger generation and others (young adults), as relevant to achieving social change and meeting the higher level aspirations of early childhood outcomes.

4.6.1 Limitations

Government funding cycles create much confusion and uncertainty, impacting on the SCfC program's contribution to social change and meeting community priorities. My engagement with the PWAC was cohesive and coordinated throughout the study period. As a partnership, we had an understanding of how the evaluation would unfold, a timeline in place, regular teleconferences and correspondence and a confirmed process relating to recruitment and training community researchers to administer the survey to collect the information required for the evaluation. However, unknown funding arrangements impacted on the recruitment of participants and resulted in incomplete surveys for many of the program activities under the SCfC. Further, changes in the operational team were apparent, the CEO and SCfC coordinator both resigning due to the uncertainty of ongoing funding.

The concept of community members undertaking research in communities is supported with CBPR frameworks and can work well (4). However, I found that competing timelines, being external to the community, funding uncertainty and numeracy and literacy levels reduced the ability of the community researchers to administer the survey. Additionally, the change in study design was affected by external challenges relating to funding decisions. Originally I wanted to compare participants in the SCfC program and non-participants, to explore the difference made by the SCfC in supporting cultural participation, and to explore the relationship between cultural participation and wellbeing. A pragmatic approach was required when the cohort approach was not

feasible. I was required to default to a case series design, which falls lower in the hierarchy of evidence.

4.6.2 Recommendations

A summative evaluation to collate information on the overall impact and effectiveness of the SCfC program would be a next step. Administering the same survey to capture more participants in the different SCfC program activities and more non-participants should also be included in the study design. The survey could then be provided to new participants in the program and to those who drop out of the program, thus providing service delivery with a mechanism to monitor and evaluate participation. This intended study approach will have the ability to measure change over time and collate evidence that can inform SCfC program activities at the local level and the SCfC collective impact framework. More importantly, the study would provide an opportunity for the Wadeye community to have ownership of local level data that can contribute to community-led decision-making.

A proposed study that includes a mixed methods approach could explore:

- To what extent does the SCFC program support cultural participation through the established program activities?
- How effective were the original design of the SCFC program and the program activities in capturing participation?
- To what extent have activities evolved and changed?
- Has implementation proved to be effective enough to merit further funding and extension of the program?

Further community researcher training would be required for the summative evaluation. This would require a collaborative approach and commitment from the program coordinators.

4.7 Conclusions

Complexities in evaluating policy-driven programs within remote setting such as Wadeye, require consideration of historical experiences relating to trauma; large amounts of government activity in the form of programs, funding and service delivery at the Commonwealth and state levels, multiple organisations competing for funding; and layers of social challenges impacting on the community, such as community violence, mental health, substance misuse, cycles of poverty and unemployment (13). Acknowledging the contested spaces of policy versus community perspectives is important. Often indicators of the program are decided without community input and there is a reliance on performance reporting data (43). The implications of this is that there is a reliance on organisations to be directed by the reporting requirements but not having tools to measure change. Cohort study designs have this ability. To capture measurement of items that are meaningful to the people, families and community is important and can help to inform the policy as to what can work. This requires a balance of western notions and Indigenous worldviews, and acknowledging that culture is integral to wellbeing.

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Chapter 5 Teaching

Masters of Applied Epidemiology: course requirements

- Lessons from the field
- Teaching to 1st year MAE cohort

Prologue

My role and lessons learned

The Masters of Applied Epidemiology (MAE) requires scholars to facilitate two teaching sessions, a ‘Lessons from the field’ and teaching to the first year MAE cohort. My two teaching experiences involved teaching about program logic models. I first came across program logics in my evaluation study. I found it a practical and engaging tool for the study, and while I am a novice, I recognise its value in evaluation practice. The lessons from the field session aimed to teach to my peers the necessary components of developing a program logic model for the purpose of directing an evaluation of the MAE program. I discovered through my learning that program logic models can be time-consuming to develop, particularly when including other stakeholders in the design. There are also other factors to consider in the model, such as theory of change and exploring the assumptions of a program relating to the outputs, outcomes and impacts. Due to time constraints with the lessons, the level of prior knowledge and keeping the content easy to follow, I did not include the theory of change or the assumptions within the logic model. My main aim was for the scholars to understand the role of a logic model in an evaluation and the core components contributing to the model and to identify the relevant information and design a logic model.

The lesson of teaching to the first year MAE cohort was a group lesson with two other colleagues, Cushla Coffey and Jana Sisnowski. The group session aimed to facilitate a basic understanding of program logic models relating to evaluating health interventions and required the group to contribute to the development of a logic model.

5.1 Lessons from the field

5.1.1 *Learning objectives*

- To describe what a logic model is
- To identify when a logic model might be useful
- To construct a logic model to direct an evaluation

5.1.2 *Scenario*

As a team we have been tasked with evaluating the MAE by the ANU. There is limited baseline data available on overall program outcomes, however there are data available on completion of coursework. Our first cohort will be the 2016 cohort to capture baseline data, given they have completed the MAE. Our aim is to produce a program logic model to inform the direction of the evaluation.

5.1.3 *Lesson*

The ‘lessons from the field’ session included reading material and a video for the scholars to watch to assist them with their learning. They were provided with a series of questions and activities to address based on the learning. This approach was helpful to evaluate who had grasped the main concepts of developing a logic model with the answers to the activities provided by the scholars. In developing up the lesson, the following criteria guided me:

- Complexity of concepts
- Time required to complete the reading and video
- Time required to complete the lesson exercises
- Relating the learning to a topic familiar to the scholars

A one-hour Zoom webinar was conducted to provide feedback to the group. All appropriate answers were collated into one logic model to include the scholars’ contributions. I facilitated the conversation with my peers on the development of the

model, allowing each person to provide input into the discussion. During the webinar we also discussed other relevant stakeholders who could provide input into the model. Additionally, identifying evaluation questions for the evaluation was included in the lesson.

Overall I felt comfortable with the delivery of the lesson and that the amount of content was sufficient to meet the learning objectives. Zoom provided an interactive platform to facilitate peer learning, and I had the capability to share the PowerPoint to guide the lesson. I also felt that my peers were engaged in the session and I received positive feedback from them. I chose to not undertake a survey to evaluate the lesson, as there were only three participants. The lesson plan and activity is at Appendix 11.

5.2 Teaching to the first-year MAE cohort

The opportunity to teach to the first year MAE cohort was a little daunting however working collaboratively to co-facilitate the session was fun. Taking into account that the first-year scholars had been in three weeks of intensive learning for the start of the MAE program, our main objective for the lesson was to be easy to follow, have interactive and engaging with the activities and not to be too demanding on the brain. The flow of the session provided an overview and challenges of public health interventions. We then moved on to the design and purpose of developing logic models. Each component of the logic model included examples. To consolidate the learning into practice, we engaged the scholars to contribute to developing a logic model. To achieve this, we provided a scenario of a public health intervention. The intervention was an advertisement for the Olympic Games in Russia which involved doing 20 squats in front of a train ticket machine. If you achieved the 20 squats you received a free train ticket. We thought it was a novel approach to increasing incidental physical activity and have convinced Canberra to introduce this scheme for its buses and the new tram. After showing the YouTube video of the initiative, we invited the scholars to get up and perform 20 squats. They were then allocated into groups and were required to contribute their ideas on the initiative into a logic model. My colleagues and I had developed a basic, incomplete, pipeline model with only the headings: ‘Inputs’, ‘Activities’, ‘Outputs’,

‘Outcomes’ and ‘Impacts’. The task for the scholars was to write up their answers and allocate them to the appropriate section of the logic model on the sticky notes provided.

The session was evaluated using an online survey tool, Survey Monkey. The majority of the learners rated the content, presenters’ style and format of the session being useful and highly useful.

Figure 13 First year MAE responses to the usefulness of the content in the lesson

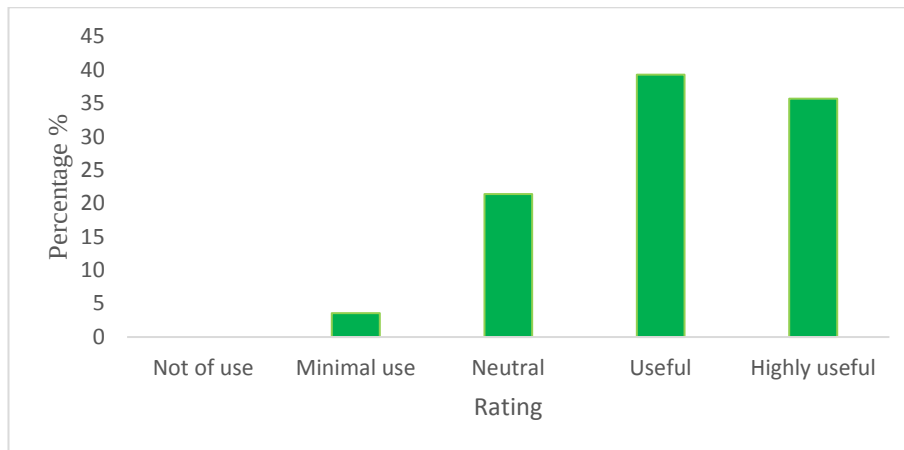


Figure 14 First year MAE responses to the presenters’ style of teaching the lesson

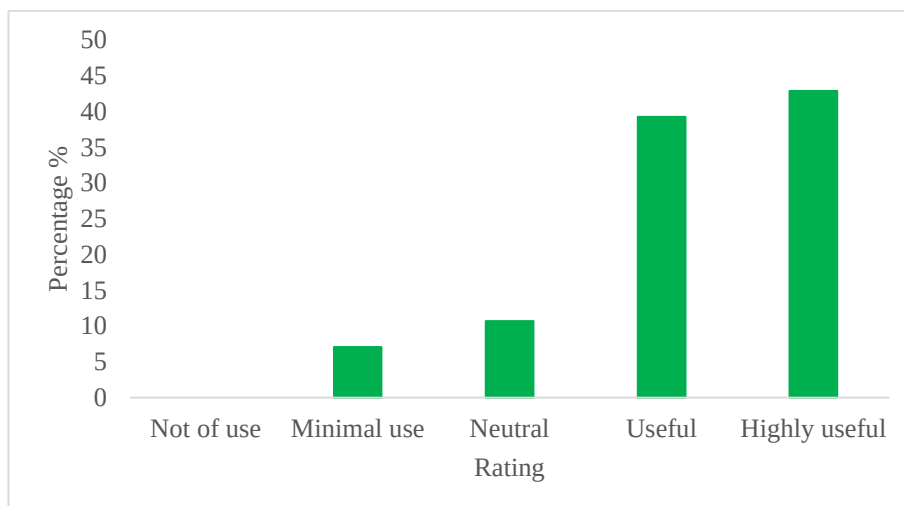
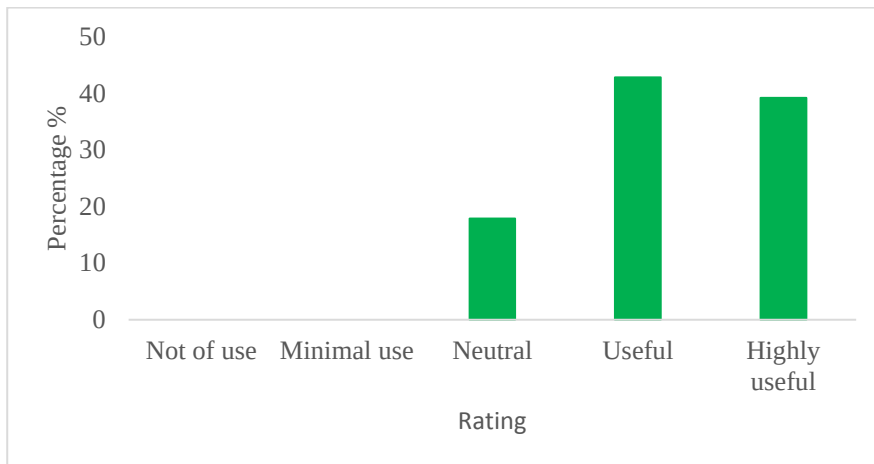


Figure 15 First year MAE responses to the format of the lesson

The overall session was engaging, fun and interactive. The energy of the scholars lifted during the interactive components of the session and they all participated and were engaged in the session. Additionally, placing the scholars in groups provided an opportunity for them to enhance their team-building skills. Please refer to Appendix 12 to review the PowerPoint of the session and results of the evaluation.

Appendix 1 – 12

Appendix 1

ABSTRACT

Background: There is growing awareness nationally that building local community capacity is important in outbreak responses. A recent mumps outbreak in an Aboriginal community in Qld, provides valuable insights into the benefits of partnership with the local Aboriginal Community Controlled Health Service's workforce to undertake an outbreak investigation. The community's vaccination coverage is high, yet the community experienced a rise in mumps cases, December 2017 – March 2018.

Method: Case notifications were extracted from the *Communicare* patient information system at the local Aboriginal Community Controlled Health Service. A questionnaire was co-designed and administered with Aboriginal Health Workers (AHWs) to follow-up cases, establish severity of symptoms, knowledge on mumps, contacts and overcrowding.

Results: There were 36 confirmed cases and 25 probable cases from December 2017 to March 2018, the index case presented in December 2017. Over half of all cases were aged 5-19 years (n=41/61), and 62% (n=38/61) were males. The AHWs were instrumental in facilitating a pathway between myself and community members, assisting in additional data collection, locating cases in the community and enabling culturally respectful and safe data collection. Adapting the follow-up questionnaire to include the social determinants of health provided further insight into barriers impacting on reducing transmission. Collecting local level information provided further insight into barriers impacting on reducing transmission. Further, the AHWs could transfer their current skill set of contact management and clinical engagement to an outbreak investigation setting.

Conclusion: The public health importance of outbreak investigations in Aboriginal communities have implications beyond the outbreak. Epidemiologists working in these settings are required to have skills in building working relationships, trust and respect with the community, clinic and government health service is paramount. Engaging with the community and working in partnership, primary health care settings and public health units could develop infection control strategies that consider the local community and social context. AHWs were vital in the follow-up of cases. There is an opportunity to build and utilise the capacity of this workforce to assist in responsiveness to outbreaks in communities where resources are limited. Further, outbreak investigations also prompt us to evaluate and question 'how can we do this better next time?'

Key words: Mumps, Aboriginal, Vaccination, Aboriginal Health Workers, Community Outbreak, Aboriginal Community Controlled Health Service, Community Engagement

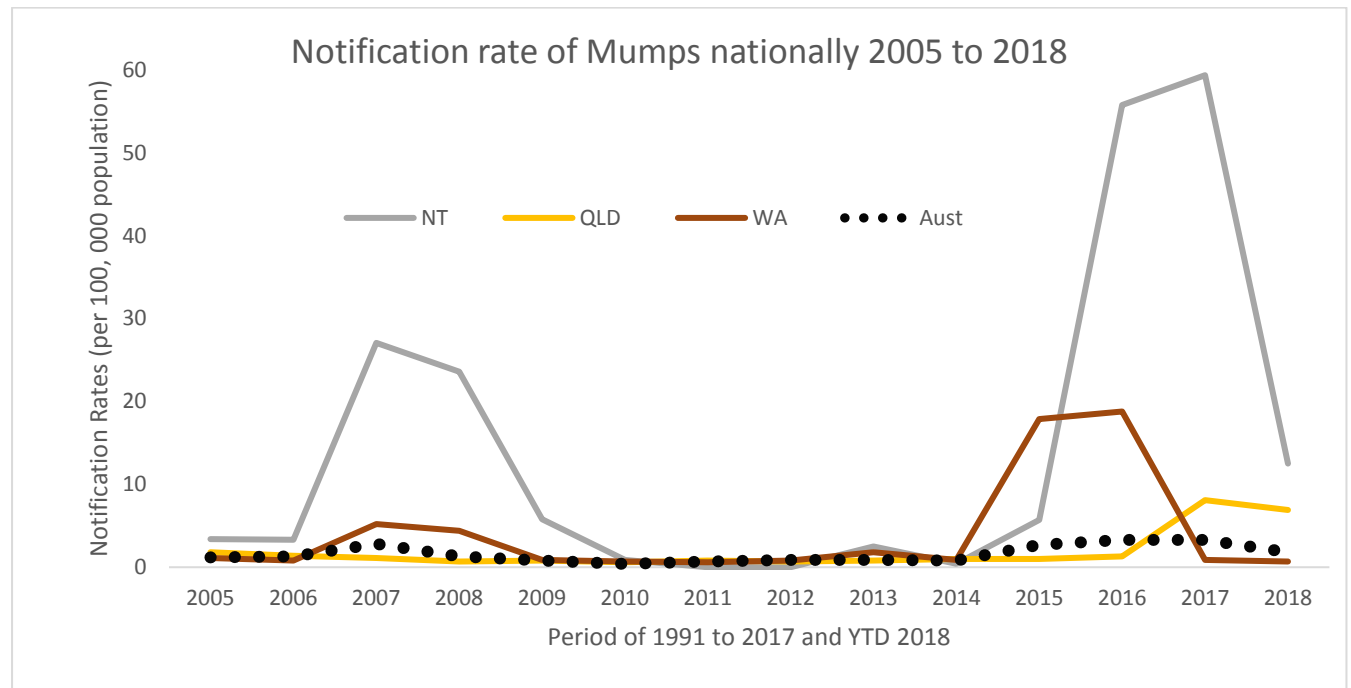
Introduction

Mumps is a vaccine preventable infectious disease caused by the paramyxovirus (1, 2). Characteristics of mumps include swelling of the salivary glands, or parotitis, affecting one or more glands. Transmission occurs through direct contact and the incubation period is between 12 and 25 days. The most infectious time is from 7 days prior to any onset of parotid swelling to 9 days after; asymptomatic features are common during this time and transmission can occur unknowingly (1, 3). Though mortality and morbidity outcomes are low overall, a number of rare complications can result such as encephalitis, orchitis and meningitis. These complications can have serious implications, including negative affect on fertility, and require hospitalisation.

The mumps vaccine was first introduced in Australia into the National Immunisation Program in 1980 and a second dose was added in 1992 (4). The vaccine is referred to as the MMR vaccine. A first dose is recommended for children at 12 months and a second dose at 18 months (5). The MMR vaccine contains the genotype A Jeryl Lynn strain, a live attenuated strain of the mumps virus (6).

Australia is experiencing a resurgence in mumps virus notifications. Data from the National Notifiable Disease Surveillance System (NNDSS) captures a trend in rising notifications in the total population, predominantly in the NT, Western Australia (WA) and Queensland (Qld) 2006-2010 and 2014-2018 (Figure 1). The NNDSS notification data, indicate a rise in notification rates in WA from 2014 to 2015. A similar pattern is seen in the NT from 2015 to 2017. An increase in Queensland notification rates is indicated in 2016 to 2018 and potential links associated to cases in the NT outbreak. The total number of notifications is higher in WA and Queensland, compared to the NT where the population size is smaller than the other jurisdictions.

Figure 1. Notification rate of mumps 2005 to 2018 (NNDSS) (per 100,000 population) in NT, WA, WA and Australia.



Source National Notifiable Disease Surveillance System (7)

In 2007-2008 the Kimberly region in northern WA experienced a prolonged outbreak of mumps and 92% (n=141/153) of cases were Aboriginal (6). The NT also experienced increased mumps notifications around this time and epidemiological links were made to the WA outbreak (8). Later, in 2015-2017, a mumps outbreak in the Northern Territory (NT) reported 92.2% (n=261/283) of cases were Aboriginal people (2). The majority of cases in the identified outbreaks were between the ages of 10 to 19 years of age (2, 6, 8). The rise in mumps cases despite effective immunisation campaigns has occurred recently in other first world countries ((8, 9). Characteristics common among mumps outbreaks globally and nationally include associations with institutional settings, such as high schools and universities, and with close-knit communities (6, 10-12). The US experienced large outbreaks in university settings where vaccination coverage was high, affecting university students, staff, and community members. Social mixing, close contacts and shared housing are likely to have contributed to the propagation of the outbreak (12). Similar social contexts have also been recorded in Israel, Guam, New Zealand, and Australia (2, 6, 11, 13-17).

Aims

1. Describe a mumps outbreak in a Qld Aboriginal community. The outbreak started in December 2018, the study period was between December to mid-March 2018, and 61 cases were identified via the Aboriginal Community Controlled Health Service's (ACCHS) patient information system. As of July 2018, the outbreak is continuing; and
2. Share the lessons learned from this mumps outbreak investigation; contribute to the existing body of knowledge recommending respectful engagement with Aboriginal communities during outbreak events; reflect on barriers that impact on preparedness and timely responsiveness for emerging outbreaks in community settings; and share strategies to minimise transmission within close-knit Aboriginal community settings.

Methodology

Within ACCHS settings, Aboriginal Health Workers (AHWs) provide unique cultural brokerage skills that are used in the clinical and community settings. During the outbreak investigation, the AHWs provided cultural brokerage between the trainee epidemiologist (BM) and community members during the outbreak investigation. This was particularly relevant for locating cases in the community, administering a follow-up questionnaire to cases and building trust between BM and the community. The AHWs contributed to the design and adaptation of standard epidemiology tools, such as the follow-up case questionnaires. The questionnaires were adapted to address health literacy levels and framing clinical questions to be aligned with the context of the community. Harnessing this model of practice to promote community engagement at the local level supported cultural safety and appropriateness during the investigation. Health service data was extracted at the service level from the ACCHS *Communicare* patient information and recall system and was the primary source of data used to describe the outbreak.

Material and Methods

Context

In December 2017, an index case of mumps was reported in an Aboriginal community, in the far northern Qld region. The 2016 census recorded the population of the community at approximately 2,600 people, with 97.3% of the population being Aboriginal and/or Torres Strait (ref). Tropical medicine and public health services are provided by the Cairns Tropical

public health services to the far northern Qld region. Primary health care services are provided through the local ACCHS in the community. The ACCHS was the first in Queensland to transition from a state run clinic to Aboriginal community control in 2014. The ACCHS provides culturally appropriate primary health care to the community and extended family from Cairns and the surrounding region who travel to the community for health services (18). A state run Emergency Department, serviced by Qld Health, provides after hours services and shares the same building as the ACCHS.

Study period

We analysed mumps notification data on the ACCHS *Communicare* system from December 2017 to 12 March 2018. Follow-up questionnaires were administered to confirmed cases during the outbreak investigation period 12 to 22 March 2018.

Outbreak investigation

Health service data

We extracted data from the health service's *Communicare* system. The data was coded as confirmed and unconfirmed, and using date of onset information we collated the data to create an epidemiological curve. The epidemiological curve provided a visual picture of the overall amount of notifications and the time cases had heightened in the community. The epidemiological curve was used as an education tool for the AHWs and other clinical staff.

Questionnaire

The AHWs and BM adapted the mumps case follow-up form (sourced from the Australian Capital Territory (ACT) public health unit), into a questionnaire (Appendix A) that ensured cultural appropriateness and literacy levels were addressed. The AHWs guided this process and cross checked information in the questionnaire with other team members. We adjusted standard public health questions relating to the duration of illness, level of understanding of public health information, contact history, immunisation and travel history. This included adjusting the use of clinically focussed questions to language that was relevant to the community context and literacy levels. We added social environment questions to identify the number of bedrooms in the house, number of people in each bedroom and faulty taps. Facial diagrams were also included for cases to identify the area where symptoms of swelling were experienced. The questionnaire was administered to a small number of cases at different time intervals of the outbreak.

Queensland Health Notifiable Conditions System

Queensland Health guidelines require that notifiable diseases are laboratory confirmed. These notifications are then reflected on the NOCS. The ACCHS took throat swabs from cases for the period 15 December 2017 to mid-February 2018. This practice is considered standard public health practice in outbreak investigations, particularly when there are a sufficient number of confirmed cases (19). After this time, cases presenting at the health service with clinical symptoms and an epidemiological link were considered confirmed cases, as per public health advice. These cases were not captured on the NOCS, as Queensland positive pathology is automatically notified to the NOCS, to reduce the burden on primary health care staff.

Data analysis

The outbreak investigation was undertaken over a two week period. We analysed de-identified data from the *Communicare* patient management system at the ACCHS. This data was analysed to describe the outbreak and was the primary source of data, as access to the NOCS data was denied due to Qld Health internal administrative processes and approvals.

Immunisation status

Immunisation status was not included in the analysis, due to unavailability of complete immunisation data to cross check cases with information from the Australian Immunisation Registry or the Vaccination Information and Vaccination Administration System in Qld. The data was analysed using Microsoft Excel.

Ethics

Ethics approval from the Australian National University Human Research Ethics Committee, Protocol: 2017/909 was granted to undertake the outbreak investigation.

Results

The index case was from the community and was identified in December 2017. Cases continued to present at the local ACCHS after December 2017. Overall 61 cases for the study period 1 December 2017 to 12 March 2018, included 36 confirmed cases and 25 unconfirmed cases. Over half of all case-patients were aged 5-19 years ($n=41/61$), and 62% ($n=38/61$)

were males. Symptoms included bilateral swelling 34% (n=21/61) and unilateral swelling 66% (n=40/61).

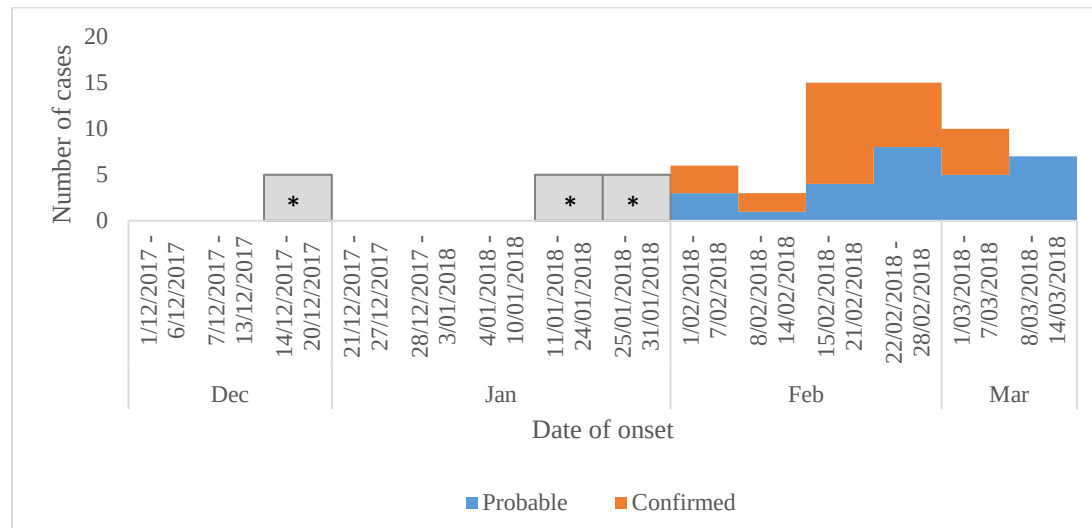
We collected questionnaire responses (n=15/61) from cases during the outbreak period, the median days of illness were 8.3 days. The table below includes a summary of the questionnaire results.

Table 1. Results from the follow-up questionnaire

Age range	# of surveyed cases (n=15)	% of surveyed cases
<i>5-19 years</i>	10	67
<i>20-29 years</i>	2	13
<i>30+ years</i>	3	20
Social characteristics		
<i>Overcrowding – more than two people in one bedroom</i>	9	60
<i>Travel – had travelled outside of the community or had visitors to the community</i>	5	33
Environmental factors		
<i>Faulty taps</i>	5	33
<i>Smoking in the home</i>	1	7
Clinical characteristics		
<i>Hospitalisation</i>	*	7
<i>Immunisation status – were fully immunised</i>	10	67
<i>Had contact with an infected case</i>	7	47
Laboratory testing information		
<i>Swab taken</i>	13	87
<i>Results confirmed</i>	11	73
Knowledge		
<i>Type of information received</i>		
• <i>Pamphlet</i>	6	40
• <i>Verbal</i>	5	33
• <i>Self-research</i>	1	7
• <i>Missing information</i>	3	20
<i>Understood the information relating to mumps, transmission and isolation</i>		
• <i>Yes</i>	13	87
• <i>No</i>	2	13

*small cells (n ≤5) are confidentialised to protect patients' privacy

Figure 1. Epidemiology curve of mumps cases in the Qld community December 2017 to March 2018



**small cells (n ≤ 5) are confidentialised to protect patients' privacy*

Discussion – marrying the system and setting

Usual public health practice requires public health units to monitor notifications and manage outbreak events, including communication and raising community awareness, active case finding and introducing control measures to reduce case numbers (20). Access to notifiable disease data during an outbreak event provides insight into the frequency of notifications within a population and can assist in understanding the severity and impact at the local level. These data are easily accessible within public health units; however, they are more challenging to access for those working in a primary health clinical setting. Primary health clinics are not designed to lead outbreak investigations as they generally do not have the health hardware or workforce with epidemiological skills and public health practice. Two of the people whose case we followed up reported not understanding the information provided by clinicians. This could reflect the extra demand of increased number of cases presenting to the clinic on top of their usual primary health care core business and quality of service delivery being compromised. *Communicare* system is a patient information system and has the ability to run reports on particular diseases and infections; however, there are limitations in how clinical notes are recorded, varying between practitioners. Consistent data collection requires consistency in staff training on the *Communicare* system, and can be challenging with staff turnover and temporary locum staff.

The current *Communicable Disease Control Guidance* provides advice, information and guidance relating to mumps and managing transmission in outbreak events. The management section recommends exclusion from school or the workplace for 5 days after the onset of parotitis if susceptible contacts are present (21). This presents challenges when social factors such as poor living environments, including household overcrowding, means that the person in 'quarantine' may infect others who share a bedroom or home.

Bridging together a community development framework with public health practice was an important element of this particular outbreak. The approach placed the community, the ACCHS and AHWs at the centre and contributed to the study design and methods used in the investigation. The AHWs' role as cultural brokers facilitated engagement between BM and community members. The AHWs and BM adapted standardised collection tools, such as the follow up case questionnaires, to address health literacy levels and frame questions to align with the context of the community. Health service data were extracted at the service level from the ACCHS *Communicare* patient management system; this was the primary source of data used to describe the outbreak.

A partnership between the ACCHS, AHWs and me assisted in raising community awareness and building the capacity of AHWs in components of field epidemiology outbreak response. We were successful in following up a small series of cases within a short timeframe to develop a picture of the local evidence and enhance the description of the outbreak. AHWs' role in health care varies between different primary health care settings (22). They are a valuable asset to their primary health care setting, and bring clinical and cultural brokerage skills that can add value to outbreak investigations (23, 24). Epidemiological information, particularly the epi curve, was used as an educational tool for clinicians and AHWs to understand the local context of the outbreak and the impact on the community.

Lessons

Infectious disease outbreak events provide an opportunity to evaluate and reflect on lessons learned. Special considerations are necessary in Aboriginal community settings that consider the local and cultural context and consideration of social and environmental factors such as overcrowding, mobility and close social interactions. Establishing relationships with the local ACCHS and community members are an important element of working in partnership, and including the local needs and perspectives of community members is essential.

- Workforce

The AHWs involved in this outbreak investigation were paramount to helping forge a pathway and building partnerships with community members, locating cases in the community, enabling the collection data in a culturally respectful and safe way. The process was seen as a two-way learning and contributed to increasing their own knowledge in infectious diseases, contributing to raising community awareness and local level knowledge of cases that completed the questionnaire. They were able to build on their current skill set of contact management and clinical engagement.

- Adaptation of public health tools

Public health tools have limitations in their current form when used in Aboriginal community settings. Adjusting the language and clinical concepts in the case follow-up forms increased the cultural appropriateness for the community context. Adding new items to the questionnaire enabled us to better understand patterns within the community relating to symptom severity, health literacy and knowledge, and social factors. The questionnaire also aided as an educational tool to answer questions from community members and raise awareness relating to symptoms, complications and transmission.

- Strengthening relationships between public health and primary health care

Forging a working relationship between public health units and primary health care clinics offers an opportunity to inform better public health response and preparedness strategies in outbreak settings. Bringing together public health knowledge into the primary health care setting enables AHWs to be involved in field epidemiology practice and assist in strengthening communication and awareness at the local level.

- Community engagement opportunities

There were a number of environmental (overcrowding) and social (high levels of social interaction) factors that require careful consideration in the Indigenous context and for recommending control measures. Sole services that serve the whole community, kinship structures, and housing designs that do not account for large family structures and increased social interaction. In this context, isolation is challenging as a control measure to implement when there are upwards of 15 people in a home. It is also hard to implement isolation when cultural obligations require a high degree of social interaction. Provision of health promotion and education about the need for vaccination and delivery of vaccination is required.

Working closely with communities and ACCHSs to develop infection control and

communication strategies is required. This could include increasing community education and health promotion relating to reducing transmission through the use of tissues, soap, hand gels and sanitising products. Engaging with the local shop and pharmacy to ensure they have adequate stock for the increased demand and that the products are offered at a price that is affordable for the community would contribute to preparedness.

Recommendations

A stakeholder workshop had been recommended to the ACCHS and community where the outbreak is continuing. The purpose of the workshop is to engage with community members, AHWs, clinicians and public health officers to develop an infection control and communication strategy that is culturally appropriate to the community setting. The workshop would be useful for not only the ongoing mumps outbreak, but for infections with similar transmission modes such as the flu.

Acknowledgements

W: 2810

Original research

- Maximum 2500 words (main text only)*
- 25 references* (print and online)
- 250-word structured abstract (see below)
- Maximum 140 characters: supply a single statement for the *MJA* to tweet which shares the most important message from your article, this can include an optional figure
- Box containing dot-points using the following headings/content: “The known” [the starting point for your investigation], “The new” [your major novel finding] and “The implications” [the consequences of your finding] with maximum 100 words

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Appendix 2

RESEARCH

Open Access



'Telling our story... Creating our own history': caregivers' reasons for participating in an Australian longitudinal study of Indigenous children

Katherine Ann Thurber^{1*} , Anna Olsen¹, Jill Guthrie¹, Rachael McCormick², Andrew Hunter², Roxanne Jones¹, Bobby Maher¹, Cathy Banwell¹, Rochelle Jones¹, Bianca Calabria¹ and Raymond Lovett¹

Abstract

Background: Improving the wellbeing of Indigenous populations is an international priority. Robust research conducted with Aboriginal and Torres Strait Islander peoples is key to developing programs and policies to improve health and wellbeing. This paper aims to quantify the extent of participation in a national longitudinal study of Aboriginal and Torres Strait Islander (Indigenous Australian) children, and to understand the reasons why caregivers participate in the study.

Methods: This mixed methods study uses data from Wave 6 of *Footprints in Time*, the Longitudinal Study of Indigenous Children. We conducted descriptive analysis of quantitative variables to characterise the sample and retention rates. We applied conventional content analysis to 160 caregivers' open-ended responses to the question, 'Why do you stay in the study?', identifying themes and overarching meta-themes.

Results: The study has maintained a high retention rate, with 70.4% ($n = 1239/1671$) of the baseline sample participating in the study's 6th wave. We identified seven themes related to why participants stay in the study: telling our story, community benefit, satisfaction, tracking Study Child's progress, study processes, receiving study gifts, and valuing what the study stands for. These related to two meta-themes: reciprocity, and trust and connection. Caregivers reported that participation was associated with benefits for their family and community as well as for the study. They identified specific features of the *Footprints in Time* study design that built and maintained trust and connection between participants and the study.

Conclusions: Our findings support the assertion that Aboriginal and Torres Strait Islander people want to be involved in research when it is done 'the right way'. *Footprints in Time* has successfully recruited and retained the current-largest cohort of Aboriginal and Torres Strait Islander children in Australia through the use of participatory research methodologies, suggesting effective study implementation and processes. Participants indicated ongoing commitment to the study resulting from perceptions of reciprocity and development of trust in the study. *Footprints in Time* can serve as a successful model of Aboriginal and Torres Strait Islander health research, to promote good research practice and provides lessons for research with other Indigenous populations.

Keywords: Indigenous population, Longitudinal studies, Research design, Trust, Ethics, Motivation

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Background

Improving the wellbeing of Indigenous populations is an international priority [1]. Aboriginal and Torres Strait Islander peoples are Australia's First Peoples, and maintain some of the longest continuing cultures in the world [2]. The 3% of Australians who identify as Aboriginal and/or Torres Strait Islander are a heterogeneous peoples, comprising a diversity of cultures and experiences. The intergenerational impacts of colonisation include trauma, forced disconnection from land and culture, persisting socioeconomic disadvantage, and systemic, institutional, and interpersonal racism. While Aboriginal and Torres Strait Islander peoples have demonstrated resilience in the face of this, the population is over-represented in poor health and wellbeing outcomes [3, 4]. Many of the health and social inequities experienced by Aboriginal and Torres Strait Islander peoples in Australia are also experienced by other Indigenous populations internationally [1].

Robust research conducted with Aboriginal and Torres Strait Islander peoples is key to developing programs and policies to improve health and wellbeing [1, 5, 6]. Holistic views of health are commonly held by Aboriginal and Torres Strait Islander peoples, encompassing a whole-of-life view of the social, emotional, and cultural wellbeing of the community, as well as the individual's own physical health and wellbeing [7, 8]. To enable meaningful analysis of Aboriginal and Torres Strait Islander wellbeing, it is therefore critical that studies collect comprehensive data on a broad range of social, cultural, and environmental factors at the individual, family, and community levels. Longitudinal studies are particularly valuable as they enable examination of the complex interplay of factors on wellbeing across the life course, including providing insight into causal pathways [9, 10].

It is challenging in any population to retain participants in a longitudinal study [11, 12], which may have implications for the validity of the data and findings. There is some evidence that retention rates are lower for Aboriginal and/or Torres Strait Islander participants compared to non-Indigenous participants in large-scale Australian longitudinal studies [13–16]. For example, retention of Aboriginal participants at the first wave of follow-up in the 45 and Up Study was significantly lower than retention of non-Aboriginal participants (45% versus 61%; age-sex-adjusted participation rate ratio 0.72, 95%CI:0.66,0.78) [16]. Lower retention rates may reflect additional barriers to research participation for Aboriginal and Torres Strait Islander, compared to non-Indigenous, Australians. Many Aboriginal and Torres Strait Islander communities face a large respondent burden, with frequent invitations to participate in research [17, 18]. Aboriginal and Torres Strait Islander peoples are

more likely than non-Indigenous people to live in hard-to-reach areas, and to be mobile, which can make following and communicating with participants challenging [9, 18–20]. In addition, many Indigenous populations internationally share a history of negative and exploitive research practices, which has had a lasting legacy, including enduring mistrust in research [9, 21–24].

Despite potential challenges recruiting and retaining participants, some longitudinal studies of Aboriginal and Torres Strait Islander children and adults exist [25–27]. In addition to improving understanding of Aboriginal and Torres Strait Islander peoples' health and wellbeing, these studies provide an opportunity to better understand enablers of research participation by Aboriginal and Torres Strait Islander peoples. This information can inform development of future studies, to improve retention and the validity of data. It can also support the conduct of ethical and respectful research, enabling positive research experiences and outcomes for Aboriginal and Torres Strait Islander peoples.

Previous literature, from the perspective of researchers, has identified contributors to the retention of Aboriginal and Torres Strait Islander participants in longitudinal studies, including the use of Indigenous research methodologies, partnerships and relationships between researchers and community members, flexibility, transparent communication, and cultural sensitivity [9, 12, 18, 27, 28]. To our knowledge, only one peer-reviewed study has examined reasons for research participation from the perspective of Aboriginal and Torres Strait Islander peoples, and this study was restricted to a small ($n = 8$), localised sample [5]. The current analysis serves to extend this knowledge by exploring perspectives on research participation in a larger, heterogeneous sample. The aims of this mixed methods paper are to quantify the extent of participation in a national longitudinal study of Aboriginal and Torres Strait Islander children, *Footprints in Time*, and to understand (qualitatively) the reasons why caregivers participate in the study.

Methods

Study population

This paper uses data from *Footprints in Time*, the Longitudinal Study of Indigenous Children (LSIC), a national study managed by the Australian Government Department of Social Services, and overseen by an Aboriginal-majority Steering Committee. The Steering Committee were key advisors in the development of the *Footprints in Time* study, including ensuring extensive community engagement and a participatory approach [28]. Starting in 2003, representatives from the *Footprints in Time* study held 23 consultation meetings with Aboriginal and Torres Strait Islander stakeholders; meetings were held

in every capital city and at least one regional or remote area in each State and Territory [27]. The study then trialled data collection methods and community engagement and dissemination strategies in three geographic areas, from 2004 to 2005 [27]. Based on these consultations, the study's primary research question is, 'What do Aboriginal and Torres Strait Islander (Indigenous) children need to have the best start in life to grow up strong?' [29].

In 2008, Aboriginal and Torres Strait Islander children aged 0.5–2.0 years and 3.5–5.0 years were recruited through purposive sampling. Follow-up surveys are conducted annually, and the study is ongoing. The sample includes a total of 1759 children, representing 5–10% of the total Aboriginal and Torres Strait Islander population in these age groups, and their caregivers. *Footprints in Time* is not intended to be representative of all Aboriginal and Torres Strait Islander families, consistent with its longitudinal study design [30]; it is intended to provide a picture of life in a range of different environments by sampling from 11 diverse sites across Australia [27]. Further details on the study design are provided elsewhere [27].

Aboriginal and Torres Strait Islander Research Administration Officers (RAOs) conduct face-to-face surveys with participating families, usually in the family's home. RAOs often live in the region in which they conduct interviews, and where possible, the same RAO conducts the survey with each family from one year to the next [18, 31, 32]. Separate interviews are conducted with multiple informants within each family including the study child and their primary caregiver [27]. The primary caregiver is usually the mother or step-mother, but can also be the Grandmother, Aunt, father, step-father, or other, reflecting the diversity in structure and composition of Aboriginal and Torres Strait Islander families [33]. In addition to collecting quantitative data, qualitative data are collected through 'free-text' responses to open-ended questions [18]. Responses are transcribed verbatim or summarised by RAOs with the assistance of computer technology. These responses are confidentialised prior to their release to remove any potentially identifying information [18].

Interviews with the primary caregiver are the most comprehensive, ranging in time from 20 min to 3 h, and include questions about the study child, their caregivers and other family members, the household, and the community [27]. Interviews with the study child are shorter, ranging in time from two to 50 min [27]. Across waves, the average total household time per survey is around 1.5 h [34].

To support ongoing relationships with participants and communities, *Footprints in Time* has developed a feedback and dissemination strategy, which includes:

internal feedback loops to incorporate community and RAO input into survey design; sending Community Feedback Sheets, which provide results specific to each of the 11 sites; Community Booklets, which summarise findings across the cohort; and, Research Feedback Sheets based on specific research projects [27, 35]. The study results and information are provided in accessible, plain language. Families receive incentives for participation at each wave of the study, which have included t-shirts and towels. Every year, participating families also receive a *Footprints in Time* calendar that includes photos of participating children, taken (with consent) at the previous wave.

In this paper we examine data from families who participated in Wave 6 of *Footprints in Time* (collected in 2013), using Data Release 7.0. All data utilised in this paper are self-reported by the primary caregiver in the face-to-face interview, except remoteness and area-level disadvantage, which are derived from participants' addresses.

Research methodology

Indigenous ways of knowing and participatory methodology formed an overarching research model for this analysis. Indigenous ways of knowing involves grounding the research in a model that respects cultural history, knowledge, and protocols [36]. Approaches to participatory research (action research, experience-based co-design, participatory action research, community-based participatory action research) involve collaboration between researchers and community [37, 38]. Instead of seeing 'experts' (e.g. university researchers) as the only legitimate source of knowledge, participatory research recognises and values the knowledge of community members. Participatory research models are intended to challenge researchers to share influence and control over aspects of a research project such as questions and design, research processes, data collection, interpretation, dissemination, and translation. Participatory research is increasingly popular with Indigenous communities as the approach can counter the colonising effects [39] of historical research on Indigenous peoples, and can help avoid the misrepresentation of 'Indigenous societies, culture and persons by non-Indigenous academics and professionals' ([39] p. 855).

Meaningful engagement of community members in research encourages the building of trusting relationships, establishment of new data collection methods, shared interpretation of results, and mutual benefit. Participatory approaches aim to generate research findings that are 'useful and useable to all of those participating in the process' ([40] p. 190). To achieve this, people who are members of the community are often engaged as

researchers (community researchers, co-researchers, peer researchers) [38].

Both the original study (*Footprints in Time*) and this secondary analysis of quantitative and qualitative data from the study draw on participatory research methodologies. In *Footprints in Time*, this was achieved through processes including ongoing consultation and feedback processes, employment of Aboriginal and Torres Strait Islander RAOs, and involvement of the Aboriginal and Torres Strait Islander-majority Steering Committee (described above) [28]. Following the participatory structure of *Footprints in Time*, the approach and analysis employed in this paper were co-designed by Aboriginal and non-Aboriginal researchers (including one Aboriginal member of the Steering Committee) and *Footprints in Time* community researchers (RAOs). A knowledge exchange focus group was held in July 2017 with eight *Footprints in Time* RAOs to discuss and contextualise preliminary findings, and synthesise key messages to include in a research feedback sheet for participants. The RAOs' reflections are incorporated into the results and discussion sections.

Variables

Quantitative data

Characteristics of the sample reported in this paper comprise: primary caregiver age, gender, and identification as Aboriginal and/or Torres Strait Islander; the relationship between the study child and their primary caregiver; the level of geographical remoteness (measured according to the Level of Relative Isolation scale); and, the number of waves of *Footprints in Time* in which families participated, up to and including Wave 6.

Qualitative data

Qualitative data included in this paper comprise responses from primary caregivers when asked, 'Why do you stay in the study?', with the follow-up prompt, 'What do you like about Footprints in Time?'. Participants could provide a response, indicate that they did not know why they stayed in the study, or choose not to provide any response.

Analysis

We conducted descriptive analysis of quantitative demographic variables to characterise the sample using Stata 14.

Qualitative data were analysed using conventional content analysis [41] and managed using Microsoft Excel. In the first phase, 130 free text responses (approximately 10% of the sample) were randomly selected for analysis.

The procedure of analysis was informed by existing models [41–43]. Guided by the survey questions along with an inductive approach to establishing themes [41, 42], three

analysts (AH, RM, KT) undertook the qualitative data analysis. Each analyst independently read the complete transcript and re-read responses line-by-line before reflecting and identifying preliminary themes. They then systematically coded the text using preliminary themes, aiming to stay close to the text rather than trying to infer underlying meaning(s) [42]. The analysts then met as a group to compare their initial themes and to work towards an agreed theme structure for the initial sample of 130 responses.

Data were coded using the theme structure developed by the group. An additional random sample of 30 responses was reviewed to assess if saturation had been reached [44–47]; no new themes were identified. This analysis includes the initial set of 130 responses and additional 30 responses, for a total of 160 responses (our subsample).

Following Onwuegbuzie's method for ascertaining frequency effect sizes in qualitative data [48], the next step was to count the number of times a theme was identified (frequency). The next step involved interpretative analysis, comparing and contrasting themes in order to elucidate relationships between themes and to develop meta-themes, providing an overarching framework to interpret findings. A focus group was then held with *Footprints in Time* RAOs to check the theme structure and to contextualise themes and meta-themes.

Results

Retention rate and sample characteristics

The families participating in Wave 6 of *Footprints in Time* represented 70.4% (1239/1671) of the baseline sample (Fig. 1). Sixty-five percent ($n = 807/1239$) of families participating in Wave 6 had participated in all six waves of the study to date (Fig. 2), corresponding to six years of involvement in the study.

Over 90% ($n = 1133/1239$) of caregivers participating in Wave 6 provided a free-text response explaining why they chose to participate in *Footprints in Time*; the remaining caregivers either did not provide a response or responded that they did not know.

Characteristics of caregivers in our sub-sample and of all families participating in Wave 6 are presented in Table 1. Characteristics of our sub-sample were similar to those of the total sample. The majority of caregivers identified as Aboriginal and/or Torres Strait Islander, were female, and were the study child's mother or step-mother; a small proportion were fathers or other relatives. Given the small number of male primary caregivers in our sample, the gender of caregivers will not be linked to their responses in order to protect confidentiality. A high proportion of participating families

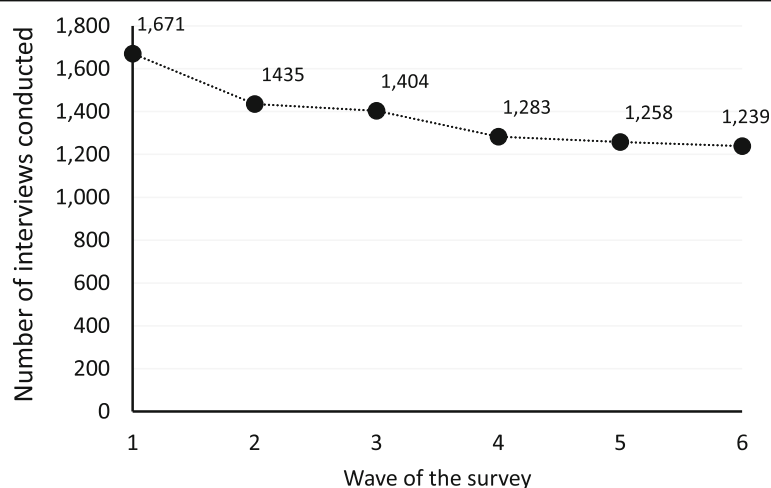


Fig. 1 Number of participating families in Waves 1 to 6 of *Footprints in Time*. * Numbers refer to interviews with the primary caregiver. The total sample of 1759 families includes 1671 Wave 1 (baseline) participants and 88 new entrants who joined the study in Wave 2

lived in inner regional areas, followed by major cities, remote/very remote settings, and outer regional areas.

Thematic analysis

Seven themes related to why participants stay in the study were identified in the content analysis: telling our story, community benefit, satisfaction, tracking Study Child's progress, study processes, receiving study gifts, and valuing what the study stands for. Theme definitions and frequency of their occurrence are provided in Table 2.

Noting conceptual interrelationships between the themes, our final analytical step involved exploring the underlying meanings within our theme structure, from which we developed two overarching categories: (1)

reciprocity and (2) trust and connection. We use these meta-themes and their interrelationship to describe findings below (see Fig. 3).

Meta-theme: Reciprocity

Research participation is often presumed to be altruistic (i.e. participants provide their time, their body, or their information for science or public good). However, caregivers in this study reported that, in addition to being beneficial for the study, they felt that their participation was associated with benefits for their family and community. These benefits included the exchange of information (telling our story; tracking Study Child's progress; study processes), enjoyment and developing relationships with interviewers

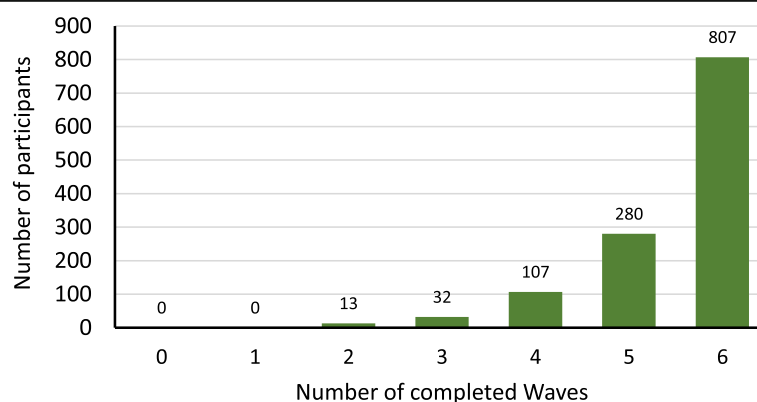


Fig. 2 Number of *Footprints in Time* interviews completed by Wave 6 participants. * Numbers refer to interviews with the primary caregiver. This graph presents the number of LSIC interviews completed by families participating in Wave 6 of the study. The minimum number of completed interviews is two interviews, as families needed to have participated in the first or second wave to be part of the cohort, and needed to have participated in Wave 6 to be included in this analysis. The maximum number of completed interviews is six interviews, representing families who participated in every single wave of the survey up to that date

Table 1 Profile of caregivers in the content analysis sub-sample ($n = 160$) and the total Wave 6 sample ($n = 1239$)

	Distribution in content analysis sub-sample		Distribution in full sample	
	%	(n/N)	%	(n/N)
PRIMARY CAREGIVER CHARACTERISTICS				
Gender				
Female	96.3	(154/160)	96.9	(1201/1239)
Male	3.8	(6/160)	3.1	(38/1239)
Age (years)				
21–30	33.1	(53/160)	29.7	(368/1239)
31–40	45.0	(72/160)	46.3	(574/1239)
41 and over	21.9	(35/160)	24.0	(297/1239)
Indigenous identification				
Aboriginal	69.4	(111/160)	71.0	(879/1238)
Torres Strait Islander	8.8	(14/160)	7.4	(92/1238)
Aboriginal and Torres Strait Islander	5.0	(8/160)	3.7	(46/1238)
Neither Aboriginal nor Torres Strait Islander	16.9	(27/160)	17.9	(221/1238)
Relationship to study child				
Mother or step-mother	88.8	(142/160)	88.0	(1090/1239)
Father or step-father	3.8	(6/160)	2.9	(36/1239)
Grandmother, Aunty, or other	7.5	(12/160)	9.1	(113/1239)
HOUSEHOLD CHARACTERISTICS				
Level of remoteness				
Major city	24.4	(39/160)	27.8	(344/1239)
Inner regional area	51.3	(82/160)	50.8	(629/1239)
Outer regional area	10.6	(17/160)	12.8	(158/1239)
Remote or very remote	13.8	(22/160)	8.7	(108/1239)
Number of Waves of LSIC completed				
2–4	11.3	(18/160)	12.3	(152/1239)
5	24.4	(39/160)	22.6	(280/1239)
6	64.4	(103/160)	65.1	(807/1239)

*Numbers may not sum to total due to missing data. Level of remoteness defined according to Level of Relative Isolation

(satisfaction; study processes), incentives for participation (receiving study gifts), and benefits for the broader community (community benefit). Reciprocity encapsulates this mutual benefit.

Telling our story

Over a quarter of responses (26.3%, $n = 42/160$) encompassed the concept of ‘telling our story’. These focused on the value of ‘recording what life is like’; contributing to official statistics, research, government, organisations, or other; preserving and sharing culture; and collecting data about Aboriginal and Torres Strait Islander children.

Many caregivers specifically identified value in ‘keeping data on’; ‘keeping track of’; and ‘keeping an eye on’

all Aboriginal and Torres Strait Islander children as exemplified by statements such as:

I think it is a good idea to gather information about all the children that live in different environments.

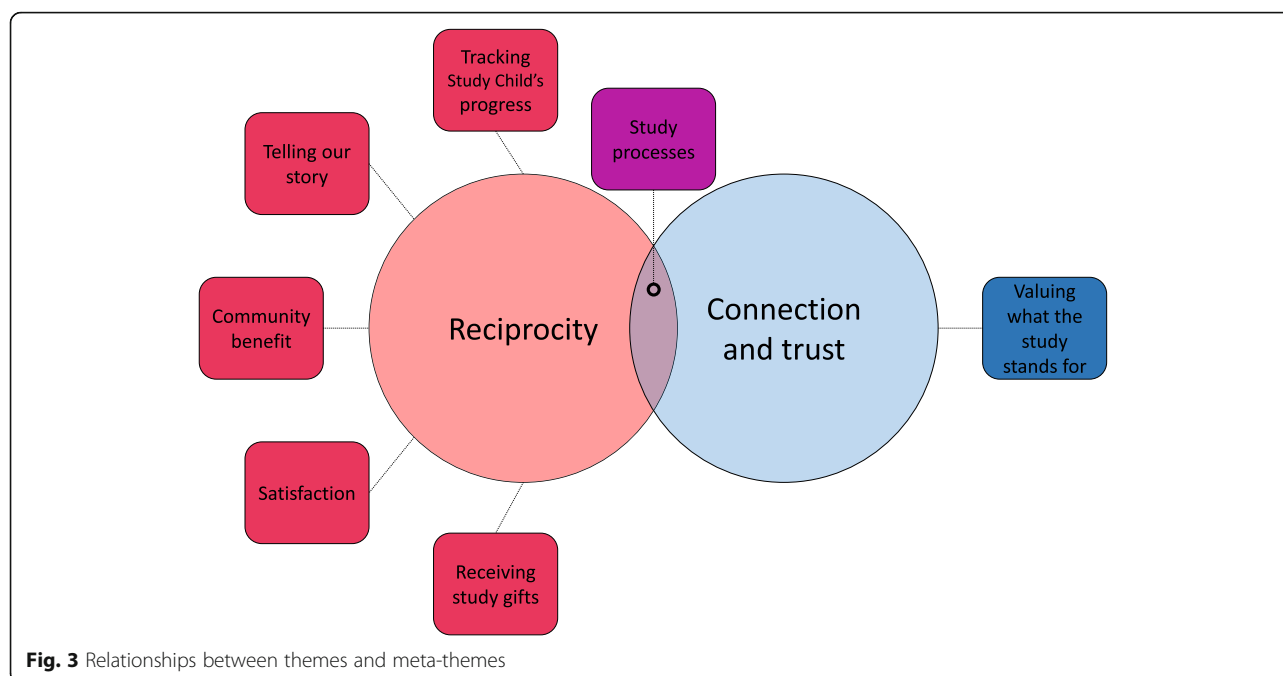
Caregivers not only described participation as an opportunity to create a repository of information about Aboriginal and Torres Strait Islander life, but also as an empowering experience of recording culture and diversity from their perspective:

.... telling our story... creating our own history.

I want our culture to stay strong and the only way to do that is to record the information that is out there.

Theme	Sub-themes	Frequency (% of total)	Definition	Example quote	Meta-theme	
					Reciprocity	Connection and trust
Telling our story	Contributing information; data about Indigenous kids; educating the public; recording what life is like; protecting and maintaining culture.	42 (26.3%)	Refers to recording and contributing information, including for research, government, organisations, and the public.	'Telling our story... creating our own history'	X	
Community benefit	–	33 (20.6%)	Refers to perceived benefit for the broader Aboriginal and Torres Strait Islander community and future generations.	'I think it is deadly this sort of research, it will all come together and help our kids in the future'	X	
Satisfaction	P1 enjoys or finds it interesting; SC enjoys; good for SC; connect SC to Aboriginality and culture.	37 (23.1%)	Refers to caregivers or children's satisfaction through participating in the study, such as enjoyment and interest.	'I really like it. I love it'	X	
Tracking Study Child's progress	Track progress and set goals; a record or time capsule; independent way to monitor SC; help P1 to understand SC.	35 (21.9%)	Refers to recording or tracking how their child is progressing over time.	'Am able to see how my son is improving and progressing each year'	X	
Study processes	Time; feedback sheets; building relationships; confidentiality.	36 (22.5%)	Refers to specific study processes, such as the timing of interviews and feedback processes.	'The feedback is really helpful'	X	X
Receiving study gifts	–	55 (34.4%)	Refers to gifts or incentives provided to participants by the study.	'... enjoy seeing the excitement on my child's face when they have been given gifts'	X	
Valuing what the study stands for	Support the study; focus of the survey on Aboriginal children, culture.	14 (8.8%)	Refers to perceived value of the study, including the importance of the study's focus and its findings.	'... because I like what it stands for'		X

SC Study Child, P1 Primary caregiver



Caregivers felt that the study findings could be used to support education about Aboriginal and Torres Strait Islander life, in particular, positive or 'good' stories:

I think it is a very good idea for this information to get out to the community so that we can educate other people about our people and our culture.

I want the general public to know that there are good statistics on Indigenous children.

Caregivers expressed the desire for information from the study to be 'fed to organisations and the government.' Caregivers explained that it was important to provide information to:

... get the right statistics for government

... help the government understand the needs of Aboriginal [people]

In some cases, respondents anticipated that this community benefit could arise through identifying methods for improvement, informing policy, or attracting funding or resources:

I hope the Government will listen to what we are saying

... hopefully it will change where they direct the funding

If you don't know what's broken you don't know how to fix it

Community benefit

More than one in five caregivers (20.6%, $n = 33/160$) mentioned an anticipated benefit for the broader Aboriginal and Torres Strait Islander community and future generations – not just their own child or their own community. Responses focused on making a positive difference in the community through the identification of 'good things', 'ways of improving', 'help' and 'funding'. Community benefit was not anticipated to be immediate but over the long-term. Many caregivers mentioned that participating in the study would contribute to a better future for Aboriginal and Torres Strait Islander people; for example, 'Looking forward to the future'; and to 'see outcomes in the long run'. These future gains were particularly important for their children:

... the study is useful for the future; our kids are our future.

I think it is deadly this sort of research, it will all come together and help our kids in the future.

Satisfaction

Almost one quarter of caregivers (23.1%, $n = 37/160$) described satisfaction from, enjoyment in, and perceived benefits from participating in the study, for both themselves and their child. Caregivers reported that they found the study 'interesting', and that they enjoyed participating in the study and being a part of the annual interviews, providing comments such as:

I like being in the study... I like these interviews.

I really like it. I love it!

Many caregivers reported that their child enjoyed doing the survey (particularly the activities), and that their child looked forward to participating: 'It is something for the [child] to look forward to'. Caregivers' responses indicated that they perceived participation in the study was inherently good for their child:

I like to have positive outcomes for my children.

It's helping [child] along.

During the focus group, RAOs explained that participating in *Footprints in Time* is an important way for participants to reconnect with culture, particularly for families who feel disconnected. This connection can be fostered through the provision of time and a safe space for participants to answer questions about culture and think about ways to be involved with culture. RAOs reported facilitating cultural connection not only through the study visits, but also by sharing information with families about local cultural groups and events. Echoing the RAOs perspective, several caregivers mentioned that participation in the study strengthened children's connection to their culture, such as:

... help [child] to connect with her Aboriginality.

Link Aboriginal children with their culture.

Tracking study Child's progress

Thirty-five caregivers (21.9%) reported that the ability to record and track their own child's development was a reason for participating in the study. Participating in the study provides families with an opportunity to see how their child is progressing, in terms of growth, development, and schooling:

[I] am able to see how my son is improving and progressing each year.

Through participating in the study, families felt that they were better able to understand their child and to set goals for the child:

...gives parents a better understanding of their children.

... it helps me to understand my daughter more as she is growing up.

... makes families look at the goals for their Aboriginal children.

Caregivers mentioned that they valued that the study provided an opportunity for independent monitoring of the child, outside of the immediate family. For example, one caregiver reported that through participating in the study she '... would be able to see if she was doing the right thing with her parenting'.

Caregivers also commented on the value of creating a record or 'time capsule' of their child. For example, one mentioned that participating allows her to '... see the history and see the progress as she gets old. Like the funny things we just put in it will be there forever...'. Others mentioned the value on having the data recorded:

... have something to look back on

Knowing that I can look back at this information in years to come and see where [child] is as a person

Study processes

Many responses referred to specific features of the *Footprints in Time* study design, such as the feedback sheets sent to participating families every year, which represent another form of knowledge exchange and reciprocity. These feedback processes allow families to track progress in their community and in the cohort overall, and to stay informed of research findings from the study. For example, caregivers said:

... it is good that Footprints keep in touch.

I like to read the reports that are sent out - the feedback sheets.

It is interesting to see the newsletter and the graphs.

The feedback is really helpful.

Other study processes that were described positively by participants are described below under the meta-theme trust.

Receiving study gifts

The incentives provided in *Footprints in Time* were appreciated by participating children and families, and also served to connect participants to the study.

Over a third (34.4%, $n = 55/160$) of caregivers mentioned that they accepted and enjoyed the gifts received for participating in the study; multiple responses mentioned the calendar: 'always look forward to the calendar'; 'the kids get to be in the calendar'. Caregivers also

reported enjoyment in 'seeing the excitement on my child's face when they have been given gifts'.

During the focus group, RAOs explained that the incentives provided also enabled children and families to connect to their Aboriginal and/or Torres Strait Islander identity; for example, gifts with *Footprints in Time* logos reinforce the child's identification as a participant in the study, along with a sense of pride and connection.

Meta-theme: Connection and trust

Participants' responses suggest that specific features of the *Footprints in Time* study design (study processes) worked to build and maintain trust and connection, or rapport, between participants and the study. For example, the longitudinal study design, and continuity of RAOs across study waves, ensures frequent contact and enables relationship building between participants and the study. Participants also reported that they valued 'what the study stands for', suggesting that the study topic is of interest and priority to participating families and communities, supporting their trust in and connection to the study.

Study processes

Thirty-six caregivers (22.5%) mentioned specific features of *Footprints in Time* that contributed to their participation, and fostered a sense of trust in and connection to the study.

Many responses alluded to the concept of time, particularly that the regular contact with the study was a positive experience. Several responses referred to the consistency of the annual visits, commenting, 'the service is regular' and 'that you came out to visit my child every year'. One commented that she appreciated that the survey 'doesn't take much out of your time' (despite the fact that the average participating household spends 1.5 h on each annual survey).

Responses conveyed the development of trust and rapport between participants and RAOs over the course of the study. Multiple caregivers commented that having the same RAO every year enabled them to build a relationship, with comments including:

If it was a different person each year I probably wouldn't do it

I like [RAO name] doing my survey, I don't like change

In the focus group the RAOs also reflected on the establishment of relationships with participating families. For example, one RAO explained that over the course of three annual surveys the RAO progressed from conducting the survey outside one family's house to being welcomed inside their home.

Many caregivers described a strong sense of connection to and trust in the RAOs and appreciated the social support received through engaging with the RAOs during the annual face-to-face interview.

I love you guys [RAOs]... you are all lovely people

... we love you.

I feel very comfortable having the RAOs in my home.

... the interviewers are friendly and easy to talk to about the questions.

Some reported that they enjoyed telling the interviewers about their child and 'having a yarn' (yarning is an Aboriginal term used to describe talking or telling stories, a process through which knowledge has been transmitted across generations [7], and through which connections and relationships can develop [49]). Several stated that the study interviews were not intrusive, 'respectful of the community', and the 'best way to research'. One participant explicitly stated that she appreciated that the interviews were conducted by Aboriginal and Torres Strait Islander, rather than non-Indigenous, people. During the focus group RAOs explained that they follow community protocols and reschedule interviews if families are undergoing difficult personal circumstances or if there is an event occurring in the community.

Valuing what the study stands for

Fourteen caregivers (8.8%) reported that they were involved in *Footprints in Time* because of 'what it stands for'. Continuing the theme of connection, participants appreciated that the study asks questions about things of value to Aboriginal and Torres Strait Islander families, allowing them to share parts of their life and 'story' that are important to them. Participants valued the holistic approach to considering the broader family and community context beyond the individual child, as well as the centrality of culture to the study. For example, one participant commented that she appreciated that the study wanted 'to know about our culture and what [place] is like'.

The most common value that connected participants to the study was its focus on children, and in particular, the focus on improving Aboriginal and Torres Strait Islander children's wellbeing:

It's good that the study takes an interest in our children's development.

I believe that it is good to focus on the needs of Aboriginal children.

... there is an organisation out there that has time to care about our kids.

Discussion

Footprints in Time has successfully recruited and retained the current-largest cohort of Aboriginal and Torres Strait Islander children in Australia. More than 8000 surveys were completed across the first six waves of the study, from 2008 to 2013; this represents a contribution of around 12,000 h of time by families of Aboriginal and Torres Strait Islander children. At the 6th annual survey, the study had retained over 70% of the total cohort; the majority (65%, $n = 807/1239$) of families who participated in Wave 6 had participated in every one of the preceding five surveys. The qualitative data collected in *Footprints in Time* provides valuable insights as to why the study was successful in retaining families. Namely, participants indicated ongoing commitment to and interest in participating in the study due to perceptions of reciprocity and the development of trust in the study. This was enabled by the participatory approach to developing and implementing the study.

There is no established definition of a satisfactory retention rate, but previous studies of Aboriginal and Torres Strait Islander peoples have described retention rates between 45 and 85% as satisfactory [12, 16, 19, 25]. The retention achieved in *Footprints in Time* (70.4% at Wave 6) matches that of longitudinal studies of the total Australian population conducted by Department of Social Services. The Longitudinal Study of Australian children maintained 72.4% of the baseline sample at the 6th wave of follow-up ($n = 7301/10,090$); the study of Household, Income and Labour Dynamics in Australia maintained 72.2% of the baseline sample at the 6th wave of follow up ($n = 12,905/13,969$) [50]. The ability of *Footprints in Time* to maintain an equivalent response rate despite additional complexities (including high mobility and respondent burden, and negative research experiences [12, 16, 19, 51, 52]) suggests effective study methodology and implementation.

The two meta-themes identified in this study, reciprocity and trust/connection, align with key ethical principles for the conduct of research with Aboriginal and Torres Strait Islander peoples [53–55] (and other Indigenous populations internationally, e.g. [56, 57]), reinforcing the importance and appropriateness of these principles. For example, reciprocity is a core principle for the conduct of ethical Aboriginal and Torres Strait Islander health research, recognising that research participants – not just the researchers – need to gain from the research process. This contrasts common experiences of Aboriginal and Torres Strait

Islander research that has ‘taken away’ but not ‘given back’ to the community [58–60].

Reciprocity encompasses two key components: benefit and inclusion [52, 55]. The first component, benefit, entails the enhancement of capacities, opportunities, or outcomes of interest and value to Aboriginal and Torres Strait Islander peoples [55]. Respondents described a number of valued individual- or family-level benefits to participating [61]; this included the identity affirming nature of the study, study incentives, mutual knowledge exchange [22, 58, 59], and satisfaction inherent to completing the annual surveys. Responses also described anticipated benefits for the broader community over the long term. The emphasis on community, in addition to individual, benefit is consistent with previous research [5] and with holistic and collective views of wellbeing often held by Indigenous peoples [7, 8]. Respondents’ views also indicate that they felt included and valued as members of the study, particularly in relation to knowledge exchange. Inclusion in research entails ‘equitable and respectful engagement with Aboriginal and Torres Strait Islander Peoples, their values and cultures in the proposed research’ ([55] p. 10). This second component of reciprocity is tightly linked to trust, and is facilitated by the study’s ongoing community engagement and feedback processes, and by RAOs’ flexibility and respect for families and community protocols. Establishing study designs in which information is provided to participants, not just taken, is considered an essential component of collaborative, decolonising methodologies [22, 58, 59].

Connection, particularly as a facilitator of trust, has similarly been identified as a key element of ethical research practice [5, 62]. Australia’s key guidelines for ethical research with Aboriginal and Torres Strait Islander communities include principles related to generating and maintaining trust and integrity in research [53–55], which can be supported through reciprocity [62]. Participants contribute their time, body, and/or information to research, trusting the researchers that this will at some point translate to benefit [62]. As described under reciprocity, our findings suggest that caregivers trust that their participation in the *Footprints in Time* study will generate valued benefits for their family, and for the broader community over the long term. Participation in research also requires trust that any data collected will be used appropriately. Data about Aboriginal and Torres Strait Islander people have often been misused and have misrepresented participants; literature has documented ongoing concerns about the use of data [5, 58, 59]. Several participants expressed their confidence that the study would generate ‘good’ or the ‘right’ (not just any) statistics about Aboriginal and Torres Strait Islander children and families. That is, participants placed trust in *Footprints in Time* to use their stories to

accurately and appropriately portray their lives, informing government and the public about Aboriginal and Torres Strait Islander strengths and needs, cultures, and diversity.

Implicit within the participatory research paradigm is a strength-based research focus, contrasting the dominant deficit discourse permeating health research which focuses on disparities and serves to problematize Indigenous peoples [7, 63–65]. This strength-based approach has been strongly advocated for by community members and organisations, researchers, and increasingly by government [58, 59, 66–71]. *Footprints in Time* is purposefully designed to have a strength-based focus, as demonstrated by the study's guiding research question; the focus on positive assets and resources of individuals, families, and communities; and the collection of information about culture [28]. Aligned with this strength-based research focus, most participant responses to why they participated in the study focused on strength – such as measuring children's strength and progress, and their future as well as maintaining Aboriginal and Torres Strait Islander culture and improving policy. Another component of strength-based approaches is understanding and valuing diversity [28, 59, 72], to enable an accurate portrayal of the diverse lives and experiences of Aboriginal and Torres Strait Islander peoples. Multiple participants in our study commented on the importance of the study capturing diversity. *Footprints in Time* is currently the only national study of Aboriginal and Torres Strait Islander children [27]; the diverse sample in this study – in terms of life circumstances, experiences, location, and cultures – is critical to enabling a more accurate portrayal of Aboriginal and Torres Strait Islander life [17]. We note that the *Footprints in Time* study is not intended to be representative of all Aboriginal and Torres Strait Islander families, but rather to provide a snapshot of life in a diverse range of environments [27].

The building of connection and trust in research needs to be earned and developed over time; it is 'difficult to establish, but easy to destroy' ([62] p. 373). If trust is lost, participants are unlikely to continue to participate in research and share their stories [62]. *Footprints in Time* was developed and is conducted in partnership with Aboriginal and Torres Strait Islander communities and organisations [18, 27, 66]; this has been key to cultivation of participants' and communities' trust [5, 62]. An extensive community consultation process was undertaken during the study development phase, and outcomes of these consultations are reflected in the study design. For example, these consultations have ensured that the study focuses on Aboriginal and Torres Strait Islander community priorities; that it takes a holistic approach, considering the child's wellbeing in the context of their family, community, and culture; that the study is conducted in a participatory and culturally respectful

manner (including employment of Aboriginal and/or Torres Strait Islander interviewers, adherence to community protocols); and that it reflects the diversity of the population [22, 66, 73, 74]. The design of *Footprints in Time* inherently privileges and values Aboriginal and Torres Strait Islander voices and perspectives, which have so often been omitted from research [21, 75, 76]. Consistent with findings from Guillemin et al. [5], participants appreciated the opportunity to contribute their story to research and statistics, and to record aspects of their lives that might be lost if left unrecorded. Our findings indicate that this partnership approach and the study's processes have supported maintenance of trust, and therefore study participation, over many years. Participants' reflections on their reasons for engaging in the study suggest a sense of reciprocity and trust between families and the study team. Enjoyment in and perceived benefits to participation, including building relationships with the RAOs, were described as a key part of this.

Our findings support, and add strength to, previous literature on research participation and ethical research with Indigenous populations. This study is the first to incorporate perspectives from a large number ($n = 160$) of Aboriginal and Torres Strait Islander families and shows that Aboriginal and Torres Strait Islander people want to be involved in research when it is done 'the right way'. While the current analysis focuses on the reasons participants contribute to the *Footprints in Time* study, there were a number of responses that emphasised the importance of future use of the data provided by participants. In particular, several caregivers indicated that it was important to them that the collected data were used, and used appropriately. Participatory methodologies are intended to not only engage participants in the research development and collection phases, but also in the analysis and implementation phases. Data collection for the *Footprints in Time* study remains ongoing, and analysis is underway. The next challenge for the study will be to engage in strategies that increase the translation of findings into policy and practice, in a way that is inclusive and relevant to Aboriginal and Torres Strait Islander peoples.

Strengths and limitations

Our study was limited to caregivers of Aboriginal and Torres Strait Islander children who decided to participate in *Footprints in Time*, and who participated in the 6th annual survey. We therefore lack perspectives (i.e. reasons for non-participation) from persons who chose not to continue to participate in the study, or who joined the study but did not participate in the 6th survey. Further, this research is based on analysis of the primary caregiver's reasons for participating only; it does not

incorporate the study child's views, or the views of secondary or other caregivers.

Caregiver responses may have been influenced by social desirability bias, particularly as they were collected face-to-face with the RAOs. However, caregivers did have the option to indicate that they did not know why they stayed in the study, or to decline to respond; this option was chosen by less than 10% of participants.

This analysis capitalised on free-text collected in a primarily quantitative survey, supporting previous literature on the potential value of these types of data [77, 78]. A random subset of responses were analysed and we stopped analysing data when saturation was reached, according to our protocol. There is the possibility that responses from participants in our random sub-sample may not be fully representative of all responses from the total sample. However, our sub-sample was selected at random and was generally similar to the overall Wave 6 sample in terms of demographic characteristics. The present analysis provides information based on a Aboriginal and Torres Strait Islander sample substantially larger and more diverse than previously published ($n = 8$) [5].

Conclusion

Our findings support the assertion that Aboriginal and Torres Strait Islander people want to be involved in research when certain conditions are met. The *Footprints in Time* study has demonstrated the ability to recruit and retain a substantial number of families of Aboriginal and Torres Strait Islander children over six waves of data collection, from 2008 to 2013. This is enabled by the development and maintenance of a sense of connection and trust, and a mutually beneficial relationship between participants and the study. Specific processes and elements of participatory research can be implemented to cultivate reciprocity and trust in research, including building relationships between participants and researchers, involving local people in the design and data collection, ensuring individual and community benefit from the research, and ensuring that the research is of value to participants. Our findings reinforce the importance of doing research 'the right way', encompassing existing principles for the conduct of ethical research with Indigenous populations. Given historical power relations between Indigenous peoples and settler societies, meaningful investment in reciprocity at all research stages can help redress this negative past at the community level [61, 79]. Learnings from this study may be transferable to research with other Indigenous populations, to facilitate participation and retention in research, and support the generation of meaningful and relevant research findings that can contribute to improved wellbeing.

Abbreviation

RAOs: Research Administration Officers

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Availability of data and materials

Data from the *Footprints in Time* Study are available through application to the Department of Social Services. Prospective users need to sign a deed of licence and complete an application for the dataset, including a disclosure of the context of their research; data users also need to adhere to strict security and confidentiality protocols. The LSIC webpage (<http://dss.gov.au/lsic>) provides additional information on the LSIC data and access arrangements. Queries about the study or the data should be sent to [LSICdata@dss.gov.au]; queries about applying for the data or licensing arrangements should be sent to [NCLD@dss.gov.au].

Authors' contributions

KT and RL conceived the study. KT, RL, and AO designed the analysis. KT, AH, and RM conducted the content analysis. KT drafted the manuscript. All authors interpreted and synthesised findings, provided comments on the manuscript, and approved the final version.

Ethics approval and consent to participate

The *Footprints in Time* Study is conducted with ethics approval from the Departmental Ethics Committee of the Australian Commonwealth Department of Health, and from Ethics Committees in each state and territory, including relevant Aboriginal and Torres Strait Islander organisations. The Australian National University's Human Research Ethics Committee granted ethics approval for the current analysis of *Footprints in Time* data, and for engagement with RAOs (Protocol No. 2016/534). Participation in the *Footprints in Time* Study, and in the focus group for this analysis, was voluntary, and occurred with informed, written consent.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Appendix 3

Mumps

[Fact sheet](http://conditions.health.qld.gov.au/HealthCondition/condition/14/217/99/mumps) [http://conditions.health.qld.gov.au/HealthCondition/condition/14/217/99/mumps] - Health conditions directory

Mumps is an infection of the salivary glands caused by the mumps virus. The most common gland affected is the parotid gland which causes swelling at the angle of the jaw in front of the ear.

Public health management guidelines

- Read [Queensland Health guidelines for public health units](https://www.health.qld.gov.au/cdcg/index/mumps.asp) [https://www.health.qld.gov.au/cdcg/index/mumps.asp]

Notification

Pathology laboratories

- [Notification criteria for pathology laboratories](https://www.health.qld.gov.au/cdcg/documents/notif-criteria-guide.pdf) [https://www.health.qld.gov.au/cdcg/documents/notif-criteria-guide.pdf] (PDF, 55kB)
- [Notification procedure](https://www.health.qld.gov.au/cdcg/index/mumps.asp#np) [https://www.health.qld.gov.au/cdcg/index/mumps.asp#np]

Notification resources

- List of all [Pathological, clinical and provisional diagnosis notifiable conditions](https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/diseases-infection/notifiable-conditions/list/default.asp) [https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/diseases-infection/notifiable-conditions/list/default.asp]
- List of [Public Health Unit](https://www.health.qld.gov.au/system-governance/contact-us/contact/public-health-units/default.asp) [https://www.health.qld.gov.au/system-governance/contact-us/contact/public-health-units/default.asp] contacts
- [Notifiable conditions report form for Queensland clinicians \(PHA S70\)](https://www.health.qld.gov.au/publications/clinical-practice/guidelines-procedures/diseases-infection/notif-conditions-rpt.pdf) [https://www.health.qld.gov.au/publications/clinical-practice/guidelines-procedures/diseases-infection/notif-conditions-rpt.pdf] (PDF, 48kB) - if faxing notification, follow up by phone.

Enhanced surveillance for public health units

- [Case report form](https://www.health.qld.gov.au/cdcg/documents/cr-generic.pdf) [https://www.health.qld.gov.au/cdcg/documents/cr-generic.pdf] (PDF, 504kB) - used by public health units to collect and manage more detailed information for enhanced case surveillance.

Resources for health professionals

Immunisation

- [Immunisation](https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/diseases-infection/immunisation/default.asp) [https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/diseases-infection/immunisation/default.asp] – Queensland Health website for health professionals.
- [Australian immunisation handbook](http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/Handbook10-home~handbook10part4) [http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/Handbook10-home~handbook10part4] - provides clinical guidelines for health professionals on the safest and most effective use of vaccines in their practice.

Epidemiological data and reports

- View [communicable diseases data for notifiable conditions in Queensland](https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/diseases-infection/surveillance/reports/notifiable/default.asp) [https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/diseases-infection/surveillance/reports/notifiable/default.asp].

Appendix 4

Mumps Case Investigation Form

Confirmed Case: ☐ **NMPHC:** ☐

Demographic Details

Surname: _____ Given Names: _____

Alternate contact name: _____ Phone: _____

Date of Birth: _____ Age: _____ Gender: _____

School/Childcare/Occupation: _____

Country of Birth: _____ Doctor: _____ Dr Phone: _____

☐ Aboriginal ☐ Aboriginal and Torres Strait Islander ☐ Not Indigenous

☐ Not stated ☐ Torres Strait Islander ☐ Information not collected ☐ Unknown

Case first notified: _____ Notified by: _____

Key Investigation Components

- Clear onset date for swelling of salivary glands
- Incubation period 12 to 25 days
- Vaccination history
- Appropriate exclusion
- Contact with anyone with a similar illness
- Infectious period 7 days before to 9 days after onset of swelling

Case History

Swelling of salivary glands Y N U ☐ Bilateral ☐ Unilateral Swelling onset date: ____/____/____

☐ Parotid Duration of swelling _____

☐ Sublingual Fever Y N U Temperature: _____

☐ Submandibular Headache Y N U

☐ Other glands, specify: _____ Myalgia Y N U

Comments: _____

Exposure History

During the incubation period (____ / ____ / ____ to ____ / ____ / ____) was the case:

- Associated with a known outbreak Y N U
- A close contact of a confirmed or presumptive case Y N U
- In contact with someone with a similar illness Y N U

Vaccination History

Mumps containing vaccine received in the past: Y N U

Vaccine	Date	Provider	Verified by

Contact Management (only required if a confirmed case)

During the infectious period (___ / ___ / ___ to ___ / ___ / ___) did the case attend:

☐ Child care ☐ School ☐ Work Date/s attended: _____

Case advised to be excluded (for at least 9 days after onset of parotid swelling, or until swelling goes down, whichever is sooner)

Y N U

Comments: _____

Contact Management (only required if a confirmed case)

Close contacts	Relationship to case	Age/DOB	Contact number	Susceptible <i>(Not vaccinated or history of clinical disease)</i>

Case DefinitionLaboratory Definitive EvidenceIsolation of mumps virus (culture) ☐**OR**Detection of mumps virus by nucleic acid testing (PCR) ☐**OR**IgG seroconversion or a significant increase in antibody level or a fourfold or greater rise in titre to mumps virus EXCEPT when there has been recent mumps-containing immunisation ☐→ Confirmed Case ☐Laboratory Suggestive EvidenceDetection of mumps-specific IgM antibody (in the absence of recent mumps vaccination) ☐**A
N
D**Clinical EvidenceA clinically compatible illness characterised by swelling of the parotid or other salivary glands lasting two days or more without other apparent cause ☐→ Confirmed Case ☐Clinical EvidenceA clinically compatible illness characterised by swelling of the parotid or other salivary glands lasting two days or more without other apparent cause ☐**A
N
D**Epidemiologic EvidenceContact between two people involving a plausible mode of transmission (see case definition) ☐**AND**At least one case in the chain of epidemiologically linked cases (which may involve many cases) is laboratory confirmed ☐→ Confirmed Case by epi link ☐

Does not fit any of above case definitions

→ Case NMPHC ☐

Completed by: _____ Signed: _____ Date: _____



Mumps Case Investigation Form

Demographic Details

Surname: _____ Given Names: _____

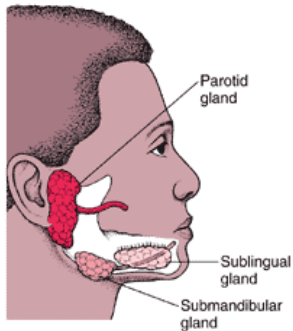
Alternate contact name: _____ Phone: _____

Date of Birth: _____ Age: _____ Gender: _____

School/Childcare/Occupation: _____

- ☐ Aboriginal
 ☐ Aboriginal and Torres Strait Islander
 ☐ Not Indigenous
☐ Not stated
 ☐ Torres Strait Islander
 ☐ Information not collected
 ☐ Unknown

Case History

 Face swelling Y N U
 ☐ Both sides L & R
 One side – L ☐ R ☐


When did you notice the swelling? _____

How long did you have the swelling for? _____

When did you first feel unwell? (Date and time) _____

Length of time feeling unwell _____

Did you experience any of these?

Fever Y N U

Testicular pain Y N U

Headache Y N U

Ovary pain Y N U

Lethargy/Tiredness Y N U

☐ Other glands, specify: _____

Muscle pain Y N U

Did you see a doctor when you first became unwell? Y N U

Clinic ☐ Emergency Department ☐

Were you tested for mumps? Y N U

Did the doctor take a mouth swab? Y N U

Do you know the results? Y N U

What information have you received on mumps? _____

Did you understand the advice provided? Y N U

Comments: _____

Did you go to the hospital? Y N U

How long did you stay in hospital for? _____

Contact Management

On the 4 days prior to becoming unwell did you attend?

☐ Child care ☐ School ☐ Work Date/s attended: _____

Work details: _____

Were any family members around you unwell? Y N U (if Y, provide details in the Contact Management section below)

Did they present to the clinic? Y N U

Have you travelled recently from Yarrabah, and/or Qld? Y N U

Location and length of stay: _____

Have you had any visitors prior to feeling unwell? Y N U (if Y provide details in the Contact Management section below)

Where are they from and how long did they stay for? _____

Contact Management (Please complete if you were in contact with anyone who had mumps, prior to you being unwell)

Close contacts	Relationship to case	Age/DOB	Date of contact	Susceptible (Not vaccinated or history of clinical disease)

Vaccination History

Have you received a vaccine containing mumps? Y N U

Dose 1 ☐ Dose 2 ☐ Asked but couldn't remember ☐

Environmental factors

Number of people in house _____

Number of adults _____

Number of children _____

Number of bedrooms _____

Number of people in each bedroom

☐ Room 1 ☐ Room 2 ☐ Room 3 ☐ Room 4

Are you a smoker? Y N U

Is there smoking inside the house? Y N U

Are there faulty taps in the house? Y N U

Completed by: _____ Signed: _____ Date: _____

Appendix 5

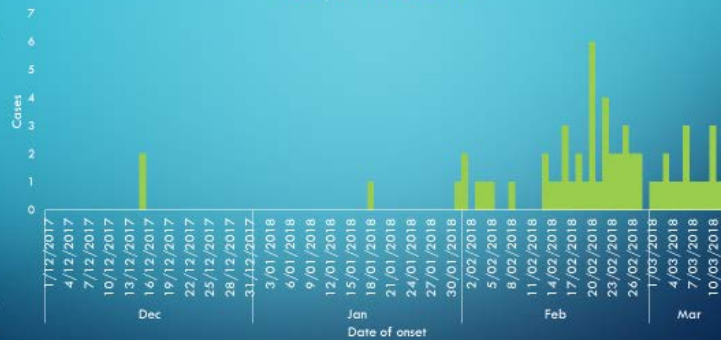
- Transmission via droplets similar to the flu i.e. sneezing, coughing
- Incubation period is roughly 17 days
- Higher risk of infection is 2 days prior to symptoms and 4 days after

DROPLET TRANSMISSION

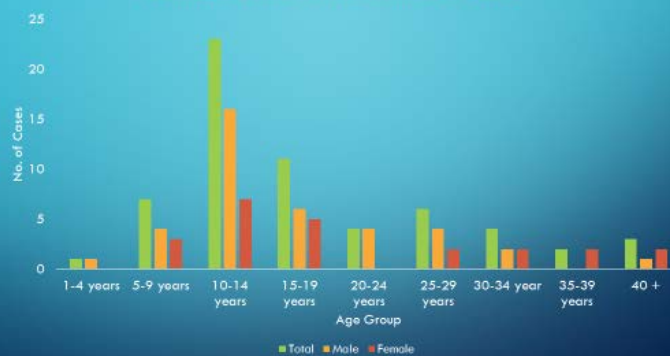
Droplets should come in contact with mucus membrane directly or indirectly through sneezing, coughing, talking etc. Examples of droplet transmission include influenza, meningitis etc.



Mumps Yarrabah



Demographic characteristics of cases



Capturing cases on Communicare



THANK YOU

Gurriny Yealamucka Health Service

- Dr Andrew Baade
- Dr Peter Roach
- Health Workers – Savanna, Lynn and Lynese
- All other Gurriny staff
- Dr Jason Agostino & Dr Ross Andrews - ANU

Appendix 6



GURRINY YEALAMUCKA
HEALTH SERVICE ABORIGINAL CORPORATION

Gurriny Yealamucka

Health Service Aboriginal
Corporation

Address 1 Bukki Road
Yarrabah Q 4871

Phone 07 4226 4103

Fax 07 4056 9368

Email info@gyhsac.org.au

Web gyhsac.org.au

Australian National University
Human Research Ethics Committee

Dear Chairperson

Letter of Support – Ms Bobby Maher

I write to confirm that Bobby Maher (Masters of Philosophy in Applied Epidemiology, ANU) has engaged the Gurriny Yealamucka Health Service in discussions on her research project relating to the recent mumps outbreak in the Yarrabah community. Bobby has already established relationships with Gurriny Yealamucka Health Service and community members when she was recently investigating the community mumps outbreak in Yarrabah. We confirm our support to participant in the follow up research project, which will involve community members, Aboriginal health workers and clinicians participating in a focus group activity. The purpose of the research project is to develop an infection control strategy and communication resources that are culturally appropriate and include community perspectives, with the aim to reduce further transmission of mumps, or any infectious disease that may present in the future in Yarrabah.

Gurriny Yealamucka Health Service has a history of partnerships with ANU students undertaking research with community members. Bobby has shown a commitment to work with us and listen to research priorities and ideas. As such, we are interested in further working with Bobby in partnership on her mumps outbreak project. I can be contacted on 07) 40560013 or ruth.fagan@gyhsac.org.au to discuss this letter of support further.

Regards

Ruth Fagan (Business Development & Research Manager)

17th April 2018

ABN 31 210 982 991

Appendix 7

Fact Sheet: Stronger Communities for Children



Australian Government

What is Stronger Communities for Children?

Stronger Communities for Children (SCfC) is a flexible initiative that works with Northern Territory communities to identify and implement local, integrated services and activities that create a safe and positive environment for children and families.

SCfC aims to give children and young people the best possible start in life by:

- making families and communities safer
- nurturing young children
- providing children, young people and families opportunities for participation in cultural events
- supporting children to be school-ready
- supporting young people to attend school and gain an education
- building community capacity to lead, plan and prioritise services that children and families need
- building the capacity of Indigenous organisations to deliver these services.

SCfC projects are community-led. Local people have a real say in what services they need and the way they are delivered. Services should be provided by locals too, with support available for Indigenous people to learn new skills to do these jobs if necessary.

Funded under the Indigenous Advancement Strategy's Children and Schooling Programme, the Australian Government has committed \$25.45 million to SCfC through to 30 June 2018.

How does it work on the ground?

A non-government organisation is assigned in each community to be a SCfC Facilitating Partner. Their job is to work with a local Community Board to determine which child, youth and family services are most-needed. The Facilitating Partner then works with other organisations in the community to make sure these services are delivered.

For example, a Community Board may identify that there isn't enough support available for local young mothers. The Board would discuss this with the Facilitating Partner and together they would agree that parenting workshops should be introduced. The Facilitating Partner would then find a service provider to deliver the workshops and work with that provider to ensure the workshops met the community's needs.

To help Community Boards and Facilitating Partners identify the right services and activities to meet their needs, they can seek advice from the SCfC Quality Service Support Panel. The Panel features two research-based organisations: Ninti One (the lead organisation) and Menzies School of Health Research. The Panel provides information and resources around data collection, impact assessment, community engagement and service delivery.

Fact Sheet: Stronger Communities for Children

Who is Stronger Communities for Children for?

- **Children from 0-5 years:** to improve the health and wellbeing of families and the health, wellbeing and early development of young children.
- **Children from 6-11 years:** to assist parents and families build their confidence and parenting skills in meeting their children's developmental needs, ensuring children are nurtured and educated so that they can grow up strong, healthy and confident.
- **Young people 12 years and over:** to improve life choices and outcomes for young people.
- **Families:** to promote safe and healthy social interaction of women, men and families.
- **Men and women:** to provide men and women with greater capacity to meet the needs of their families.
- **Indigenous community services:** to strengthen cooperation and collaboration and avoid duplication of existing community services.
- **Wider community** – to strengthen community capacity, staff development and organisational governance for Community Boards and local service providers.

Where is it happening?

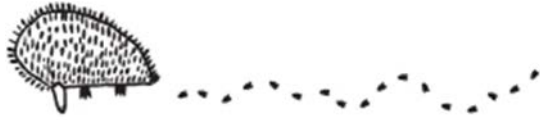
Stronger Communities for Children projects were established in Ngukurr, Galiwin'ku, Wadeye, Ntaria and Santa Teresa in 2013.

In 2015, an additional five projects are being established in Gunbalanya, Maningrida, Utopia Homelands, Atitjere (encompassing Engawala and Bonya) and Lajamanu. Local Community Boards are being established and the Facilitating Partner is consulting with communities on what services are required.

Who are the Facilitating Partners?

- Australia Red Cross in Galiwinku
- Katherine Regional Aboriginal Health and Related Services Inc (KRAHRS) in Ngukurr
- Tharmarrurr Regional Authority Aboriginal Corporation (TRAAC) in Wadeye
- Tjuwanpa Outstation Resource Aboriginal Corporation in Ntaria
- Atyenhenge-Atherre Aboriginal Corporation (AAAC) in Santa Teresa
- Malabam Health Board Aboriginal Corporation in Maningrida
- Adjumarllarl Aboriginal Corporation in Gunbalanya
- Jesuit Social Services Ltd in Atitjere, Engawala and Bonya
- Life Without Barriers in Lajamanu
- Central Australian Youth Link-up Service – Tangentyere Council in Utopia Homelands.

Appendix 8



Stronger Communities for Children Program Evaluation

Community member survey

Stronger Communities for Children Program Evaluation

The SCFC Wadeye program aims to help the community to have a strong connection to country and culture, and that people can enjoy their connections to the lands through cultural activities such as going out bush, fishing, artwork, music and dancing. We want to understand how Aboriginal culture links to health and wellbeing.

We invite you to complete this survey to help us understand how culture links to health and wellbeing, and how the SCFC program helps to support this.

When completing the survey on paper, fill in the whole circle (●) or box (■). Do not tick. You must fill in the whole thing. If you make a mistake, cross it out (✕) and fill in the right circle or box.

I am age 16 years or older ☐ Yes ☐ No

If you are less than 16 years, do not complete this survey. Pass this survey to another Aboriginal person.

I would be willing to participate in a short interview (20-30 minutes) to discuss my participation in the program/s in the SCFC program ☐ Yes ☐ No

I have been provided with information about the SCFC evaluation (in the Participant Information Sheet) including how the evaluation will gather, store, use and disclose information about me. I have been given an opportunity to ask questions and have been fully informed about the SCFC evaluation.

Full name (print): _____

Signature: _____ Date today: ____/____/____

Aboriginal identity, language and culture

Who are your tribal group(s) or Clan(s)? <i>You can list multiple answers.</i>	Tribe(s): _____ Clan(s): _____ Skin name (s): _____ Other: _____ ☐ Unsure
Who are your mother's tribe(s)?	_____ _____ ☐ Unsure
Who are your father's tribe(s)?	_____ _____ ☐ Unsure
Do you know all your (totems) dreaming?	☐ Yes ☐ No ☐ Unsure ☐ Don't have a totem
Do you currently live on your country?	☐ Yes ☐ No ☐ Unsure
How much of your life have you lived on your tribe's country? <i>This includes all country you follow.</i>	☐ None ☐ A little bit ☐ A fair bit ☐ A lot ☐ All of my life ☐ Unsure
<u>If you don't live on your tribe's/mob's country, how often do you visit?</u> <i>Skip this question if you currently live on your tribe's/mob's country.</i>	☐ None ☐ A little bit ☐ A fair bit ☐ A lot ☐ Unsure ☐ Want to but can't
Whose country(s) are you connected with? <i>Select all that apply.</i>	☐ Mother's ☐ Father's ☐ Mother's & father's ☐ Other country ☐ None ☐ Unsure
Do you have special cultural responsibilities for country? <i>Select all that apply.</i>	☐ Yes, mother's side ☐ Yes, father's side ☐ Yes, both mother and father's side ☐ Yes, for other country ☐ No ☐ Unsure
What is Aboriginal culture for you?	

What is the name of the camp, where you live? _____

Aboriginal Language

What is your first language? ☐ Aboriginal language
☐ English ☐ Other

What language do you speak? ☐ English ☐ Marri Amu ☐ Marri Tjevin ☐ Magati Ke
☐ Manthiyangarl ☐ Marrithyel ☐ Marithiel ☐ Marri Ngarr
☐ Murrinh Kura ☐ Murrinhpatha ☐ Djamindjung ☐ Gadjerong ☐ Other

Who in your family speaks Aboriginal languages? *Tick all that apply.*
☐ Partner/Spouse ☐ Children ☐ Parent(s)
☐ Grandparent(s) ☐ Sibling(s) ☐ Cousin(s)
☐ Aunt/uncle(s) ☐ Other family ☐ No one ☐ Unsure

Who in your family speaks English? *Tick all that apply.*
☐ Partner/Spouse ☐ Children ☐ Parent(s) ☐ Grandparent(s) ☐ Sibling(s) ☐ Cousin(s) ☐ Aunt/uncle(s)
☐ Other family ☐ No one ☐ Unsure

Tell us about your Aboriginal language.	Want to but can't	Not at all	A little bit	A fair bit	A lot	Unsure
I am confident in speaking words and language.	☐	☐	☐	☐	☐	☐
It is important that I use words and language.	☐	☐	☐	☐	☐	☐
I feel good when I use words or language.	☐	☐	☐	☐	☐	☐
I am learning language.	☐	☐	☐	☐	☐	☐
My family is interested in keeping language strong.	☐	☐	☐	☐	☐	☐
My community is interested in keeping language strong.	☐	☐	☐	☐	☐	☐
Do you want to speak more English?	☐ No ☐ Yes					

Cultural knowledge and practice: These are things that Aboriginal people have said are important to their culture, but not all Aboriginal people do these things, and that doesn't make you more or less Aboriginal

How much time do you spend...	Want to but can't	Not at all	A little bit	A fair bit	A lot
1. With someone who has cultural knowledge (elder, knowledge holder)?	☐	☐	☐	☐	☐
2. Learning, and using knowledge from Aboriginal Law?	☐	☐	☐	☐	☐
3. Getting or eating bush tucker?	☐	☐	☐	☐	☐
4. Learning culture, Law, kinship and respect?	☐	☐	☐	☐	☐
5. Making art, music and paintings?	☐	☐	☐	☐	☐
6. Passing on cultural knowledge?	☐	☐	☐	☐	☐
7. Participating in social events related to Aboriginal (such as NAIDOC week, Sorry Day events, cultural festivals, corroboree, marches/rallies)?	☐	☐	☐	☐	☐
8. Contributing to your community (e.g. participating in community meetings, organising events, volunteering, healing, being on committees or boards)?	☐	☐	☐	☐	☐
9. Receiving Aboriginal healing methods (e.g. traditional healers, bush medicine)?	☐	☐	☐	☐	☐

Have you ever felt disconnected from culture? ☐ Not at all ☐ A little bit ☐ A fair bit ☐ A lot ☐ Unsure

If you have ever felt disconnected, have you ever done any of these? Skip if you answered 'not at all' above.

	Want to but can't	Not at all	A little bit	A fair bit	A lot
Corroboree	☐	☐	☐	☐	☐
Caring for country	☐	☐	☐	☐	☐
Going out on country	☐	☐	☐	☐	☐
Hunting for bush tucker	☐	☐	☐	☐	☐
Learning language, culture and kinship	☐	☐	☐	☐	☐
Art, music or painting	☐	☐	☐	☐	☐
Bush medicine/healing	☐	☐	☐	☐	☐
Talking to elders	☐	☐	☐	☐	☐
Yarning	☐	☐	☐	☐	☐
Other: _____	☐	☐	☐	☐	☐

Community relationships/cohesion

In my Aboriginal community....(where I live now)	Not at all	A little bit	A fair bit	A lot
1. There are people with cultural knowledge (cultural bosses, elders) I can go to or yarn with.	☐	☐	☐	☐
2. There are places where people meet (can come together).	☐	☐	☐	☐
3. There are leaders.	☐	☐	☐	☐
4. We cope with problems (violence).	☐	☐	☐	☐
5. We work together.	☐	☐	☐	☐
6. Local Aboriginal people make community decisions.	☐	☐	☐	☐
7. We respect the decisions made by our local community leaders.	☐	☐	☐	☐
8. The decisions we make are respected by outsiders.	☐	☐	☐	☐
9. Outsiders have the final say in decisions about the community.	☐	☐	☐	☐
10. I can get involved in community discussions.	☐	☐	☐	☐
11. I trust the leaders.	☐	☐	☐	☐
12. I feel listened to.	☐	☐	☐	☐
13. I feel respected.	☐	☐	☐	☐
14. I feel safe.	☐	☐	☐	☐
15. I feel like a role model.	☐	☐	☐	☐
16. I feel like a leader.	☐	☐	☐	☐
17. I feel like I belong.	☐	☐	☐	☐

Have you ever participated in:
Select all that apply

- ☐ Women's Culture Program ☐ Early Childhood Program
☐ Youth Leadership Program ☐ After Hours Program ☐ AFL Program
☐ Men's Shed Program ☐ Healthy Homes Program

Have any children in your care, and are under the age of 16 years, participated in:
Select all that apply

- ☐ Youth Leadership Program ☐ After Hours Program ☐ AFL Program

How many months have they participated in this program(s)? _____ months

How much do they enjoy attending the program(s)?	Not at all	A little bit	A fair bit	A lot
1. Youth Leadership Program	☐	☐	☐	☐
2. After Hours Program	☐	☐	☐	☐
3. AFL Program	☐	☐	☐	☐

About you:

What is your gender?

☐ Male ☐ Female ☐ Other

Date of birth (day/month/year)

___/___/___

Have you ever had any children?

☐ No ☐ Yes

If yes, how old were you when you had your first child? ___ years

How many children do you care for (in the home and outside the home)?

___ ☐ None

Do you sleep in the same place/ house each night?

☐ No ☐ Yes

Who lives with you? *Select all that apply.*

- ☐ My partner or spouse ☐ My children ☐ Someone else's children
☐ My parent(s) ☐ My grandparent(s) ☐ My sibling(s)
☐ My cousin(s) ☐ My Aunt(ies) or Uncle(s) ☐ Other family
☐ Other friends or visitors

What best describes your current relationship situation?

☐ Married ☐ Separated ☐ Divorced
☐ Widowed ☐ De facto ☐ Single ☐ Other

Which of the following describes your employment? *Select all that apply.*

- ☐ Casual paid work ☐ Part-time paid work ☐ Full-time paid work
☐ Self-employed ☐ Studying full-time ☐ Studying part-time
☐ Part-time unpaid carer ☐ Full-time unpaid carer
☐ Paid carer (carer's pension) ☐ Disabled/sick
☐ Retired ☐ Unemployed ☐ Other, specify: _____

What is the highest education you have completed?

- ☐ No school ☐ Primary school
☐ Year 10 (School or Intermediate certificate)
☐ Year 12 (Higher school, leaving certificate, College)
☐ Certificate or diploma (e.g. child care worker, mechanic)
☐ University

Have you ever been in prison or youth detention?

☐ No ☐ Yes, prison ☐ Yes, youth detention

Select all that apply.

Which words best describe your family's money situation?

- ☐ We have a lot of savings
☐ We can save now and then
☐ We have just enough to get us to the next payday
☐ We run out of money before payday
☐ We are spending more than we get
☐ Unsure

Do you receive any welfare payments? (*Centrelink*)

☐ No ☐ Yes ☐ Unsure

Do you have a Basics Card? (*Cashless debit card*)

☐ No ☐ Yes ☐ Unsure

Wellbeing and health

How would you rate your general health? ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

How satisfied are you with your life? ☐ A lot ☐ A fair bit ☐ A little bit ☐ Not at all

How much are you in control of your life? ☐ A lot ☐ A fair bit ☐ A little bit ☐ Not at all

In the last 4 weeks about how often did you ...	All of the time	Most of the time	Some of the time	A little of the time	None of the time
... feel happy?	☐	☐	☐	☐	☐
... feel worried?	☐	☐	☐	☐	☐
... feel nervous?	☐	☐	☐	☐	☐
... feel hopeless (have no hope)?	☐	☐	☐	☐	☐
... feel restless or jumpy?	☐	☐	☐	☐	☐
... feel everything was an effort (have no energy)?	☐	☐	☐	☐	☐
... feel sad?	☐	☐	☐	☐	☐
... feel pain? If yes, what kind of pain: _____	☐	☐	☐	☐	☐

Are you woken up in the night? ☐ Not at all ☐ A little bit ☐ A fair bit ☐ A lot

How often do you eat bush foods? ☐ Not at all ☐ A little bit ☐ A fair bit ☐ A lot ☐ Want to but can't

Are there days when you don't have enough food and feel hungry? ☐ No ☐ Yes ☐ Unsure

If yes, how often does this happen? ☐ Never ☐ More than once a week ☐ Once a week
☐ Once a month ☐ A few times a year ☐ Unsure

In the last 6 months, how many times have you gone to the clinic? ____ times ☐ Unsure

In the last year, have you had a Health Check? ☐ No ☐ Yes ☐ Unsure ☐ Not relevant

Mark the box for the day you exercised <u>last week</u> ? Exercise is walking for 10 minutes or more. Tick all the days you did exercise.	Day of the week						
	Mon	Tues	Weds	Thurs	Fri	Sat	Sun
	☐	☐	☐	☐	☐	☐	☐
How long did you exercise?	___ min	___ min	___ min	___ min	___ min	___ min	___ min

Your experiences

Are any of these a problem in the community?	Not at all	A little bit	A fair bit	A lot	Unsure
1. Dogs?	☐	☐	☐	☐	☐
2. Feeling unsafe?	☐	☐	☐	☐	☐
3. Drinking too much grog?	☐	☐	☐	☐	☐
4. Tobacco smoking?	☐	☐	☐	☐	☐
5. Drugs?	☐	☐	☐	☐	☐
6. Sniffing?	☐	☐	☐	☐	☐
7. Racism?	☐	☐	☐	☐	☐
8. Gambling (card games)?	☐	☐	☐	☐	☐
9. Family violence?	☐	☐	☐	☐	☐
10. People fighting or not getting along?	☐	☐	☐	☐	☐
11. Humbugging (people wanting stuff all the time)?	☐	☐	☐	☐	☐
Other problems? Explain: _____	☐	☐	☐	☐	☐

In the last year, have you had problems with any of these in your home?	No	Yes	Not relevant
1. Problems with the water connection or plumbing?	☐	☐	☐
2. Problems with water quality (for example, taste bad, wrong colour)?	☐	☐	☐
3. Problems with gas supply and/or electricity?	☐	☐	☐
4. Problems with stove, oven or other cooking facilities?	☐	☐	☐
5. Problems with fridge and/or freezer?	☐	☐	☐
6. Problems with facilities for washing/laundry?	☐	☐	☐
7. Not able to make the home warm enough during winter?	☐	☐	☐
8. Not able to make the home cool enough during summer?	☐	☐	☐
9. Not able to get things fixed?	☐	☐	☐
10. Pests such as cockroaches, spiders?	☐	☐	☐

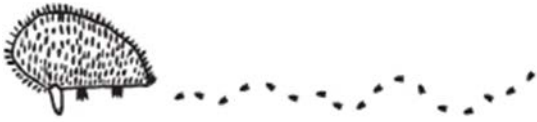
Have any of these happened to you in the last year?	No	Yes	Not relevant
1. Been badly hurt or sick?	☐	☐	☐
2. Family member or friend passed away?	☐	☐	☐
3. Lost a job?	☐	☐	☐
4. Problems at work?	☐	☐	☐
5. Humbugged (people wanting stuff all the time)?	☐	☐	☐
6. Had an alcohol or drug problem?	☐	☐	☐
7. Experienced or saw violence?	☐	☐	☐
8. Had stuff stolen (mobile phone, other valuables)?	☐	☐	☐
9. Been arrested, been in youth detention or prison, or had problems with the police?	☐	☐	☐
10. Children seeing bad fights in the family?	☐	☐	☐
11. Split up / relationship breakdown?	☐	☐	☐
12. Children were taken away?	☐	☐	☐

Family support and connection

In my family...	Not at all	A little bit	A fair bit	A lot
1. We get on together and cope in the hard times.	☐	☐	☐	☐
2. We like to remember and celebrate special days/events.	☐	☐	☐	☐
3. We talk with each other about the things that matter.	☐	☐	☐	☐
4. We are always there for each other.	☐	☐	☐	☐
5. We manage money and make good decisions.	☐	☐	☐	☐
6. We have common interests.	☐	☐	☐	☐
7. People are accepted for who they are.	☐	☐	☐	☐
8. We have good support from mob.	☐	☐	☐	☐
9. We have family knowledge and traditions that we pass on to our children.	☐	☐	☐	☐

Thank you very much for taking part.

Appendix 9



Stronger Communities for Children Program Evaluation

Community Researcher Training Manual



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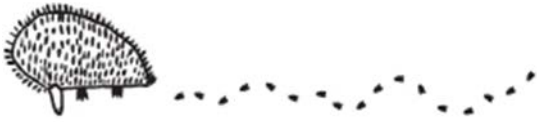
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1. Mayi Kuwayu Study Framework

The National Study of Aboriginal and Torres Strait Islander Wellbeing (Mayi Kuwayu) will be the first comprehensive Study to look at how Aboriginal and Torres Strait Islander culture relates to health and wellbeing. This includes how connection to country, cultural practices, ritual, spirituality and language use impact health and wellbeing outcomes over time.

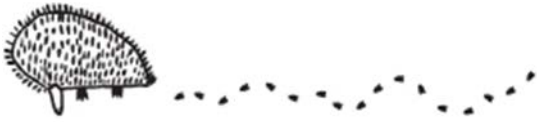
The SCFC program evaluation is informed by the Mayi Kuwayu National study framework. An adapted version of the study survey will be administered in the SCFC program evaluation.

2. What is the Stronger Communities for Children (SCFC) Program evaluation about?

The SCFC Wadeye program includes a number of program activities for the Wadeye community, and they are:

- Women's Culture program
- Men's Shed program
- Early Childhood program
- Youth Leadership program
- Wadeye AFL program
- Healthy Homes program
- After Hours program

The SCFC Wadeye program aims to help the community to have a strong connection to country and culture, and that people can enjoy their connections to the lands through cultural activities such as going out bush, fishing, artwork, music and dancing. The program also helps people in the community to be healthy by playing sport, cooking classes and having healthy homes.



The Aims of the SCFC evaluation

The evaluation will use a survey, focus groups and interviews to ask people about their culture, community, families and wellbeing. This information will help the SCFC program, to see if the program activities (listed above) are helpful or not helpful for people and their families in Wadeye. It is also important to find out information even if community members are not part of any of the program activities. The evaluation is interested in capturing how community members in Wadeye view culture, and what culture means to them. The SCFC survey will capture if community members participate in culture, and if the SCFC program helps this to happen.

The evaluation will provide baseline data for the SCFC program, which will help to inform the program activities. Administering the survey in the future at different points in time, will enable change to be measured, and show the impact of the SCFC program on the community.

STUDY ETHICS: The Evaluation of Stronger Communities for Children, Wadeye is conducted with ethical approval from Human Research Ethics Committees (HREC No 2018/096) from the Australian National University (ANU).



3. Inclusion and Exclusion Criteria

Surveys need inclusion and exclusion criteria. This means, there also needs to be rules about what makes someone suitable or unsuitable for the surveys. If you are talking to a person about participating and they are angry, or very anxious, you should not interview them. Safety for the interviewer and the interviewee must be the overriding principal. It might be difficult to assess these criteria yourself. Trust your own opinion and always make sure someone is in the vicinity for any assistance.

Inclusion Criteria

- ☒ Anyone living in Australia who identifies as Aboriginal and/or Torres Strait Islander
- ☒ Any Aboriginal and/or Torres Strait Islander person 16 years or older.

Exclusion Criteria

- ☒ Anyone who is not Aboriginal and Torres Strait Islander
- ☒ Anyone Drunk / stoned / high
- ☒ Anyone displaying signs of extreme distress or mental illness
- ☒ Anyone showing signs of anger / distress
- ☒ Anyone aged younger than 16 years



4. Outcomes and Future Plans

The primary expected outcome from information from the SCFC evaluation will give us a better understanding of how Aboriginal people in Wadeye participate in culture and how it relates to health and wellbeing.

At the completion of the evaluation a report will be provided to the SCFC Facilitating Partner, and the results will be provided back to the community. In addition, the methods utilised for each component of the evaluation will be documented as a resource for communities.

This evidence could also inform individual behaviour; for example, it might encourage cultural engagement and revitalisation by individuals and communities, which could in turn lead to an associated improvement in wellbeing.

Consent: Participation in the SCFC evaluation is voluntary. Participants can say no or withdraw consent at any time. Potential participants will receive a plain English information sheet about the evaluation, consent form and a questionnaire.



5. Data Collecting

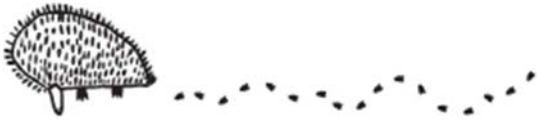
Data will be collected from multiple sources using several methods including; surveys, interviews and focus groups.

Any findings from the evaluation will require approval from the PWAC before they can be more widely disseminated. With approval, findings will be disseminated through community dissemination meetings, a community report and feedback sheets, policy briefs, manuscripts for peer-reviewed publication, conference presentations, and public seminars.

This evaluation is bound by strict privacy laws. All information collected will be treated completely confidentially and used for this evaluation only. No information will be reported in a way that will allow the participant to be identified.

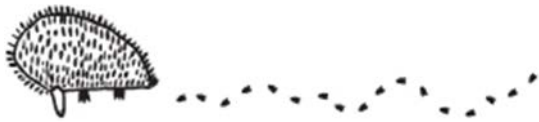
6. Follow-up surveys

Participants in the baseline survey will be followed up by survey every 12 months, or as funding allows. Follow-up surveys will maintain the core components of the baseline survey, with potential for addition or removal of questionnaire items depending on priority and resourcing. Follow-up surveys will be undertaken by the SCFC Facilitating Partner, and in partnership with community researchers.



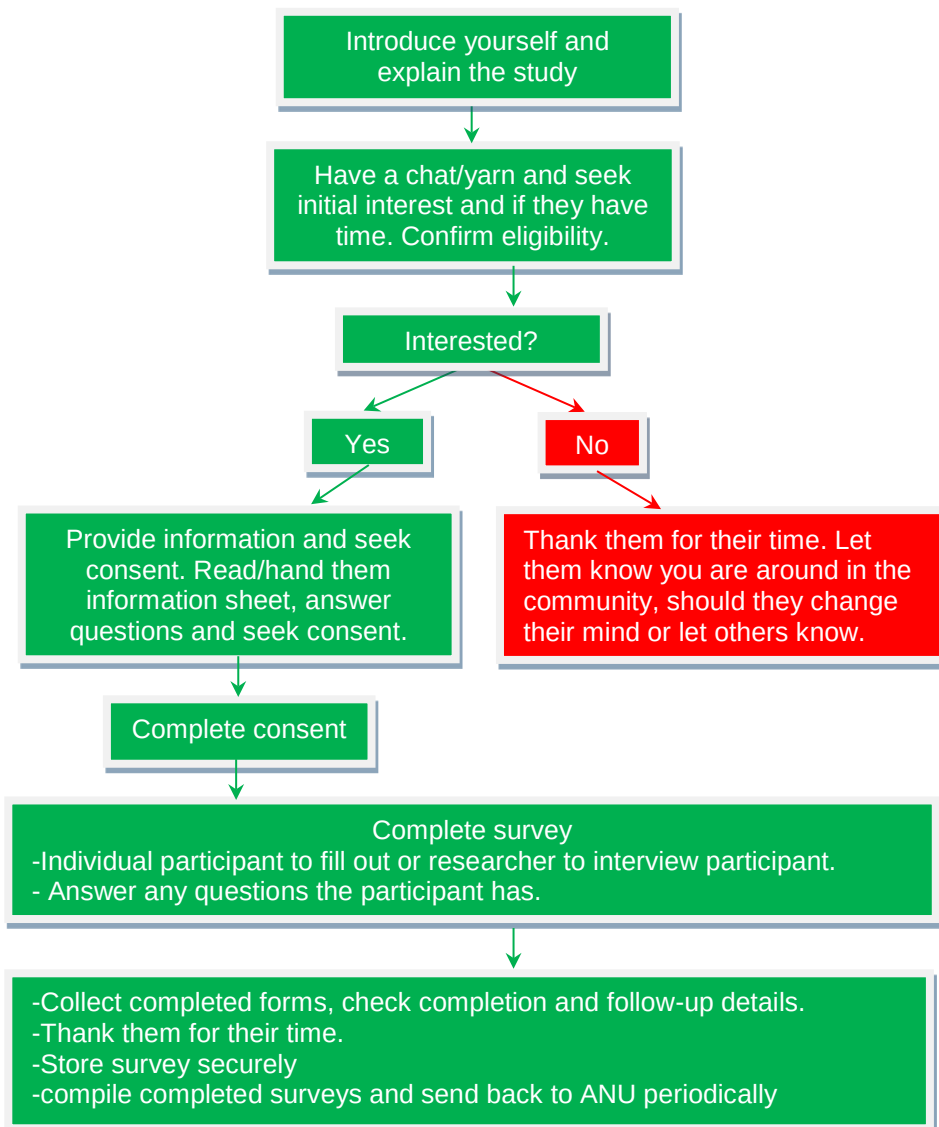
7. Procedural Instructions:

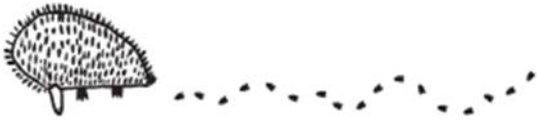
- 0 The Community Researcher should first make contact with community leaders or governing organisation within the community they are intending to visit. The contact person or organisation should be provided with all available information before any commitment. The contact may have suggestions on how and where to best commence with the surveys.
- 0 For each potential participant you will need to make an assessment that the person is ok to potentially complete the survey. Examples of when to not engage someone for participation is if they are under the influence of any drug or if they appear distressed. If someone is distressed, ensure they are referred back to PWAC or other services.
- 0 Participants will need to be completely informed about the survey. The Community Researcher must always have the SCFC evaluation Participant Information sheet for distribution. Participants can read the Information sheet or choose to have it read to them. At this stage, the participant may have questions regarding the survey. This is an appropriate time to answer any questions and concerns.
- 0 Before the survey can commence, the consent section must be completed and signed.
- 0 If the participant is at ease with completing the survey after signing the consent form then let them continue. However, if they have difficulties in completing it, you can assist the participant.
- 0 Upon completion of the survey, all paperwork is to be securely stored until either handed over to the co-ordinator, or sent to the Aboriginal and Torres Strait Islander Health Program, ANU, Building 62, Mills Road, Acton, ACT, 2601



Who can be involved in the survey, interview or a focus group?

Inclusion Criteria	Exclusion Criteria
✓ Aged 16 years and older ✓ living in Australia who is Aboriginal and/or Torres Strait Islander	✗ Aged younger than 16 years ✗ A non-Indigenous person





8. Safety Protocols

A. If a participant's is distressed, upset or angry during the survey, the Community Researcher may need to take the following actions:

1. Stop the survey and listen to the participant.
2. Encourage the participant to contact their support network (family and friends).
3. Ensure the participant has the information brochure, and it includes local support services (clinic, Lifeline, Beyond Blue).
4. Help the participant to contact a support service, if they need help.
5. Indicate that, with the participant's permission, a Community Researcher will contact him/her the next day to see if he/she is okay.

B. If the survey work is in any way associated with danger (directed at survey participant, researcher or other community members), the following actions will be taken by the Community Researcher:

1. Stop the survey.
2. Ensure the personal safety of yourself and others.
3. Communicate to the participant that their safety and the safety of others is of upmost importance.
4. Contact 000 emergency services, and if appropriate communicate to the participant/others that emergency services will be called.
5. Indicate that, with the participant's permission, a Community Researcher will contact him/her the next day to see if he/she is okay.



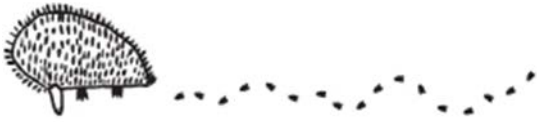
9. FOLLOW-UP OF INCIDENT

The Community Researcher / ANU Research team will complete a short report of the incident. All incidents will be discussed with in the research team and follow-up action will be agreed. Researchers involved in incident will be supported to access counselling or other support services.

The ANU Research Team will be available for advice on dealing with distress. Additionally, they will store incident reports and follow-up with the Community Researcher involved after the event.

IMPORTANT services:	Number
Wadeye Community Health Centre	(08) 8978 2360
Local Police	(08) 8978 2366
PWAC	0477 555 365
Catholic Care NT	(08) 8978 2515
Top End Mental Health Services	(08) 8999 4988
Somerville Community Services Darwin Address	(08) 8920 4100
Northern Territory Mental Health Line	1800 682 288
Kids Helpline	1800 55 1800
Lifeline	131114
Mensline	1300 789 978
Parentline	1300 30 1300
Anglicare	(08) 8928 1189
Beyond Blue	1300 22 4636

The SCFC Program Co-ordinators will be available for advice on dealing with distress, if required. Additionally, they will store incident reports and follow-up with the Community Researcher involved after the event. The SCFC Program Co-ordinators will also be available for advice on and follow-up from the de-escalation.



10. Self-Care

Self-care refers to activities undertaken with the intention of enhancing energy, restoring health and reducing stress. Having a balance across mental, physical, social & spiritual health leads to overall wellbeing.

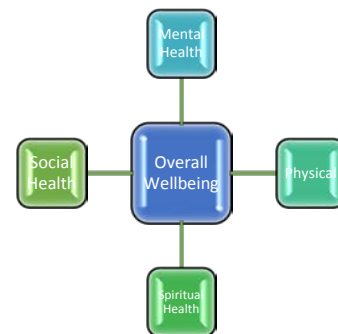
Everyone is different, and so are the ways to look after your own mental health. Strive for balance between your work and your personal life.

- Community Researchers need the ability to de-brief. As a Researcher you may choose to do this with either a professional person (Psychologist) or through counselling, a self-help group or with just talking to someone.
- Cope with stressful events and sadness;
- Maintain positive connections with others; talk to others.
- To benefit ourselves, our families and those in our care, Community Researchers need to be aware of their own health and wellbeing
- Bearing the load of community expectation can be very tiring when combined with the responsibilities of work and family. We need to be mindful of our workloads.

http://himh.clients.squiz.net/data/assets/pdf_file/0011/10541/Wellbeing-and-self-care-Final.pdf

Reach out for support when you need it, through:

- Family
- Friends
- GP
- Psychologist
- Work colleague
- Lifeline
- 24-hour support service





11. Contacts

Name	Role	Location	Phone	Email
PWAC	Community Organisation	Wadeye	0477 555 365	scfc.admin@wpw.org.au
Ray Lovett	Research team	Canberra, ANU	0418627446	raymond.lovett@anu.edu.au
Bobby Maher	Student – Research team	Canberra, ANU	0416 876 896	U6265603@anu.edu.au
Men's Shed Program	Program Coordinator	Jason Sellaiah	0403 453 010	Jason.Sellaiah@thamarrurr.org.au
Women's Cultural Program	Program Coordinator	Isabelle Walsh	0438 200 809	scfc.projects@wpw.org.au
Early Childhood Program	Program Coordinator	Miromiro Kelly	0477 555 365	ECEC@wpw.org.au
Youth Leadership Program	Program Coordinator	Justin Crawley	0458 235 482	Justin@ty.org.au
After Hours Program	Program Coordinator	Justin Crawley	0458 235 482	Justin@ty.org.au
AFL Program	Program Coordinator	Josh Connell	0424 038 133	Josh.Connell@afl.com.au
Healthy Homes Program	Program Coordinator	Nola Foster	0438 754 436	nola.foster@thamarrurr.org.au
ANU Ethics	Australian National University			Human.ethics.officer@anu.edu.au

Appendix 10



The Stronger Communities for Children Evaluation

INTERVIEW GUIDE TO BE USED TO GUIDE DISCUSSION WITH KEY PARTICIPANTS

NOTE: These are only guiding themes that will be covered during discussion.

Key themes for data collection from semi-structured interviews and focus groups:

We are interested in hearing about culture and what it means to you. We would like to know if you participate in culture and if the Stronger Communities for Children program helps for this to happen.

Participant information

Introduction and ethical consent

Thank participants for agreeing to take part – mention that the discussion should last about 20-30 minutes.

****Talk through participant information sheet and consent form****

Emphasis: There are no right or wrong answers – I am just interested in finding out their views and opinions. Explain that I have a series of open ended questions, and that the discussion will be directed by these and the responses provided.

Reassure the participants of confidentiality – I will not attribute comments to them.

Explain that they can choose whether to answer the questions or not, and can opt out at any point during the conversation if they feel uncomfortable.

Refer to the Consent Form re consent to record the interview or focus group discussion – for accurate record of their responses and analysis purposes.

Explain that participants should avoid disclosures of illegal behaviour (e.g. illicit drug taking or family violence) which may have mandatory reporting consequences.



General cultural participation questions

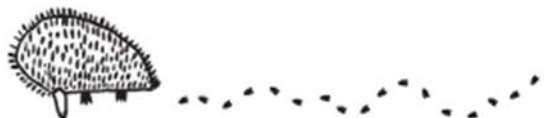
- Can you tell me a little bit about culture in Wadeye?
 - What makes culture strong? Is it a particular activities or storytelling?
 - Are there some parts of culture that doesn't get shared? Why do you think this happens?

- What activities are you doing that are helping you to connect with culture?
 - Do you do these by yourself or with other people, like family?
 - How does this make you feel when you are connecting with culture?
 - Are there other activities that you would like to be doing that connect you with culture?

- Do you think it's important to share knowledge of culture with your children or the younger members of the community?
 - Why do you think that this is important/ or not important?
 - What things about culture are important for the children and younger members in the community to know about and practice?
 - What about for teenagers and young adults, how do you think they engage with culture and is it still important to them? Why/why not?
 - How do you share culture?

- How can cultural knowledge and education work for young people and children in Wadeye? How could this work in the school? Or should this happen outside of school?
 - Is it happening in school?
 - If it is, what's happening?
 - What else is needed?

- What events could be done in the community to share culture and knowledge?



PARTICIPANT INFORMATION SHEET

Researchers: The research team undertaking the evaluation include community researchers from Wadeye community and the ANU. Community researchers will assist in translating English terminology to the Murrinhpatha language. We are Aboriginal students completing the MPhil in Applied Epidemiology (MAE) at the National Centre for Epidemiology and Population Health, at the Australian National University in Canberra. Our ANU supervisors support us, and our details are below:

Name	Department
Bobby Maher - student	Natl Centre for Epidemiology & Population Health, CHM Research School of Population Health, ANU
Raymond Lovett - supervisor	Natl Centre for Epidemiology & Population Health, CHM Research School of Population Health, ANU
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Roxanne Jones - student	Natl Centre for Epidemiology & Population Health, CHM Research School of Population Health, ANU
Tamara Riley - student	Natl Centre for Epidemiology & Population Health, CHM Research School of Population Health, ANU

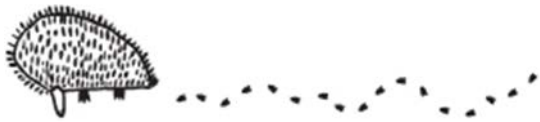
Project Title: Evaluation of the Stronger Communities for Children Program

This project is a partnership between Palngun Wurnangat Aboriginal Corporation and the Australian National University (ANU).

General Outline of the Project:

- **What is the Stronger Communities for Children program:** The SCFC Wadeye program includes a number of program activities for the community, and they are:
 - o Women's Culture program
 - o Men's Shed program
 - o Early Childhood program
 - o Youth Leadership program
 - o Wadeye AFL program
 - o Healthy Homes program
 - o After Hours program

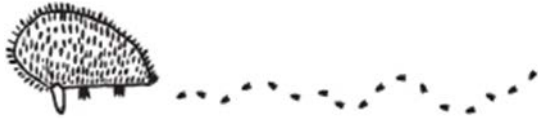
The SCFC Wadeye program aims to help the community to have a strong connection to country and culture, and that people can enjoy their connections to the lands through cultural activities such as going out bush, fishing, artwork, music and dancing. The program also helps people in the community to be healthy by playing sport, cooking classes and having healthy homes.



- **What is the evaluation for?** The evaluation will use a survey to collect information about culture, community, family and wellbeing. This information will help the SCFC program, to see if the program activities (listed above) are helpful or not helpful for people and their families in Wadeye. It is also important to find out information even if you are not part of any of the program activities.
- **Participants:** Any Aboriginal person in Wadeye who is over 16 years of age can participate in the interviews, even if they are not part of the SCFC program activities.
- **Use of Data and Feedback:** The information collected in the survey will help to understand how people are able to participate in culture and if this occurs through the SCFC program activities or through other ways. This information will feed into the main findings of the evaluation and help to write a summary report on this research that will provide relevant information to the SCFC program. The summary report will be shared with you, and there will be an opportunity for you to provide feedback and comments. The ANU research team will come back to Wadeye to share the findings from the evaluation to the community, and these can be included in the SCFC Newsletter. The main findings from the evaluation will also be included into a chapter for our thesis and potentially a journal article.

Participant Involvement:

- **Voluntary Participation & Withdrawal:** Participation in the project is voluntary. If you choose to participate in the survey, you may answer or not answer as many questions as you wish. You may decline to take part in the study or withdraw from the study at any time until the work is published. You do not need to provide a reason for not participating or withdrawing, and you will face no penalties or consequences.
- **What does participation in the research request of you?** To take part you need to complete the survey. This will take about 20 minutes and a local community researcher and a program coordinator will be there to help you. The survey will take place at the locations where the SCFC program activities are, and at PWAC. You will have options to participate in a group administered survey with a community researcher or you can complete independently with the guidance of a community researcher. You can also choose to take the survey home and complete it there with a family member, and return it back to PWAC. Your signature on the consent form is important, so please make sure that the consent form is signed before returning it. Some ANU and community researchers will follow up with some short face-to-face interviews (20-30 minutes) or focus groups to discuss the program activities, and how you engage in culture. Select this option on the front page of the survey and provide your contact details if you agree to be contacted for the interviews or focus groups.
- **Location and Duration:** The surveys will take place in Wadeye at PWAC during April and May 2018. The community researchers and SCFC program coordinators will provide assistance.
- **Risks:** There may be a risk of third-party identification, given the involvement of a community researcher who is also a member of the community. This means that it is possible that you might be identified in the research output coming from this discussion, despite my efforts to hide your identity. We will not mention any names, locations, or other identifying information in any research output. If you are concerned about the possibility of being identified, we can discuss if any particular references or comments need to be removed from research output. There is a slight possibility of distress or



discomfort from being asked to reflect on sensitive or personal matters. Please remember that you are free to refuse to answer any or all questions.

If you require any social and emotional wellbeing support, please contact Somerville (08) 8920 4100, Catholic Care NT (08) 8978 2515, Lifeline on 13 11 14 or www.lifeline.org.au or drop in to the Wadey Community Health Centre. You will be provided with a copy of a list of services providing additional support for the region. The community researchers will also have a copy.

Confidentiality:

- **Confidentiality:** Only members of our research team will be able to see the notes from our discussion. We will seek to provide confidentiality as far as allowed by law. We advise that all members of the discussion should also maintain confidentiality of the discussion, and not share anything that was discussed beyond the group. We cannot guarantee this group confidentiality. During the focus group discussion, I advise that you avoid making statements of a confidential nature or statements that are defamatory of any person.

Privacy Notice:

- **The ANU Privacy Policy** is available at https://policies.anu.edu.au/ppl/document/ANUP_010007 and it contains information about how a person can: access or seek correction to their personal information; complain about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint.

Data Storage:

- **Where:** During the project, the data (notes from the discussion) will be stored electronically, with personal identifiers removed as requested, on a password protected server at the Australian National University.
How long: Data will be stored for five years after any articles have been published.
Destruction of Data: At the end of the storage period, all copies of the data will be destroyed.

Queries and Concerns:

Contact Details for More Information: If you have any questions, comments or concerns about the evaluation, you can call Rob Faughlin at SCFC on 0477 555 365, or Bobby Maher (0416 876 896; u6265603@anu.edu.au) or Ray Lovett (02 6125 5619; Raymond.Lovett@anu.edu.au) or Katie Thurber (02 6125 5615; Katherine.thurber@anu.edu.au).

Ethics Committee Clearance:

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (Protocol 2018/096). If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager
The ANU Human Research Ethics Committee
The Australian National University
Telephone: +61 2 6125 3427
Email: Human.Ethics.Officer@anu.edu.au



ORAL CONSENT SCRIPT for Participants

Evaluation of the Stronger Communities for Children Program

I have read to you the Information Sheet about the research project. Was this information clear? Do you have any questions about the project?

Do you agree to participate in this project? (Record the answer as Yes/No)

Do you agree for this interview or focus group to be audio-recorded? (Record the answer as Yes/No)

When I prepare the research outputs, I can attribute information to you in two ways: community member, or I can use NO attribution and hold your information confidentially.

- Would you like information attributed using 'community member'? (Record Yes/No)
- Would you prefer that your information be not attributed? (Record Yes/No)

May we start the interview now?

Record the date of this script being read

Appendix 11

Lesson from the field

Bobby Maher – April 2018

Introduction to program logic models

This lesson from the field (LFF) is a self-directed learning exercise and will be emailed on Monday 9 April 2018. Please send your answers by 5pm Monday 30 April AEST. It should only take approximately 1 hour to complete.

The teleconference is scheduled for 3pm AEST on Thursday 3 May 2018. The dial-in details will be sent out 2-3 days before.

Please call 0416 876 896 if you have any problems during the teleconference.

Instructions

- This LFF requires you to:
 - read the NSW Government Health guide to Developing and Using Program Logic <http://www.health.nsw.gov.au/research/Publications/developing-program-logic.pdf>
 - watch [Logic Models in Public Health](#)
 - read the MAE Student Guide (attached with this document)
 - answer questions about constructing and using a logic model

Learning objectives

- To describe what a logic model is
- To identify when a logic model might be useful
- To construct a logic model to direct an evaluation

Scenario

As a team we have been tasked with evaluating the Masters of Philosophy in Applied Epidemiology (MAE) by the ANU. There is limited baseline data available on overall program outcomes, however there are data available on completion of coursework. Our first cohort will be the 2016 cohort to capture baseline data, given they have completed the MAE. Our aim is to produce a program logic model to inform the direction of the evaluation.

A program logic is a useful tool in program planning and evaluation because it captures the story of how the program is proposed to work and shows easily understandable relationship between program activities and the intended outcomes of the program. A program logic is a "living document", that is, it should be reviewed regularly to see if it is still an accurate representation of the program or if it needs to be adapted. As evaluators, we are able to make assumptions about the program and then test these with evidence (ref).

Question 1: List the reasons why it would be useful to construct a logic model to undertake this evaluation in your own words, including two things that are not mentioned in the resources - NSW Health document and video.

Logic model design

The team has decided that a logic model will be useful to inform the direction of the evaluation, and what components of the MAE are important to capture in the evaluation. We will use a pipeline program logic model which will include **inputs, activities, outputs, outcomes (short, mid and long term) and impact**. The next few questions ask you to fill out a logic model (Figure 1.) to gather information that is based on what you know about the MAE and your understanding of the requirements. Please refer to the MAE Student Guide. There are many different approaches to developing a logic model. We will be using a backcasting approach to construct the logic model (refer to 5.2 NSW Health document).

Impacts

It's often good to start at the "end" and fill out the program impacts section first. This should be what is expected to happen in 5-10 years, given successful implementation of the rest of the logic model. Impacts are usually expressed at the population level. Logic models rely on "if...then" logic, meaning if the preceding step is achieved (i.e., the outcomes), then the impacts are more likely occur.

Question 2

Please enter a maximum of 2-3 impacts of the program in the model.

Outcomes

These changes will be expected in the course of the MAE program (fulltime or part-time). Outcomes are the benefits of the program for the scholar, and is usually expressed at an individual level. Using the "if...then" logic, if the activities are implemented as planned then the outcomes should benefit the scholars.

Question 3

Working backwards from the impacts, please enter 2-3 outcomes into the model. One has been entered for you as an example.

Activities

For now, skip outputs and move to the activities panel. Activities are the specific actions that scholars will undertake as part of the program. Think about, *if* you have the inputs required of the program, *then* you can perform the activities.

Question 4

What activities would you implement to achieve the outcomes and impacts you listed earlier? Think about the actions that has been required of you as a scholar in the MAE, in order to meet the outcomes that you have identified. Please enter 2-3 activities into the model. One has been entered for you as an example.

Outputs

These represent evidence of the program activities, or the outputs being the results of the activities. *If* the activities are implemented as planned, *then* the intention is that the program will be delivered as intended.

Question 5

Please enter 2-3 outputs of the activities you entered earlier in the model. One has been entered for you as an example.

Inputs

Question 6

What resources do you need to complete the activities? These may include internal and external resources. Please enter these into the model. One has been entered for you as an example.

The complete model

Question 7

Looking at the completed logic model, what are the most important aspects of the program that we should evaluate?

Program evaluation

Question 9

What questions could be useful for evaluating the program at points 1 and 3?

Thanks for taking the time to complete, hope you learnt something new!

Key References:

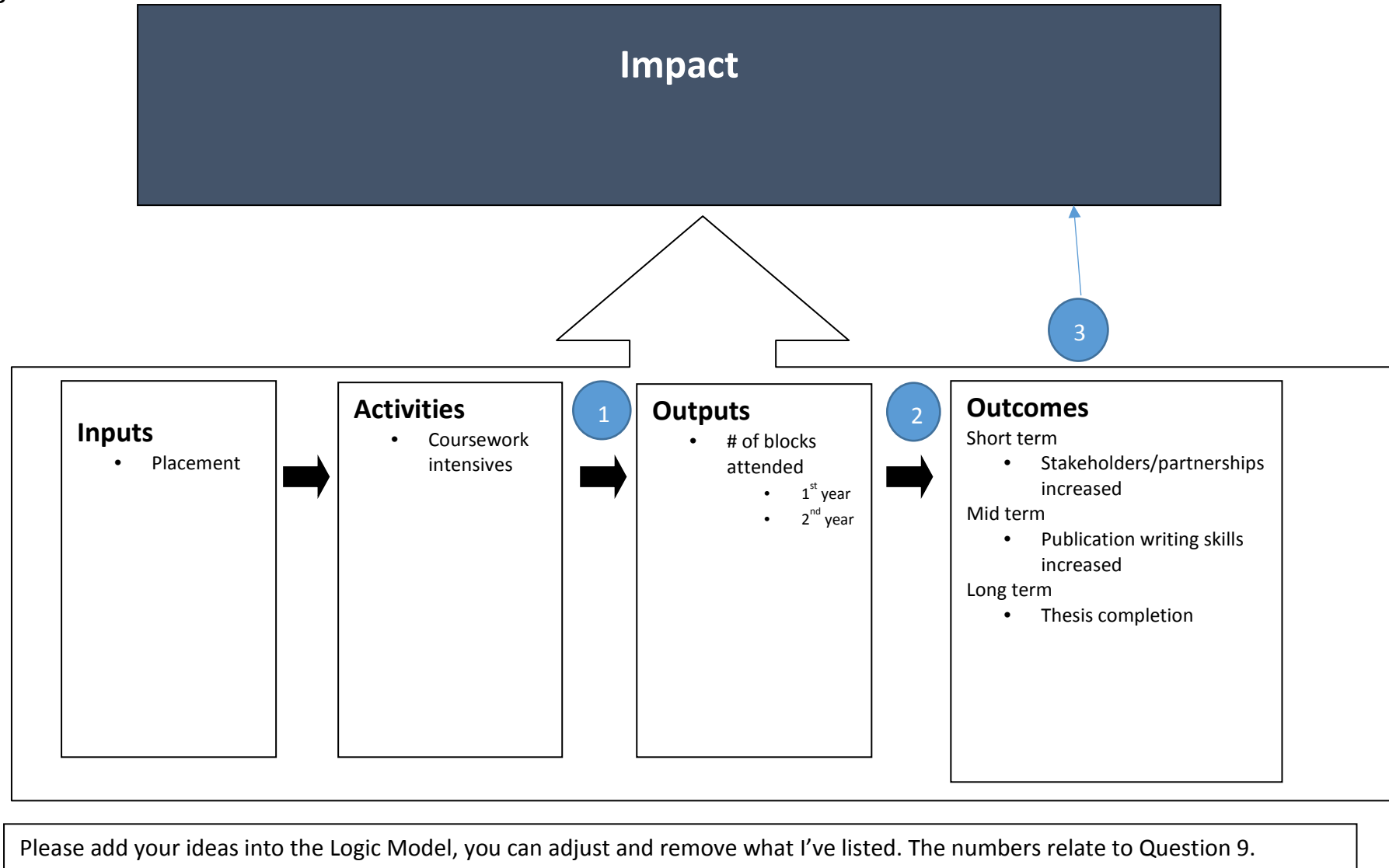
http://www.betterevaluation.org/en/resources/guide/logic-model_tutorial
(accessed March 2018)

http://www.betterevaluation.org/en/plan/define/develop_logic_model
(accessed March 2018)

W.K. Kellogg Foundation. Logic Model Development Guide. Michigan: W.K. Kellogg Foundation, 2004.
Public Health Centers for Excellence. Logic Models in Public Health, 2015.
<https://www.youtube.com/watch?v=IHep0gJRTwl> (accessed Mar 2018)

Centre for Epidemiology and Evidence. Developing and Using Program Logic: A Guide. Evidence and Evaluation Guidance Series, Population and Public Health Division. Sydney: NSW Ministry of Health, 2017

Figure 1. Logic Model



Appendix 12

Evaluating complex public health interventions

*Cushla Coffey, Bobby Maher & Jana
Sisnowski (MAE '17)*

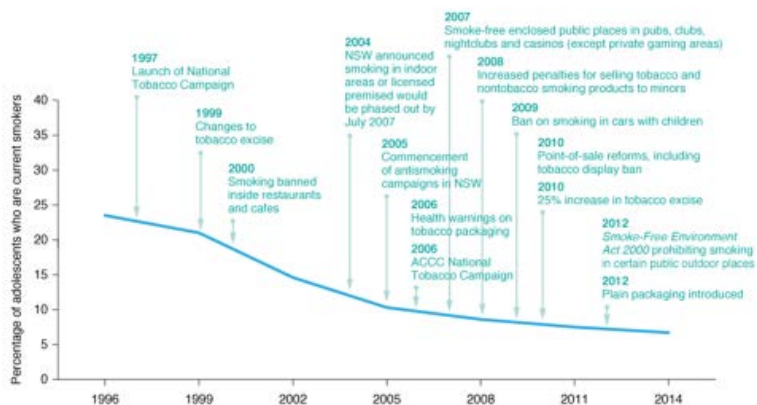
Learning objectives

- Describe the components of a logic model
- Apply a logic model to a given public health intervention
- Explain the challenges of capturing different aspects of complex public health interventions



2

Public health interventions creating impact...



3

Source: Dessaux et al. (2016)

... and having unintended consequences

Articles

Efficacy of infant simulator programmes to prevent teenage pregnancy: a school-based cluster randomised controlled trial in Western Australia

“The infant simulator-based VIP programme did not achieve its aim of reducing teenage pregnancy. Girls in the intervention group were more likely to experience a birth or an induced abortion than those in the control group before they reached 20 years of age.”

4

Source: Brinkman et al. (2016).

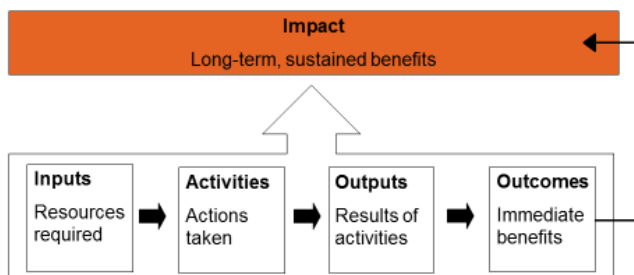
Challenges of public health interventions

- Beholden to policy cycles
- Often not trialled first
- Choice of evaluation types:
 - Formative evaluation
 - Process evaluation
 - Outcome evaluation
 - Impact evaluation
 - (Health) economic evaluation
 - Realist evaluation



5

Logic Model



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Group activity: building a logic model

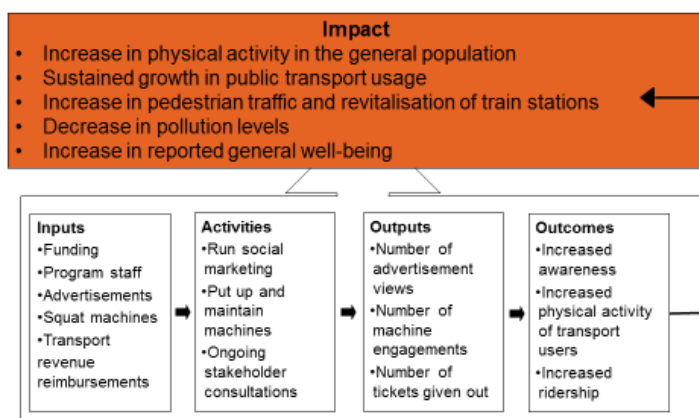
In Russia, 30 squats get you a subway ticket



12

Source: <https://www.wired.com/2013/11/squats-train-ticket/>

Logic Model



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Additional Resources

1. US Centers for Disease Control and Prevention. (2011) Introduction to Program Evaluation for Public Health Programs: A Self-Study Guide. Available from: <https://www.cdc.gov/eval/guide/>
2. Bamberger, M. et. al. (2004) Shoestring Evaluation: Designing Impact Evaluations under Budget, Time and Data Constraints. American Journal of Evaluation; 25(1):5-37.
3. Johns Hopkins University. (2006) Fundamentals of Program Evaluation. Available from: <http://ocw.jhsph.edu/index.cfm/go/viewCourse/course/FundamentalsProgramEvaluation/coursePage/index/>

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