The epidemiology of Aboriginal and Torres Strait Islander culture, health and wellbeing

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STATEMENT OF ORIGINALITY

I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at the Australian National University or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by others is explicitly acknowledged in the thesis.

Signed:

Date: 18/02/2019

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ACKNOWLEDGEMENTS

I would like to first acknowledge the Ngunnawal People as the Traditional Owners of the land in which I have had the privilege of walking, working and living on during my MAE journey. I pay my deepest respects to their Elders past and present, and would like to thank the Ngunnawal community for the opportunity to live on their beautiful country.

To my supervisors; Associate Professor Ray Lovett and Dr. Katie Thurber. I cannot thank you enough for your unwavering support and guidance throughout the past two years. There have been many times where you have gone above and beyond your role as my supervisors, and I couldn’t be more grateful. Thank you for believing in me and showing me how to believe in myself. Thank you to the entire Mayi Kuwayu team for your support.

To my deadly running family; thank you for keeping me sane. I never thought I would be up at 6am on a Sunday for a long run while it’s minus 6 degrees. But breakfast club sure made it worthwhile. Thanks for giving me a family in a new city, for the weekends away, for the tears and the laughter. You are treasures.

To my basketball family; thank you for showing me a whole new world. You couldn’t be a more welcoming and genuine bunch. I cannot wait to see what the future holds.

To my family; there’s not much else to say other than I miss and love you. Some days I feel every single one of those 2200kms between us.

ABBREVIATIONS AND ACRONYMS

ABC	Australian Broadcasting Corporation
ACSPRI	Australian Consortium for Social and Political Research Incorporated
ACT	Australian Capital Territory
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
ANU	The Australian National University
ATOR	At time of report
CDC	Centre for Disease Control and Prevention
CI	Confidence interval
ED	Emergency department
HDR	Higher degree by research
HPeV	Human Parechovirus
KLNP	Kardu Lurruth Ngala Purrungime Committee
LFF	Lessons from the field
LSIC	Longitudinal Study of Indigenous Children
MAE	Master of Philosophy in Applied Epidemiology
MK	The Mayi Kuwayu Study
NCEPH	National Centre for Epidemiology and Population Health
NITV	National Indigenous Television
NNDSS	National Notifiable Disease Surveillance System
NT	Northern Territory
PR	Prevalence ratio
PWAC	Palngun Wurnangat Aboriginal Corporation
SCfC	Stronger Communities for Children

ABSTRACT

This thesis is a compilation of applied epidemiological studies undertaken throughout the course of the Master of Philosophy in Applied Epidemiology (MAE) program. The focus of this thesis is on Aboriginal and Torres Strait Islander health and wellbeing and uses a strengths based, mixed methods approach. Community based participatory research methodologies were utilized in these studies. An outbreak investigation was also undertaken as part of the MAE competencies. This thesis includes the following studies:

- The data analysis and major epidemiological studies explore the association between caring for country, through participation in a Ranger program, and wellbeing. I conducted a cross sectional analysis of data collected in Central Australia in 2017, comparing health and wellbeing (life satisfaction, general health, psychological wellbeing and family wellbeing) among Aboriginal and Torres Strait Islander people employed as Rangers (n=43) versus not employed as Rangers (n=160).
- The Stronger Communities for Children (SCfC) program was evaluated through collection of cultural participation data (a key program outcome). Community based participatory research was utilised and community researchers were trained in delivering the survey through partnership with the Palngun Wurnangat Aboriginal Corporation, the Kardu Lurruth Ngala Purrungime Committee and the National Centre for Epidemiology and Population Health.
- An outbreak investigation was undertaken of a cluster of *Salmonella* Typhimurium with a unique MLVA pattern in Canberra, ACT. Descriptive epidemiology and an environmental investigation was undertaken to identify the source of the pathogen, and implement public health measures to mitigate risk to the public of further infection.

This thesis outlines additional activities undertaken during the MAE. Peer-reviewed articles, conference presentations, lesson plans and study proposals are included throughout.

CHAPTER ONE: INTRODUCTION

FIELD PLACEMENT

My field placement has been within the Aboriginal and Torres Strait Islander Health Program (ATSIHP) at the National Centre for Epidemiology and Population Health, The Australian National University. The ATSIHP conducts research in partnership with Aboriginal and Torres Strait Islander individuals, communities and organisations, and applies a strengths based frame to research. The team undertakes research on social and cultural determinants of Aboriginal and Torres Strait Islander health and wellbeing.

THESIS STRUCTURE

This thesis will comprise of three main study chapters, followed by an additional teaching chapter. The data analysis and major epidemiological studies have been combined, due to the large nature of the project. This chapter includes two peer reviewed publications and multiple conference presentations. The following program evaluation and outbreak chapters form a standard thesis chapter structure, with additional appendices at the end of each chapter.

SUMMARY OF CORE COMPETENCIES

The following is a brief summary of achievements and competencies undertaken for the Master of Philosophy in Applied Epidemiology program.

Field Projects

Data Analysis and Major Epidemiological study	Cultural participation and wellbeing outcomes in a Southern Tanami cohort
Evaluation of public health program	Evaluating the Stronger Communities for Children program in Wadeye, NT
Outbreak investigation	A cluster of *Salmonella* Typhimurium with a unique MLVA pattern in Canberra, ACT Development of a national database of Paediatric Human Parechovirus (HPeV) cases

Additional competencies

Literature review	Chapters two and three
Report to a non-scientific audience	Thurber, K., **Jones, R**., Lovett, R. 2018, 'Closing the Gap in child mortality: '*Ten years on*', NITV, 13 Feb 2018
Publications	**Jones R,** Thurber KA, Chapman J, D'Este C, Dunbar T, Wenitong M, et al. Study protocol: Our Cultures Count, the Mayi Kuwayu Study, a national longitudinal study of Aboriginal and Torres Strait Islander wellbeing. BMJ Open. 2018;8(6). **Jones R,** Thurber KA, Wright A, Chapman J, Donohoe P, Davis V, et al. Associations between Participation in a Ranger Program and Health and Wellbeing Outcomes among Aboriginal and Torres Strait Islander People in Central Australia: A Proof of Concept Study. International Journal of Environmental Research and Public Health. 2018 Jul 12;15(7) Thurber, K., Olsen, A., Guthrie, J…, **Jones, R.,** et al. ''Telling our story… creating our own history': caregivers' reasons for participating in an Australian longitudinal study of Indigenous children', International Journal for Equity in Health. 2018;17(143)
Conference presentations	Chiefs of Ontario 12th Annual Health Forum (Toronto, February 2018): '*Developing a National Indigenous Longitudinal Study (Mayi Kuwayu) in Australia'* South-East Australia Aboriginal Fire Forum (Canberra, May 2018): '*Mayi Kuwayu: The National Study of Aboriginal and Torres Strait Islander Wellbeing'* CAEPR and NCEPH joint seminar (Canberra, July 2018): *'Aboriginal Ranger jobs and wellbeing outcomes in Central Australia: proof of concept'*

	Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) Professional Development Conference (Adelaide, September 2018): '*Our Cultures Count: the Mayi Kuwayu Study'* Healing our Spirits Worldwide Conference (Sydney, November 2018): *'Cultural determinants of Aboriginal and Torres Strait Islander health and wellbeing'*
Teaching	First year MAE students (February 2018): *'Writing Tips'.* National Indigenous Science and Engineering Summer School (December 2017): *'Disease detectives: how epidemiologists find the cause of an outbreak'.*
Lessons from the field	Introduction into Qualtrics

Extra activities

Australian Consortium for Social and Political Research Incorporated (ACSPRI) course	Data Analysis in Stata, June 2017.
University of Melbourne	Professional Certificate in Indigenous Research, July 2018
Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)	ACT Board Director

Awards

2018	National Centre for Epidemiology and Population Health Dugaid Travel Scholarship
	ANU Vice-Chancellor HDR Travel Grant
	ACSPRI Indigenous HDR Scholarship

Chapter two: Culture, health and wellbeing of Aboriginal and Torres Strait Islander adults

Prologue

Due to the large nature of this project, the data analysis and major epidemiological requirements have been combined in this chapter.

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Appendix 2.26 Article submitted and published by Land Rights News

Acknowledgments

The Mayi Kuwayu Study has a team of professional staff, academics and students involved in various capacities of the project. I feel it is important to acknowledge their roles and contribution in the ongoing success of the Study. I am grateful for their support and encouragement throughout my MAE journey. The Mayi Kuwayu Study team members involved specifically in this project included:

- Ray Lovett
- Katie Thurber
- Jan Chapman
- Alyson Wright
- Michael Johnson

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My role

My involvement in the Mayi Kuwayu Study (and subsequently this project) commenced in the first week of my placement and has continued on throughout my entire MAE. I have been fortunate to be involved in many aspects of the Study and my various contributions are summarised below:

- Study protocol: peer reviewed publication
- Field trip: surveying Rangers (primary data collection)
- Data entry
- Data analysis
- Draft report of preliminary results
- Fieldtrip to report results back to rangers and community
- Peer reviewed publication
- Media engagement (radio interview)
- Conference presentations (one international and four domestic presentations, including one co-presenting with Rangers)

Public health impact

There are various ways in which this project has had far reaching public health impacts. Importantly, there is great benefit for the Rangers as well as for the researchers. This is highlighted below.

Impact for Rangers:

- Rangers now have the data and evidence to support how they feel their work benefits them and their community
- Use the evidence to advocate for funding and continuation of the Ranger program
- Holding a joint seminar which encouraged two Rangers to present about their work direct to policy makers
- Media coverage increased public awareness of the program and the benefits

Impact for the Mayi Kuwayu Study:

- Proof of concept findings which were used to support the development of the main survey
- Engagement with community and increased awareness of the national study
- Media coverage increasing awareness of the study to a broad audience

Broader public health impact:

- Engagement with policy makers
- Promote the continuation of the Ranger program nation wide
- Evidence of the association between culture and wellbeing, substantiating the need for the national study and further research in the area

Lessons learnt

I wouldn’t be doing this project justice if I attempted to write every single lesson that I have learnt throughout the last 2 years. There are simply too many. I feel it is important to acknowledge how this project has shaped the researcher that I have become, as I have continued to learn and grow alongside the project. Very briefly, I have listed just some of the lessons I have learnt from this project below.

- Logistics of field work
- Logistics of travelling for field work/conferences/engagement
- Challenges of interviewing/administering surveys
- Local researchers make an incredible difference in the response to surveys and the completeness of surveys

- How to use Qualtrics to enter data
- How to use Qualtrics to edit your survey
- Data entry
- All aspects of data analysis (this was the first time I had ever analysed any data)
- Writing up results
- Writing a peer reviewed publication and the revision processes involved
- Presenting at conferences, submitting abstracts, writing power points, answering questions from the audience
- Building relationships with community members and organisations
- Study design
- Survey design
- Measurement items used in surveys and the beginning of understanding the process of validating the scales
- Interacting with media

Appendix 2.10

Study Protocol: *Our Cultures Count,* the Mayi Kuwayu Study, a national longitudinal study of Aboriginal and Torres Strait Islander wellbeing

Open access Protocol

BMJ Open

Study protocol: *Our Cultures Count*, the Mayi Kuwayu Study, a national longitudinal study of Aboriginal and Torres Strait Islander wellbeing

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ABSTRACT

Introduction Aboriginal and Torres Strait Islander peoples are Australia's first peoples and have been connected to the land for ≥65 000 years. Their enduring cultures and values are considered critical to health and wellbeing, alongside physical, psychological and social factors. We currently lack large-scale data that adequately represent the experiences of Aboriginal and Torres Strait Islander people; the absence of evidence on cultural practice and expression is particularly striking, given its foundational importance to wellbeing.

Method and analysis Mayi Kuwayu: The National Study of Aboriginal and Torres Strait Islander Wellbeing (Mayi Kuwayu Study) will be a large-scale, national longitudinal study of Aboriginal and Torres Strait Islander adults, with linkage to health-related administrative records. The baseline survey was developed through extensive community consultation, and includes items on: cultural practice and expression, sociodemographic factors, health and wellbeing, health behaviours, experiences and environments, and family support and connection. The baseline survey will be mailed to 200 000 Aboriginal and Torres Strait Islander adults (≥16 years), yielding an estimated 16 000–40 000 participants, supplemented through face-to-face recruitment. Follow-up surveys will be conducted every 3–5 years, or as funding allows. The Mayi Kuwayu Study will contribute to filling key evidence gaps, including quantifying the contribution of cultural factors to wellbeing, alongside standard elements of health and risk.

Ethics and dissemination This study has received approval from national Human Research Ethics Committees, and from State and Territory committees, including relevant Aboriginal and Torres Strait Islander organisations. The study was developed and is conducted in partnership with Aboriginal and Torres Strait Islander organisations across states and territories. It will provide an enduring and shared infrastructure to underpin programme and policy development, based on measures and values important to Aboriginal and Torres Strait Islander peoples. Approved researchers can access confidentialised data and disseminate findings according to study data access and governance protocols.

Strengths and limitations of this study

- Mayi Kuwayu: The National Study of Aboriginal and Torres Strait Islander Wellbeing (the Mayi Kuwayu Study) will be a large-scale, national longitudinal study of Indigenous Australian adults, with linkage to health-related administrative records.
- With an estimated minimum 16 000 participants, the study will be an order of magnitude larger than any previous prospective study of Aboriginal and Torres Strait Islander adults.
- The baseline survey was developed through consultations with individuals and communities across Australia, and includes items on: cultural practice and expression, sociodemographic factors, health and wellbeing, health behaviours, experiences and environments, and family support and connection.
- The Mayi Kuwayu Study will be an exemplar of Aboriginal and Torres Strait Islander research governance.
- The Mayi Kuwayu Study is not intended to be population representative; the aim of the study is to generate evidence based on internal comparisons, and to examine within-population variation.

INTRODUCTION

Rationale

Aboriginal and Torres Strait Islander peoples are Australia's first peoples and have been connected to the land for at least the last 65 000 years.[1] Aboriginal and Torres Strait Islander cultures and values remain strong in contemporary Australia and are celebrated as among the longest continuing cultures in the world.

Broadly, culture may comprise the ideas and self-concepts of a group (eg, artefacts, attitudes, beliefs, customs, norms, symbols and values) and the lived practice and expression of these in differing contexts. Culture also includes historical events and standards of behaviour that evolve and change over time.[2] According to the literature, key Aboriginal and Torres Strait Islander cultural domains may include: knowledges and beliefs, cultural expressions, country and caring for country (referring to the essential relationship between a people and their traditional territories), language, self-determination and family, kinship and community.[3]

From a holistic perspective, culture can be considered a foundational component of, and contributor to, health and wellbeing, in addition to physical, psychological and social factors. Despite the potential importance of culture to health and wellbeing, there is a paucity of research exploring the association between culture and wellbeing among Aboriginal and Torres Strait Islander peoples.[4] Further, the potential mechanisms through which culture impacts on wellbeing (and vice versa) remain unknown. Aboriginal and Torres Strait Islander culture is increasingly being recognised as a critical, yet under-researched, determinant of health by communities, organisations and policy-makers.[5 6] There is a clear need for research that identifies how Aboriginal and Torres Strait Islander peoples navigate and express the differing cultures in which their lives exist, and how this relates to their health and wellbeing.

Mayi Kuwayu: The National Study of Aboriginal and Torres Strait Islander Wellbeing (Mayi Kuwayu Study) is designed to address this lack of knowledge on a national scale, generating evidence regarding culture and its relationship to health and wellbeing. 'Mayi Kuwayu' means 'to follow Aboriginal people over a long time' in Ngiyampaa language (language of the Wongaibon peoples of New South Wales, Australia). This data resource will help us to understand the role of culture in health and wellbeing. In addition, the study will be an order of magnitude larger than any previous prospective study of Aboriginal and Torres Strait Islander adults, enabling the generation of robust, needed evidence on health and wellbeing.

This study arose from the need to quantify what has been written about and often described as instinctive to many Aboriginal and Torres Strait Islander people: cultures and their relationship to wellbeing.[7] As such, this study is designed to privilege Aboriginal and Torres Strait Islander views and experiences. This study employs measures of culture that have been codeveloped with a diversity of Aboriginal and Torres Strait Islander peoples through an iterative qualitative process. The Mayi Kuwayu Study employs a salutogenic framework, enabling identification of cultural and other assets that promote wellbeing.[8]

The Mayi Kuwayu Study aims to examine health and wellbeing in relation to cultural practice and expression, taking into account the varied contexts in which Aboriginal and Torres Strait Islander peoples live. This study was developed primarily within a social epidemiology framework, concerned with the social structures, institutions and relationships that influence health and wellbeing. Culture may impact wellbeing directly, indirectly through social determinants of health and/or through other pathways.[9]

Objectives

The primary aim of this study is to enable quantification of associations and pathways between cultural practice and expression, social determinants of health, health behaviours, and health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples. Specifically, the project will generate: (1) indicators of Aboriginal and Torres Strait Islander cultural practice and expression that capture diversity and maintain meaning across contexts; (2) large-scale data on cultural practice and expression, sociodemographic factors, health and wellbeing, health behaviours, experiences and environments, and family support and connection, both cross-sectionally and over time and, (3) a state-of-the-art data resource for investigating Aboriginal and Torres Strait Islander wellbeing, which can also serve as a framework for policy and programme planning.

The primary study hypothesis is that cultural practice and expression (eg, connection to country, language use, kinship ties) is associated with health and wellbeing. Understanding and quantifying these associations could inform policy, for example, by supporting programme development that appropriately accounts for and promotes cultural engagement, in order to promote wellbeing. 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 improvement in wellbeing.

METHODS

Study recruitment

All Aboriginal and Torres Strait Islander people aged 16 years and older living in Australia are eligible to participate (figure 1).

Primary sampling frame

The intended primary recruitment method for this study is through a mail-out to people registered as Aboriginal and/or Torres Strait Islander in the Medicare Australia database. Medicare Australia is the national healthcare administration database, including all Australian citizens and permanent residents. Aboriginal and Torres Strait Islander people who choose to self-identify as Indigenous in the Medicare Australia database are recorded through the Medicare Australia Voluntary Indigenous Indicator (VII); this 'Medicare VII database' constitutes the primary sampling frame for this study.

We estimate that the Medicare VII database represents 68% of all Aboriginal and Torres Strait Islander people in Australia (total population=786 689, based on undercount-adjusted Census data[10]). As at October 2017, the Medicare VII database included 533 832 self-identified Aboriginal and Torres Strait Islander peoples, 313 732

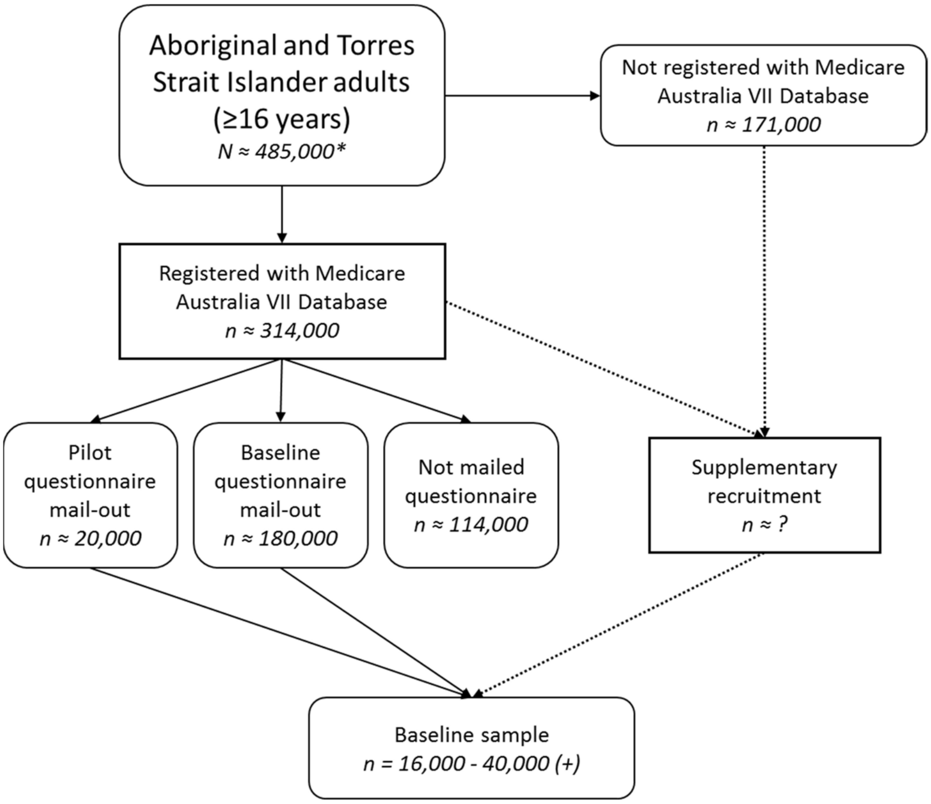

Figure 1 Flow diagram for Mayi Kuwayu Study recruitment. *Estimated undercount-adjusted population of Aboriginal and Torres Strait Islander peoples aged ≥16 years. Calculated by adjusting the raw Census count (n=414 532) for the overall 2016 Census undercount for the Aboriginal and Torres Strait Islander population (17.5%).[10] Data are unavailable on the extent of undercount by age group within the Aboriginal and Torres Strait Islander population. VII, Voluntary Indigenous Indicator.

of whom are in the eligible age range. The age and sex distribution of Aboriginal and Torres Strait Islander peoples self-identified in the Medicare VII database closely mirrors that of the total Aboriginal and Torres Strait Islander population (table 1).

The Department of Human Services extract a mailing list from the Medicare VII database, and use this mailing list to distribute survey materials (information sheet, consent form and baseline survey) to potential participants. Previous Australian studies have sampled from the total Australian population (using the full Medicare Australia database, not restricted to those self-identified as Indigenous through the VII)[11 12] and have recruited substantial numbers of Aboriginal and Torres

Table 1 Age and sex distribution of Aboriginal and Torres Strait Islander peoples in the Medicare VII database (VII) and in the overall population

	Males				**Females**				**Persons**			
	VII		**Census**		**VII**		**Census**		**VII**		**Census**	
Age group	**# (1000's)**	**%**	**# (1000's)**	**%**	**# (1000's)**	**%**	**# (1000's)**	**%**	**# (1000's)**	**%**	**# (1000's)**	**%**
16–24	38.1	11.2	56.0	13.5	41.8	12.3	53.5	12.9	79.9	23.5	109.5	26.4
25–34	39.6	11.2	44.0	10.6	43.1	12.3	44.8	10.8	82.7	23.5	88.9	21.4
35–49	35.3	11.2	51.6	12.4	38.8	12.3	56.8	13.7	74.1	23.5	108.4	26.2
≥50	36.5	11.6	50.2	12.1	41.6	13.2	57.6	13.9	78.1	24.8	107.8	26.0
Total (≥16 years)	149.4	47.5	201.8	48.7	165.4	52.5	212.7	51.3	314.7	100.0	414.5	100.0

Medicare VII database ('VII') data presented in this table includes persons registered on the Medicare VII database and aged 16 and over; persons missing age are excluded from total (n=314 732).
Census data presented in this table reflect raw 2016 Census population counts for Aboriginal and Torres Strait Islander people aged 16 years and over (n=414 532).[30] Data are not adjusted for undercount, as data are unavailable on the extent of undercount by age group and sex within the Aboriginal and Torres Strait Islander population.
VII, Voluntary Indigenous Indicator.

Strait Islander people through this process (n=1985).[11] However, no studies to date have purposely sampled the Aboriginal and Torres Strait Islander population using the Medicare VII database.

We intend for Mayi Kuwayu Study materials to be distributed to a mailing list of 200 000 people from the Medicare VII database. Previous mail-out surveys using the Medicare Australia database in the total Australian population have achieved response rates of 18%–44%.[11 12] Given potential additional barriers to recruiting Aboriginal and Torres Strait Islander participants (such as increased mobility, respondent burden, mistrust in research), we conservatively estimate a response rate of 8%–20%, which would result in a total of 16 000–40 000 participants through the primary recruitment method.

The aim will be to achieve a baseline sample that aligns with the population distribution across age group (16–24; 25–34; 35–49; ≥50 years), sex (male; female) and remoteness (major cities; inner and outer regional areas; remote and very remote). To achieve this, we will use stratified sampling, with strata based on the sex, age group and remoteness categories specified above. We will conduct a pilot mail-out of 20 000 surveys to estimate response rate for each stratum (age group by sex by remoteness). This will inform the extent to which strata need to be oversampled in the main mail-out, allowing for differential response rates by age, sex and remoteness, to achieve the desired sample distribution, and a minimum of 500 participants in each stratum.

The study materials distributed in the pilot mail-out will match the materials distributed in the full mail-out. Surveys completed in the pilot study phase will be included in the baseline data collection.

All participants who receive a survey through the pilot and main mail-out will have the option to complete the paper-based survey or to complete the survey online or over the phone.

Supplementary recruitment methods

While the Medicare VII database will serve as the primary sampling frame for the baseline survey, participation in the Mayi Kuwayu Study is not restricted to those who are registered with the Medicare VII database. All Aboriginal and/or Torres Strait Islander persons aged 16 years or over are eligible to participate, regardless of whether or not they receive a survey through the mail-out process.

Field testing during the development phase indicated that face-to-face (versus self-complete) delivery supported participation by those with low literacy levels. Therefore, supplementary recruitment will occur through face-to-face surveying in selected areas expressing an interest, and/or areas demonstrating low response rates or high levels of missing data on completed surveys in the pilot mail-out. All participants recruited through the supplementary recruitment method will also have the option to complete the survey online or over the phone.

Supplementary recruitment may also occur through study promotion (such as advertising via social media and through local community-controlled organisations and word of mouth). Any eligible person can complete the survey online or over the phone, or contact the Mayi Kuwayu Study to request a paper survey.

Given that this recruitment method potentially enables participants to complete the survey multiple times, baseline data will be checked for duplicates based on name, address and other identifying information.

Study components

The Mayi Kuwayu Study encompasses four main components: (1) cultural indicator and survey development; (2) baseline survey (including pilot mail-out); (3) repeat follow-up surveys and (4) data linkage, which are briefly outlined below(figure 2).

Cultural indicator and survey development

Survey items, including indicators of Aboriginal and Torres Strait Islander culture, have been developed through reviewing the literature and through consultation with a total of 165 Aboriginal and Torres Strait Islander peoples attending 24 focus groups across Australia from 2014 to 2017. Participants in this process were aged 16 to >70 years and represent a diversity of contexts and lived experiences. Early versions of the Mayi Kuwayu baseline survey were pilot tested with 160 and 209 Aboriginal and Torres Strait Islander participants in two 'proof-of-concept' studies, respectively.

The iterative processes of developing and refining the cultural indicators and other survey items will be detailed elsewhere. This process was critical to developing appropriate and meaningful questions about culture, to enable quantification of cultural expressions and contexts, and their associations with health and wellbeing outcomes, across diverse settings.

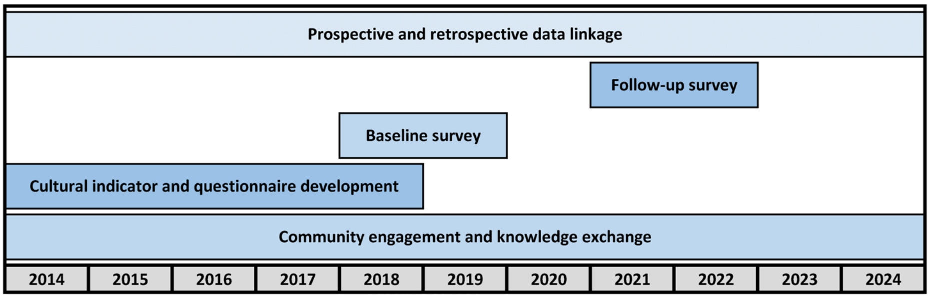

Figure 2 Mayi Kuwayu Study timeline.

Table 2 Key domains and measures included in the baseline survey

Domain	Theme
Cultural practice and expression	Country and connection to country, Indigenous beliefs and knowledge, cultural expression, self-determination and leadership, language, family, kinship and community, identity
Sociodemographic factors	Age, sex, housing, education, employment, financial situation, household composition
Health and wellbeing	Life satisfaction, health status, health conditions, medication use, social and emotional wellbeing, functional limitation
Health behaviours	Physical activity, alcohol and tobacco use, health service use
Experiences and environments	Services in the community, experiences of racism,community safety, environmental conditions, life events
Family support and connection	Family cohesion and connectedness, caring for others, stolen generation

Baseline survey

The baseline survey will contain survey items on cultural practice and expressions, sociodemographic factors, health and wellbeing, health behaviours, experiences and environments, and family support and connection. Key survey themes within each domain are summarised in table 2. All survey items included in the survey are based on established instruments, modified instruments or instruments developed through the community consultation process.

To enable data linkage and recontact for follow-up surveys, the baseline survey will collect data on participants' first and last name, postal address, phone number and email address. In addition, the baseline survey will collect contact details for an additional family member or friend (close contact) who can be approached to provide information to assist in recontacting the participant if required.

Follow-up surveys

Participants in the baseline survey will be followed up by survey every 3–5 years, or as funding allows. Follow-up surveys will maintain the core components of the baseline survey, with potential for addition or removal of survey items depending on priority and resourcing. Follow-up surveys will be distributed directly to participants (mail, email or phone). Participants will be able to nominate their preferred method of contact on the baseline survey.

Data linkage

Retrospective and continuing prospective linkage of baseline survey data to health-related records will provide ongoing outcome data independent of resurvey. The types of linkage datasets pursued will include hospitalisation, cancer registrations, deaths and disease notifications.

Patient and public involvement statement

The Mayi Kuwayu Study arose from community-identified priorities, and has been developed through extensive consultation; these processes have enabled the generation of a survey that can meaningfully and appropriately collect data about Aboriginal and Torres Strait Islander cultures and wellbeing across diverse settings.

Study governance mechanisms will ensure that engagement is ongoing throughout the implementation of the baseline and follow-up surveys, and during research question prioritisation, data analysis and interpretation. In addition to supporting the generation of meaningful results, this will support ongoing cohort retention. For example, participants can nominate to receive study newsletters, and appropriate social and Aboriginal and Torres Strait Islander media and forums will be used to inform participants of study progress and key outcomes.

The Mayi Kuwayu Study will create a collaborative resource governed by Aboriginal and Torres Strait Islander organisations, researchers and communities. The study is Indigenous led, with direct involvement from Aboriginal and Torres Strait Islander researchers (including the Study's lead) who are leaders in their field and who are well respected in their communities, bringing a depth of experience and accountability to ensure adherence to appropriate community protocols. The governance structure will ensure that Aboriginal and Torres Strait Islander peoples and partner organisations from across Australia are involved at every level and every stage of the project.

STATISTICAL METHODS

Statistical analyses will involve both cross-sectional and longitudinal methods. This will include estimates of prevalence, incidence and changes over time of cultural and health risk factors and health and wellbeing outcomes, and examination of their inter-relationships at baseline and over time. We will examine whether cultural or other factors moderate or mediate associations between risk factors and health outcomes. Analyses will be informed by a conceptual framework developed for each research question and include a range of methods appropriate for cross-sectional, longitudinal, and linked data and causal modelling, adjusting for correlation of measures within individual over time and missing data, where appropriate.

We conservatively estimate that at least 16 000–40 000 Indigenous adults will participate in the baseline survey, based on the expected 8%–20% response rate to baseline survey mail-out and supplementary recruitment. All participants in the baseline survey will be included for data linkage. If there is 20% loss to follow-up, there will be 12 800–32 000 participants with longitudinal survey data.

For analyses of the prevalence, incidence and changes over time for cultural, health or other factors, the study will allow highly precise estimation within sex and

5-year age groups, with 95% CI for the smallest group within ±1.0%–3.5% and 0.1 SDs for proportions and means, respectively. For cross-sectional and longitudinal analyses, the study will have at least 80% power, with a 5% significance level, to detect sex-specific ORs of 1.2–1.3 for binary outcomes and HRs of 1.2–1.4 for time-to-event analyses, for exposures of ≥10% prevalence and binary outcomes of 2%–5% prevalence.

ETHICS AND DISSEMINATION

Development, recruitment, retention and dissemination strategies used in the Mayi Kuwayu Study are based on principles of Indigenous data sovereignty and best practice for cohort studies of Aboriginal and Torres Strait Islander peoples.[13–16] It is intended that the study be perceived as an Indigenous community activity that promotes Indigeneity, building on Indigenous relationality and the importance of family and kin networks.

Consent

Participation in the Mayi Kuwayu Study is voluntary. Potential participants will receive a plain-language information sheet about the study, along with the consent form and survey. The study uses a structured, staged consent form, where participants opt-in to specific study components (baseline survey, data linkage and/or recontact), rather than a blanket consent form covering all study components. This empowers individuals to participate only in aspects of the study with which they are comfortable. This staged approach has been previously used in an Aboriginal and Torres Strait Islander cohort study, and has been demonstrated to be an appropriate method for recruiting and retaining Aboriginal study participants.[17] Participants can withdraw consent at any time.

Dissemination

Dissemination of findings from the Mayi Kuwayu Study will be subject to approval from the governing body. With approval, findings will be disseminated through forms including community dissemination meetings, community reports and feedback sheets, policy briefs, manuscripts for peer-reviewed publication, conference presentations and public seminars.

DISCUSSION AND IMPLICATIONS

Representativeness

The Mayi Kuwayu Study is not intended to be representative of the entire Aboriginal and Torres Strait Islander adult population. However, the study aims to capture much of the diversity of the Aboriginal and Torres Strait Islander population nationally, with sufficient heterogeneity across exposures. The aim of the study is to generate evidence based on internal comparisons, and to examine within-population variation in these associations.

While this has not been explored specifically within the Aboriginal and Torres Strait Islander population, in general, representativeness is not necessary for reliable quantification of exposure–outcome relationships.[18 19] Algebraic work and simulation studies provide evidence on the validity of internal comparisons in the face of varying response rates.[20] Moreover, experience over time from a wide range of epidemiological research has also shown this to be the case. For example, the British Doctors' Study, where doctors are clearly not representative of the general population, yet findings based on internal comparisons remain valid (that is, the association between smoking and mortality)[21]; pooled analyses incorporating cohort studies, case–control and other study designs tend to find materially similar findings among studies with varying response rates.[22] Further, a representative sample may not contain sufficient numbers of specific exposures or outcomes of importance. Thus, while high response rates and representativeness are essential to censuses and population health surveys (where the main aim is to accurately estimate point prevalence), these features are not essential or recommended for cohort studies.[23]

Implications

The Mayi Kuwayu Study will establish an ethical, community-focused and Aboriginal-controlled resource that will contribute to a holistic and robust understanding of Aboriginal and Torres Strait Islander culture, health and wellbeing. It will be an Aboriginal-controlled collaborative resource for research, conducted in strict accordance with current ethical, community and Aboriginal and Torres Strait Islander research standards.[24–29] The participatory methods will support the relevance of findings for individuals, communities, health services and policy-makers across portfolios.

This novel study will be the first of its kind, providing a large-scale national cohort study about the wellbeing of Aboriginal and Torres Strait Islander adults. It will provide the first community-derived measures of culture, and the first quantitative evidence regarding Indigenous cultural expressions and contexts at the national level. It will enable the first large-scale investigation of the relationship between culture and wellbeing for Aboriginal and Torres Strait Islander adults. This will identify opportunities to incorporate culture in programmes and policy to improve Aboriginal and Torres Strait Islander wellbeing.

There is currently limited incorporation of Aboriginal and Torres Strait Islander culture in programmes and policies—a dimension that is likely to be critical to effectiveness and acceptability. Evidence from the Mayi Kuwayu Study may increase the prioritisation of culture in the design of programme and policy.

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Appendix 2.12

Associations between participation in a Ranger program and health and wellbeing outcomes in Aboriginal and Torres Strait Islander people in Central Australia: a proof of concept study

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Article

Associations between Participation in a Ranger Program and Health and Wellbeing Outcomes among Aboriginal and Torres Strait Islander People in Central Australia: A Proof of Concept Study

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Abstract: Culture can be viewed as an integral part of Aboriginal and Torres Strait Islander health and wellbeing. This study explores the association between caring for country, through participation in a Ranger program, and wellbeing. We analyzed cross-sectional data collected in Central Australia in 2017, comparing health and wellbeing (life satisfaction, general health, psychological wellbeing and family wellbeing) among Aboriginal and Torres Strait Islander peoples employed as Rangers (n = 43) versus not employed as Rangers (n = 160). We tested if any differences in outcomes were explained by differences in key demographic or health factors. Ranger participation was significantly associated with very high life satisfaction (PR = 1.69, 95% CI: 1.29, 2.20) and high family wellbeing (PR = 1.47, 95% CI: 1.13, 1.90); associations remained significant after individual adjustment for education, income, employment, health risk factors and health conditions. The magnitude and direction of associations were similar for very good general health, but results were not significant. We did not identify an association between Ranger participation and psychological wellbeing. While based on a small sample, these findings support the assertion that participation in the Ranger program is associated with positive health and wellbeing outcomes. This supports the continuation of cultural participation and practice through the Ranger program and has implications for funding, program and policy development.

Keywords: Ranger; culture; wellbeing; Indigenous; Aboriginal; Torres Strait Islander; land management

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1. Introduction

Aboriginal and Torres Strait Islander people are Australia's First Peoples and their cultures are among the longest-continuing cultures in the world. For at least 65,000 years, Aboriginal and Torres Strait Islander people have developed and maintained cultural practices that are closely tied to their ancestral land [1]. Culture for Aboriginal and Torres Strait Islander people encompasses a wide range of beliefs, traditions and practices that have evolved over time; the expression of culture has also changed over time. Key cultural constructs for Aboriginal and Torres Strait Islander peoples include: connection to country; cultural beliefs and knowledge; language; family, kinship and community;

expression and cultural continuity; and self-determination and leadership. Each of these constructs includes a range of sub-themes [2].

Culture is described as an integral part of Aboriginal and Torres Strait Islander health and wellbeing. This is aligned with holistic views of health, which perceive health as inclusive of the physical, social, emotional and cultural wellbeing of individuals, families and their communities [3,4]. While the existing evidence base is limited, a recent review of domestic and international qualitative and cross-sectional quantitative analyses supports a positive association between Indigenous cultures and health and wellbeing [2]. For example, increased involvement in caring for country activities was significantly associated with improved health outcomes (lower odds of diabetes, obesity, and psychological distress) and an improved health risk factor profile (more frequent physical activity, greater bush food consumption, lower systolic blood pressure, and lower cardiovascular disease risk [5]) in a sample of 298 Aboriginal and Torres Strait Islander residents in the Northern Territory of Australia [6]. Caring for country activities included spending time on country, burning of annual grasses, gathering food and medicinal resources, protecting sacred sites, and producing artwork [6–8].

The current study builds on the previous literature by exploring the association between Aboriginal and Torres Strait Islander wellbeing and caring for country, through participation in an Indigenous Ranger program. Ranger programs employ Aboriginal and Torres Strait Islander people who combine cultural knowledge and experience with land conservation to protect and manage the environment. Rangers typically engage in land management activities such as protection of sacred sites (culturally significant places) and endangered species, fire management, conservation of water bodies and invasive weed control. In undertaking land management activities, Rangers draw on customary cultural knowledge and practices of traditional owners and elders. In this paper, we consider participation in the Ranger program as a proxy for cultural engagement and caring for country.

Ranger programs have been established in all jurisdictions in Australia, primarily through the Australian Government's Working on Country Program [9]. The Ranger programs are often facilitated by Land Councils and other Aboriginal and Torres Strait Islander led organizations. The programs have generated employment opportunities for Aboriginal and Torres Strait Islander people, and have improved biodiversity and land management outcomes [8,10–12]. There is also evidence indicating that participation in Ranger programs has economic benefits [13–15]. Given that participation in Ranger programs facilitates cultural engagement (for example, through caring for country and transfer of customary ecological knowledge and practices), the program may also have positive impacts on Aboriginal and Torres Strait Islander health and wellbeing. However, to date, we lack quantitative evidence on the health and wellbeing impacts of participation in Ranger programs.

To contribute to filling this gap, this study aimed to provide 'proof of concept' that participation in a Ranger program may have benefits for health and wellbeing, to form a foundation for large scale longitudinal research. To achieve this aim, this study compares the health and wellbeing of Aboriginal and Torres Strait Islander peoples employed as Rangers to those not employed as Rangers, and tests if differences in health and wellbeing among Rangers are independent of differences in education, employment, income, health conditions and health risk factors.

2. Methods

2.1. Research Approach

This study was conducted using a community-based participatory research approach. Community-based participatory research fosters partnerships between community and research agencies, with the aim of facilitating inclusivity and knowledge co-production [16]. This approach values the use of local knowledge for local action [17]. In contrast to research which has often been undertaken 'on' Aboriginal and Torres Strait Islander peoples rather than 'with' them, for the benefit of the researcher alone [18,19], community-based research redistributes power between researchers and those participating in the research. This research approach seeks to ensure reciprocity and restructure power relations, which are fundamental ethical principles for the conduct of research with Aboriginal and Torres Strait Islander peoples [20].

The current study was conducted in partnership with the Central Land Council (CLC) where a synergy was identified in late 2016. The CLC employs and supports Ranger groups to undertake appropriate care of their lands. The CLC were interested in evaluating the multiple benefits of their Ranger program, including wellbeing benefits. This aligned with the research team's work in developing and testing a range of measures of cultural engagement, expression and practice with a diversity of Aboriginal and Torres Strait Islander groups across the country as part of a national longitudinal study. The CLC invited the research team to work with the Ranger group to develop and refine the cultural indicators, and to field test the survey with the Rangers. The researchers used the data collected through this field testing to provide evidence on the health and wellbeing of participants in the Ranger program, and also to further refine the survey for the study.

Preliminary results were presented to and discussed with the CLC and Rangers in 2017. Rangers' interpretation of the results are incorporated in the discussion. Final results were presented to local organizations (including the CLC) and Rangers. Consent for publication was also obtained. A joint seminar to researchers and policy makers is planned for mid-2018.

2.2. Setting

This study was conducted in Central Australia as part of the development phase of *Mayi Kuwayu: The national study of Aboriginal and Torres Strait Islander wellbeing* (the Mayi Kuwayu Study) and to assist the CLC in evaluating the potential benefits of their Ranger program. The Mayi Kuwayu Study will be a large-scale, national longitudinal study of adults (16 years and older) who identify as Aboriginal and/or Torres Strait Islander. The aim of the Mayi Kuwayu Study is to generate robust data to enable the quantification of cultural engagement, expression and practices, and its association with health and wellbeing. The Mayi Kuwayu Study has been developed in partnership with Aboriginal and Torres Strait Islander communities and organizations, including through 24 focus groups and field testing of the survey in 2 sites. These focus groups were critical to developing and refining measures of culture and wellbeing that are appropriate and meaningful to participants across the country. Details of the Mayi Kuwayu Study are provided elsewhere [21].

The current study is based on data collected through field testing of the Mayi Kuwayu Study survey with Aboriginal and Torres Strait Islander people in Central Australia between May and November 2017. This paper reports cross-sectional analysis of these data.

2.3. Recruitment and Study Population

Rangers working in Central Australia were invited to complete the survey while attending their annual professional development camp in May 2017. All Rangers at the camp were invited to participate in the survey and participation was voluntary. Participants were provided with a plain language information sheet and consent form. Participants could self-complete the consent form and survey, or complete this with an interviewer. Of approximately 80 Rangers present at the camp, 43 completed the survey.

Non-Ranger participants were Aboriginal and/or Torres Strait Islander adults living in a similar geographic area to Rangers and have never been employed as a Ranger (referred to hereafter as non-Rangers). The recruitment and interviewing of non-Rangers was conducted by a local community organization. A purposive Indigenous field worker sampling approach was used for recruitment, with a local community researcher conducting the recruitment. In total, 160 non-Rangers completed the survey.

2.4. Data and Variables

All data used in this study are based on self-reported responses to the survey. Both self-completed and interviewer administered surveys are included in analysis.

2.4.1. Ranger Status

Participants were categorized as Rangers if they were involved in the Ranger program (full and part time), and as non-Rangers if they have not been employed as a Ranger.

2.4.2. Outcome Variables

Four health and wellbeing outcomes are included in this analysis: life satisfaction, general health, psychological wellbeing and family wellbeing.

Life satisfaction was measured according to responses to the question, 'How satisfied are you with your life as a whole', on a scale from 0 (completely dissatisfied) to 10 (completely satisfied) [22]. Scores were categorized as low to high life satisfaction (score 0–8) or very high life satisfaction (score 9–10).

General health was measured according to the question, 'How would you rate your general health?' [23]; response options were 'poor, fair, good, very good or excellent'. Responses were categorized into two groups: poor to fair general health (poor or fair) and very good general health (good, very good or excellent).

Psychological wellbeing was measured using the Kessler Psychological Distress (K5) scale, modified to include clarifying statements [24]. Responses to the five questions were summed; participants were categorized as having low/moderate (score 5–11) or high/very high levels of distress (score 12–25). Scores were only calculated for participants with complete data on the five items. For the analysis, those with 'low/moderate distress' were defined as having high psychological wellbeing; those with 'high/very high distress' were defined as having low/moderate psychological wellbeing.

Family wellbeing was measured using the Western Australian Aboriginal Child Health Survey family functioning scale [25], modified during the study development process. This was measured according to responses to a set of nine questions each with response options of 'not at all' (1) to 'very much' (5). Responses were summed (range: 9–45), and participants were categorized as having low/moderate (score 9–36) or high family wellbeing (score 37–45). Responses to the nine questions were summed for participants with complete data only; participants missing responses to any of the questions were coded as missing.

2.4.3. Sociodemographic Factors

Age was calculated based on date of birth and categorized as: 16–24, 25–34, 35–44, or >45 years. Highest attained qualification (education) was categorized into two groups: not completed Year 12 (no school, primary school and intermediate certificate); and, completed Year 12 or above (higher school, leaving certificate, diploma/certificate, trade or tertiary). Financial status was measured based on responses to the survey item, 'Given your current needs and financial responsibilities, indicate if you are: very poor, poor, just getting along, reasonably comfortable, very comfortable or prosperous'. Responses were categorized as low financial status (very poor, poor or just getting along) or high financial status (reasonably comfortable, very comfortable or prosperous). Non-Rangers were categorized as employed if they reported working part or full-time or if they were studying; and categorized as not employed if they were not working (including being retired, on a pension or an unpaid carer). All Rangers were categorized as employed.

2.4.4. Health Conditions and Health Risk Factors

Participants were asked if they had ever been told by a doctor that they had heart disease or diabetes. For analysis participants were coded as ever or never having each condition. We also created a composite health condition score that summed the number of conditions participants had ever reported (range: 0–2). Participants were categorized as having no (neither of the two health conditions) or any health conditions (one or more of the two health conditions). The health condition score was coded as missing if participants were missing data on either of the health conditions.

Participants were categorized as a current smoker or non-smoker (never or ex-smoker). Participants were asked if they had ever been told by a doctor that they had high blood pressure or high cholesterol; responses were categorized as ever or never for each. We also created a composite health risk score that summed the number of risks reported (range: 0–3). Participants were categorized as having no (none of the three health risk factors) or any health risk factor (one or more of the health risk factors). The health risk factor score was coded as missing if participants were missing data on any of the health risk factors.

2.5. Statistical Methods

2.5.1. Descriptive Analysis

We conducted a descriptive analysis of the demographic factors, health conditions and risk factors, and wellbeing outcomes for the Ranger and non-Ranger samples separately. An established protocol was utilized to confidentialize small cells. Individual cells are suppressed where the cell contains 5 or fewer observations ($n \leq 5$, with the exception of 'missing' category), such that it is not possible to identify the exact number in any category that has 5 or fewer observations.

2.5.2. Inferential Analysis

We used log-binominal models to calculate prevalence ratios (PRs) and 95% Confidence Intervals (CIs) for each outcome (life satisfaction, general health, psychological wellbeing and family wellbeing) for Rangers compared to non-Rangers. We opted to use log binomial regression models because our outcomes of interest were common [26]. All models excluded participants missing data on the outcome of interest (total included in models ranged from n = 162–178).

To test if differences in key demographic or health factors accounted for differences in wellbeing outcomes for Rangers compared to non-Rangers, we repeated each regression and individually adjusted for: education, employment status, financial status, health condition score, and health risk factor score. Given the small sample size, we did not have power to mutually adjust for all variables. Participants missing data on the exposure variable of interest were included as a separate missing category; as such, the total sample size was consistent for all models with the same outcome. Where a cell of the exposure variable contained missing data, we did not include a missing category in the regression (education and health risk score). Stata 14 was used for all analysis.

2.6. Ethics

Ethics approval for Mayi Kuwayu and this study have been received from the following Human Research Ethics Committees (HRECs): The Australian Institute of Aboriginal and Torres Strait Islander Studies HREC (approval number: E030/22052015); the Aboriginal Health and Medical Research Council of New South Wales Ethics Committee (1268/17); Central Australian Human Research Ethics Committee (CA-17-2810); the Northern Territory Department of Health and Menzies HREC (2017–2804); the Australian National University HREC (2016/767); the University of Tasmania HREC (H0016473); Aboriginal Health Research Ethics Committee (14-07-723); St. Vincent's Hospital Melbourne HREC (HREC 132/17); the Western Australian Aboriginal Health Ethics Committee (787); The Australian Government Department of Health (Project 10-2017).

3. Results

3.1. Sample Characteristics

A total of 43 Rangers and 160 non-Rangers participated in the study; 60% (n = 26) and 31% (n = 50) of participants were male, respectively (Table 1). Participants ranged from 16 to 77 years in age, with a mean age of 37 years. All Rangers were employed whereas 33% (n = 52) of non-Rangers were employed. Forty-two percent (n = 18) of Rangers reported high financial status compared to 31% (n = 49) of non-Rangers.

Table 1. Sociodemographic factors, by Ranger status.

Sociodemographic Factors	**Rangers (n = 43)**		**Non-Rangers (n = 160)**	
	%	n	%	n
Gender *				
Male	60	26	31	50
Female	28	12	65	104
Missing	12	5	4	6
Age group (years)				
16–24	≤12	≤5	17	27
25–34	33	14	29	47
35–44	16	7	17	27
>45	30	13	26	42
Missing	≤12	≤5	11	17
Education				
Not completed Year 12	44	19	54	87
Completed Year 12 or above	44	19	31	49
Missing	12	5	15	24
Employment				
Not employed	0	0	59	95
Employed	100	43	33	52
Missing	0	0	8	13
Financial status				
Low	37	16	54	86
High	42	18	31	49
Missing	21	9	16	25

* No substantial differences in PR and CI when gender was considered in outcome models.

3.2. Health Conditions and Health Risk Factors

Among Rangers, <11% ($n \leq 5$) reported ever having heart disease and 28% (n = 12) diabetes, compared to 11% (n = 17) and 18% (n = 29) in the non-Ranger group, respectively (Table 2). Over a third (35%, n = 15) of Rangers had at least one of the two conditions, compared to only 21% (n = 34) of non-Rangers. Sixty-three percent (n = 27) of Rangers were current smokers, as were 56% (n = 89) of non-Rangers.

Table 2. Health conditions and health risk factors, by Ranger status.

Health Conditions	**Rangers (n = 43)**		**Non-Rangers (n = 160)**	
	%	n	%	n
Heart disease				
No	84	36	84	134
Yes	≤12	≤5	11	17
Missing	≤12	≤5	6	9
Diabetes				
No	65	28	78	125
Yes	28	12	18	29
Missing	7	3	4	6
Health condition score				
No conditions	58	25	71	113
One or more health conditions	35	15	21	34
Missing	7	3	8	13
High blood pressure				
No	67	29	80	128
Yes	26	11	15	24
Missing	7	3	5	8
High cholesterol				
No	70	30	81	130
Yes	23	10	12	19
Missing	7	3	7	11
Smoking status				
Never smoked	16	7	36	58
Ex-smoker	≤12	≤5	7	11
Current smoker	63	27	56	89
Missing	≤12	≤5	1	2
Health risk factor score				
No health risk factors	14	6	29	46
One or more health risk factors	72	31	64	102
Missing	14	6	8	12

3.3. Wellbeing

Sixty percent (n = 26) of Rangers reported very high life satisfaction compared to 36% (n = 58) of non-Rangers. Forty-seven percent (n = 20) of Rangers reported very good general health compared to 38% (n = 61) of non-Rangers. Sixty-three percent (n = 27) of Rangers reported high psychological wellbeing compared to 53% (n = 84) of non-Rangers. Sixty percent (n = 26) of Rangers reported high family wellbeing compared to 44% (n = 70) of non-Rangers (Table 3).

Table 3. Self-reported wellbeing, by Ranger status.

Self-Reported Wellbeing	**Rangers (N = 43)**		**Non-Rangers (N = 160)**	
	%	n	%	n
Life satisfaction				
Very high	60	26	36	58
Low to high	19	8	44	70
Missing	21	9	20	32
General health				
Very good general health	47	20	38	61
Poor to fair general health	35	15	51	81
Missing	19	8	11	18
Psychological wellbeing *				
High	63	27	53	84
Low to moderate	30	13	30	48
Missing	7	3	18	28
Family wellbeing				
High	60	26	44	70
Low to moderate	23	10	45	72
Missing	16	7	11	18

* High psychological wellbeing is classified as those who scored low to moderate psychological distress on the Kessler 5 scale.

3.4. Associations between Ranger Status and Wellbeing

3.4.1. Life Satisfaction

The prevalence of very high life satisfaction was significantly higher for Rangers compared to non-Rangers (Figure 1A). The unadjusted prevalence ratio for very high life satisfaction was 1.69 (95% CI: 1.29, 2.20) for Rangers compared to non-Rangers. The association remained significant after individual adjustment for education (PR = 1.89, 95% CI: 1.43, 2.49), financial status (PR = 1.69, 95% CI: 1.32, 2.15), employment (PR = 1.57, 95% CI: 1.09, 2.26), health conditions score (PR = 1.72, 95% CI: 1.32, 2.22) and health risk factor score (PR = 1.70, 95% CI: 1.30, 2.23).

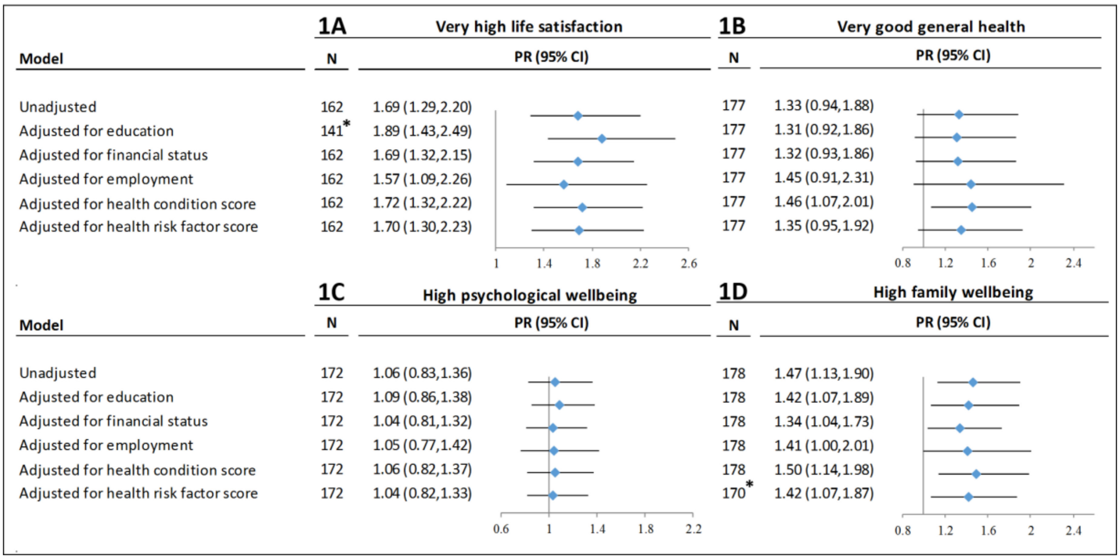

Figure 1. Associations between Ranger status and wellbeing measures. *PR = Prevalence Ratio.* * Missing category for relevant exposure variable was excluded due to zero cells.

3.4.2. General Health

There was not a significant association between Ranger status and general health in the unadjusted model (PR = 1.33, 95% CI: 0.94, 1.88), or in the models adjusted for education, financial status, employment, or health risk factor score (Figure 1B). However, after adjusting for health conditions, the prevalence of very good general health was higher for Rangers compared to non-Rangers (PR = 1.46, 95% CI: 1.07, 2.01).

3.4.3. Psychological Wellbeing

There was not a significant difference in the prevalence of high psychological wellbeing between Rangers and non-Rangers in the unadjusted model (PR = 1.06, 95% CI: 0.83, 1.36), or in models individually adjusted for each exposure (Figure 1C).

3.4.4. Family Wellbeing

The prevalence of high family wellbeing was significantly higher for Rangers compared to non-Rangers (Figure 1D). The unadjusted prevalence ratio for high family wellbeing was 1.47 (95% CI: 1.13, 1.90) for Rangers compared to non-Rangers. The association remained significant after individual adjustment for education (PR = 1.42, 95% CI: 1.07, 1.89), employment (PR = 1.41, 95% CI: 1.00, 2.01), financial status (PR = 1.34, 95% CI: 1.04, 1.73), health conditions score (PR = 1.50, 95% CI: 1.14, 1.98) and health risk factor score (PR = 1.42, 95% CI: 1.07, 1.87).

4. Discussion

We identified significant associations between Ranger participation and two wellbeing outcomes: very high life satisfaction, and high family wellbeing. In addition, the magnitude and direction of associations were similar for very good general health, but confidence intervals were wide, and results were not statistically significant for most models. While the analysis was not powered to adjust for multiple potential confounders simultaneously, associations between Ranger participation and health and wellbeing outcomes persisted after individual adjustment for key sociodemographic and health factors. Our findings are consistent with previous work and supports the argument that involvement in caring for country initiatives is associated with health and wellbeing [6,27,28]. Findings indicate that these health and wellbeing benefits may be independent of the employment and income benefits associated with participation in the Ranger program. The results were unsurprising to the Rangers, who have long argued and sensed the benefits of being involved in the Ranger program for themselves, their family and their community. However, this is the first time these associations have been quantified.

We did not identify a significant association between Ranger participation and high psychological wellbeing. This may be explained by external factors related or unrelated to Ranger work, poor question response, limitations of the measurement tool or other unknown factors. All represent areas for future enquiry and research.

It is possible that the different gender composition of the Ranger and non-Ranger samples could contribute to differences in wellbeing between the two groups. We tested this using the same analytical approach as we used to test if other key factors (education, employment status, financial status, health condition score, and health risk factor score) explained the difference between Rangers and non-Rangers in the four wellbeing outcomes. We found no material changes to the associations, indicating that differences between the two groups were not attributable to gender.

There was a high prevalence of health conditions and health risk factors among both Rangers and non-Rangers. The prevalence of heart disease was similar for Rangers compared to non-Rangers ($\leq$11% vs. 11%), 28% of Rangers and 18% of non-Rangers reported diabetes, and 35% and 21% reported at least one of the two conditions, respectively. The prevalence of diabetes observed in the Ranger group exceeds prevalence estimates for Northern Territory residents (19%) in the 2012–13 National Aboriginal and Torres Strait Islander Health Survey [29,30]. Although the prevalence of heart disease appeared similar for Rangers compared to non-Rangers, many risk factors for heart disease were particularly common in the Ranger group (e.g., high cholesterol 23% vs. 12%; high blood pressure 26% vs. 15%). The prevalence of current smoking was high in both groups (63% among Ranger and 56% among non-Rangers), and consistent with estimates for Aboriginal and Torres Strait Islander adults (aged 15 years and above) in Alice Springs (54–64%) and Central Australia (43–47%) [28,29]. Adjusting for the cumulative measure of health conditions or health risk factors did not materially change the association between Ranger participation and wellbeing outcomes. This suggests that any differences in health conditions or health risk factors between Rangers and non-Rangers did not explain differences in wellbeing outcomes. The small sample in our study restricted any further analysis.

This 'proof of concept' study contributes to the evidence on the broader benefits of Ranger programs. Economic and biodiversity benefits of Ranger work have been well-established [10–15]. This 'proof of concept' study provides novel quantitative evidence on the potential health and wellbeing benefits of participation in a Ranger program. These findings add strength to ongoing assertions from community, Aboriginal organizations and conservation groups that the Australia Government's Working on Country program is contributing towards closing gaps in health, employment and education [31,32]. Stability and expansion in policies that facilitate the development, implementation and sustainability of Ranger programs are likely to lead to improved wellbeing, health, and other gains for Aboriginal and Torres Strait Islander peoples.

While this analysis was based on a small sample, it provides support for the assertion that participation in the Ranger program is associated with improved wellbeing outcomes. We hypothesize that this is at least partly due to increased cultural engagement through the Ranger participation. It is likely there are many Aboriginal and Torres Strait Islander peoples engaged culturally; however, Ranger groups are routinely engaged in these activities. Ranger cultural engagement is facilitated by access to vehicles, to country and to those with cultural knowledge that enables them to perform their role. While not everyone can participate in Ranger programs, further investment in programs such as Ranger groups may enable wellbeing benefits among individuals and community. These benefits might come about from the promotion and transfer of cultural knowledge and skills or specific community-based activities such as school excursions to country, walking tours, guided by Rangers in partnership with traditional owners (cultural knowledge exchange). Further, if participation in the Ranger program impacts on health and wellbeing through increased cultural engagement, this would suggest that other forms of cultural engagement (outside of the Ranger program) may also be associated with benefits for health and wellbeing.

It should be noted that we were unable to determine the direction of association between Ranger participation and higher health and wellbeing outcomes due to the cross-sectional nature of the study. It is possible that Aboriginal and Torres Strait Islander people in better physical health (vs poorer) are more likely to become involved in the Ranger program, and as a result have better health and wellbeing outcomes. However, we found that Rangers had a similar, if not worse, health condition and health risk factor profile compared to non-Rangers. Further, we found that adjustment for health condition and health risk factor scores did not materially change the association between Ranger participation and health and wellbeing outcomes. Findings would be strengthened through testing for a dose-response relationship between time spent in the Ranger program and health and wellbeing outcomes, and through longitudinal analysis of cultural participation and health and wellbeing outcomes, as has been previously suggested [6]. While further evidence is required to demonstrate a causal association between Ranger participation and health benefits, taken together with previous evidence on economic and biodiversity benefits, it provides further support for the contribution of the Working on Country program to benefits beyond economic and biodiversity benefits [9].

5. Strengths and Limitations

A strength of the study is the participatory research approach and the ongoing community engagement and feedback. The research team ensured a two-way collaborative process with the Central Land Council and Rangers group in the establishment, implementation, and reporting of the research in conjunction with another community research organization. This value is reciprocal and joint seminars/presentations are planned to disseminate key messages on the research findings.

Indigenous field worker sampling was used for recruitment of non-Rangers. Indigenous field worker sampling uses formally trained field workers from the local community to identify 'hard-to-reach' populations. Indigenous field workers use local knowledge and networks to reach target populations [33]. Multiple sites are used for recruitment to enable a wide coverage of participants and therefore a larger sample population [34]. A purposive sampling approach was utilized to reach a quota of ~160 non-Ranger participants.

As a 'proof of concept' project, the research team were able to test the survey questions for the Mayi Kuwayu Study, and refine them for subsequent use in the upcoming national study [21], and potentially additional future research studies. The engagement and collaboration with Aboriginal and Torres Strait Islander communities and organizations has enabled the contextualization of research findings, and the generation of evidence that is meaningful and of value to participating communities.

A potential limitation of the study is the reliance on self-reported measures of health and wellbeing, using measures that have not all been robustly validated. However, these measures were conceptualized and developed through the conduct of over 20 focus groups with Aboriginal and Torres Strait Islander people across Australia, supporting the acceptance (face validity) of these measures [21]. Where possible, this study did employ measures of health and wellbeing that have been validated for use with Aboriginal and Torres Strait Islander adults (K5 scale), or that are commonly used (self-reported general health), with adaptations if requested through the consultation process. There is potential bias in the reporting of health conditions if participants had unequal access to healthcare/services.

This study was not intended to be representative of the entire Aboriginal and Torres Strait Islander population. While the prevalence of exposures and outcomes in this sample is not generalizable beyond the sample due to the lack of representativeness, representativeness is not necessary for reliable quantification of exposure-outcome relationships [35,36]. This study was focused on internal comparisons (i.e., differences between Rangers and non-Rangers); the results of these internal comparisons may be generalizable to other Aboriginal and Torres Strait Islander Ranger groups in Australia. This study was also not intended to provide evidence of causality or direction of association between Ranger participation and health and wellbeing. This can be explored in further research.

The relatively small sample size limited the statistical analysis that could be performed. While less than 5% data was missing for most variables, one exposure variable and one outcome variable had $\geq$20% missing data (financial status for Rangers, life satisfaction for Rangers and non-Rangers). However, the aim of this study was to provide 'proof of concept' on an association between participation in the Ranger program and health and wellbeing. Now that a 'proof of concept' association has been established, potential causal pathways can be explored in further detail in a larger sample [6,21].

6. Conclusions

This study identified significant associations between Ranger participation (compared to non-Rangers) in Central Australia and two wellbeing outcomes: very high life satisfaction, and high family wellbeing. We hypothesize that this association is at least in part explained by increased cultural engagement and expression through Ranger participation. In combination with previous evidence on economic and biodiversity evidence, this study contributes evidence on the multiple positive impacts of the Working on Country program on Aboriginal and Torres Strait Islander wellbeing.

As a 'proof of concept' study, this study was not intended to provide evidence on causality or mechanisms underlying an association between Ranger participation and health and wellbeing. This can be undertaken through further investigation on the role of cultural participation and expression on health and wellbeing in a larger sample of Aboriginal and Torres Strait Islander peoples. Longitudinal data is required to provide insight into causal relationships between cultural engagement, expression and wellbeing benefits.

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Appendix 2.13

Information sheet given to Ranger participants

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing
Our Cultures Count

Information for participants:
The Mayi Kuwayu Study

This Information Sheet is for you to keep.

Mayi Kuwayu, the National Study of Aboriginal and Torres Strait Islander Wellbeing is controlled by Aboriginal researchers at the Australian National University (ANU). In Ngiyampaa language, 'Mayi Kuwayu' means to follow Aboriginal people over time.

The research team wants to understand how Aboriginal and Torres Strait Islander culture links to health and wellbeing. We have worked with many Aboriginal and Torres Strait Islander communities over the last three years to develop survey questions about Aboriginal and Torres Strait Islander culture and wellbeing.

This Study will provide information for community, services and policy makers about things that improve Aboriginal and Torres Strait Islander health and wellbeing. We will share our findings with all participants. We want Aboriginal and Torres Strait Islander communities throughout Australia to use the Study results.

Who can participate?

Any Aboriginal and/or Torres Strait Islander person 16 years or older can complete the survey.

What do I need to do?

To take part in the Study, complete the survey on paper, online, or over the phone. Please make sure you provide your full name and signature. If you agree to be contacted by the Study in the future or to have your data linked to health records, please provide your contact details in the space provided.

Do I have to participate?

No. It is your choice to take part in the Study.

How do I know my information will be safe?

This Study is bound by strict privacy laws (Privacy Act 1988*). All information collected will be used for this research only and treated confidentially (as far as allowed by law). No information will be reported in a way that will allow you, your household or your community to be identified.

All data will be stored securely at the ANU. Data will be kept for the duration of Mayi Kuwayu Study research. The use of data from the Mayi Kuwayu Study will be strictly controlled by an Aboriginal and Torres Strait Islander governance committee.

In collecting your personal information within this research, the ANU must comply with the Privacy Act 1988. 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; or complain about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint.*

How will my information be used?

Your information will only be used for research about Aboriginal and Torres Strait Islander health and wellbeing.

How will this Study help me and my community?

By sharing your story, we aim to produce information that will contribute to better services, programs and policy.

What other information will help?

We also ask for your permission to have other health information about you included in the Study. You can agree to have your survey data linked to your Hospital records, Cancer records, and Death records. You do not have to provide access to these records. However, they would help us understand how your survey answers relate to your use of hospital services and your health outcomes over time. This information will help us to have a more detailed view of your health and wellbeing.

We would like to contact you in the future. If you agree, we will send you follow-up Mayi Kuwayu Study surveys to complete so we can track your health and wellbeing over time. We will also send you updates on the study and its findings.

Don't want to be part of the Study anymore?

You can withdraw from the Study at any time by calling us on **1800 531 600** (free) or emailing **mkstudy@anu.edu.au.** If you request to leave the Study, we will securely destroy your data.

Your consent will stay valid following your death or disablement. If you wish to be withdrawn from the study in that event, let your next of kin (or other person responsible for your affairs) know so that they can contact the Study to withdraw you from the Study.

Has the Study been approved?

The ethical aspects of this research have been approved by the following Human Research Ethics Committees: AIATSIS (Reference: E030/22052015); the ANU (2016/767); the CAHREC (CA-17-2810); the Northern Territory Department of Health and Menzies School of Health Research (2017-2804); the WAAHEC (787); the AH&MRC (1268/17); The University of Tasmania (H0016473); the AHREC (04-17-723); St Vincent's Hospital Melbourne (HREC 132/17); and the Department of Health (10-2017).

What are the potential risks?

Some questions in the survey may make you feel uncomfortable or upset. You can contact Lifeline on 13 11 14 or visit **www.lifeline.org.au**. Or you can visit **http://www.sewbmh.org.au/location/list** for a list of services in your local community.

Any questions, comments, or concerns?

If you have any questions, comments or concerns about the Study, or if you know someone else who would like to do the survey, call the Study on 1800 531 600 (free call), email us at **mkstudy@anu.edu.au** or visit http://www.mkstudy.com.au

If you have any concerns or complaints about how this research has been conducted, please contact Ethics Manager, The ANU Human Research Ethics Committee on (02) 6125 3427 or **Human.Ethics.Officer@anu.edu.au**

Mayi Kuwayu Study Partners

Funded by:

Appendix 2.14

Preliminary results report for feedback from Rangers

Summary report for CLC: Ranger wellbeing

This reports on a study undertaken to examine the benefits of being in the ranger program. We collected surveys from: 45 Rangers who completed a survey at the Ranger camp in May 2017 and 107 non-Rangers, which included Aboriginal people living in and around Alice Springs. We used this data to compare these two groups (Rangers, non-Rangers). We also asked rangers what could be improved in their job.

KEY FINDINGS:

1. All Rangers reported being very happy with their job, in particular Rangers enjoyed working on country, contributing to their communities and family, keeping their cultural knowledge strong and pride associated with the job.
2. Rangers reported feeling healthier, happier (psychological wellbeing), more satisfied with their life and to have better family wellbeing than non-Rangers.
3. Rangers were less likely to report financial hardship than non-Rangers.
4. Rangers more likely to report access to country, living on country and to have cultural knowledge, but were slightly less likely to speak an Aboriginal language and slightly more likely to report feeling disconnected from their culture.
5. Rangers reported being diagnosed with conditions of chronic health conditions (including diabetes, high cholesterol, blood pressure) more than non-Rangers.
6. Rangers are interested in PD opportunities

Ranger Job satisfaction and professional development

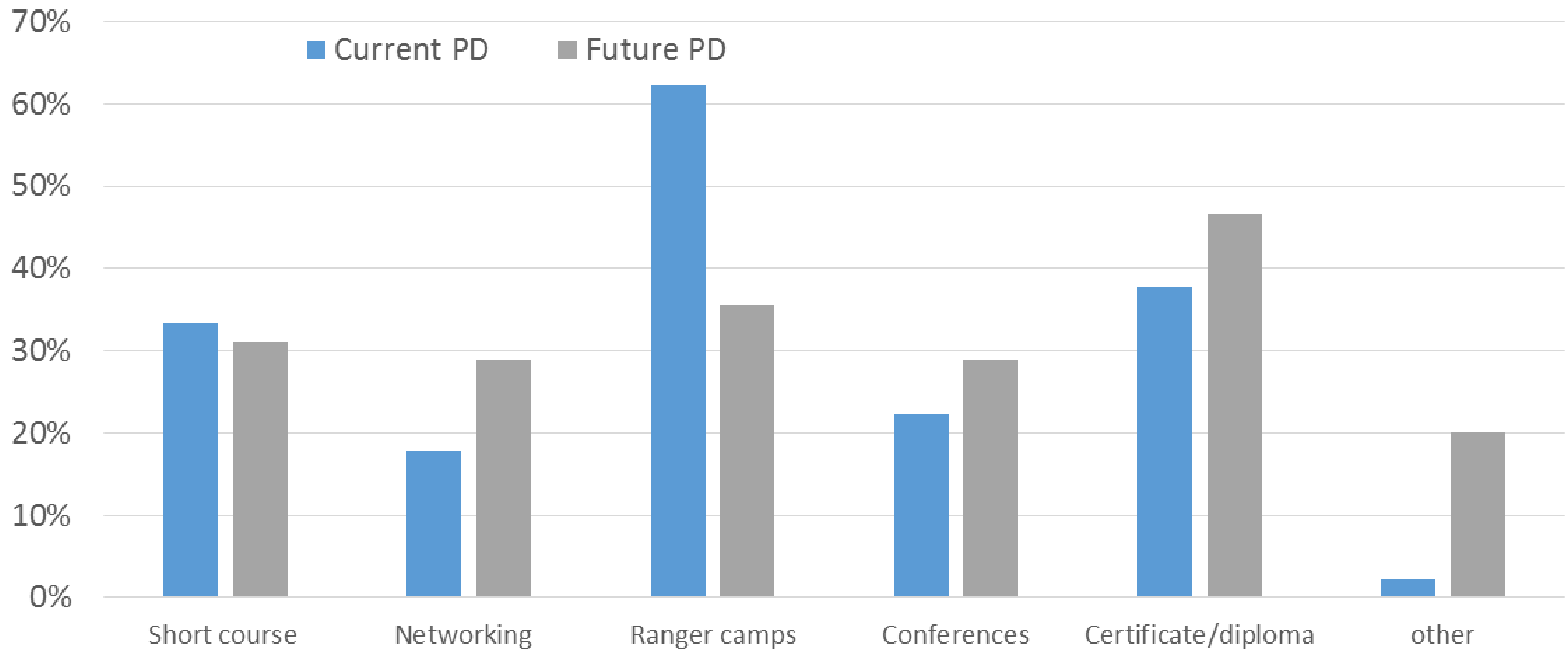
Rangers reported being extremely happy and satisfied with their job. Rangers reported personal impacts of being a Ranger included gaining new skills and employment, pride, being on country and feeling stronger or happier. The impact on their family and community was overwhelmingly pride. The thing that Rangers reported as the best part of their job was being ‘on country’. We did not find any negative responses to being a ranger.

However, there were some general employment gripes, for example toilet cleaning, snakes, weeding, being away from home and paperwork. This data exemplifies the important and real job satisfaction in the ranger program and that its beneficial impacts extend beyond the individual and connected to families and communities.

Professional development

The most commonly reported professional development that Rangers are currently involved in was the Ranger camps. Almost 40% of Rangers were involved in certificate or diploma courses as part of their job. For future professional development Rangers identified more networking, conferences and certificate and diploma courses as being important. The ‘other’ category for future PD concerned more short courses on use of computers, tour guide training, general numeracy and literacy education and University courses.

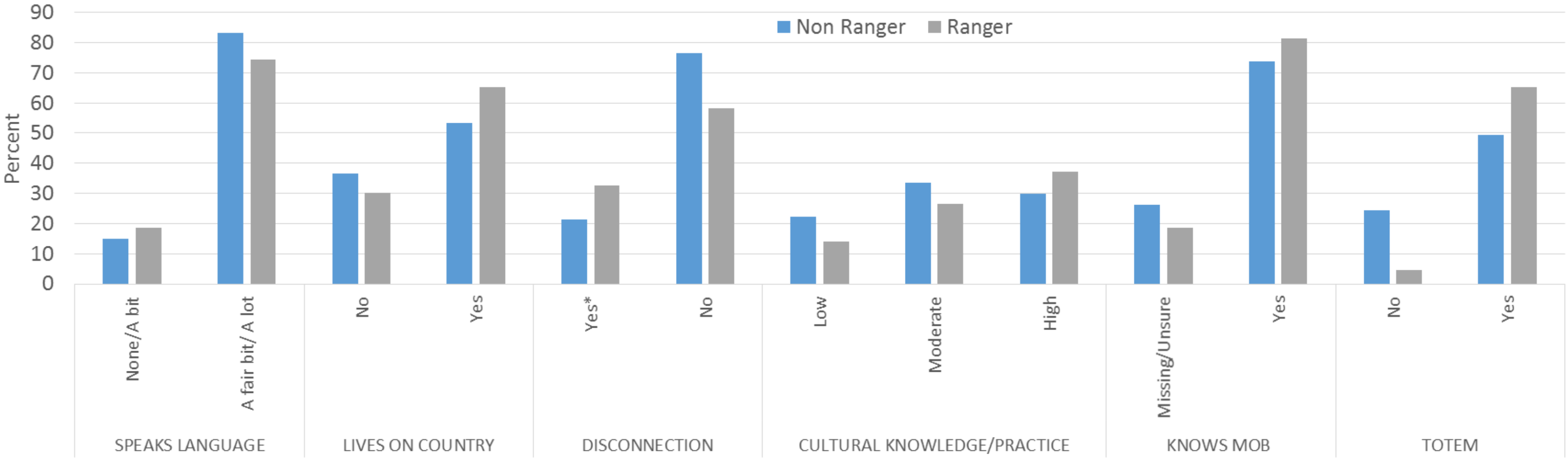
Figure 1: Ranger current and future professional development



Culture

Rangers were slightly less likely to report using an Aboriginal language compared to non-Rangers. However, Rangers were more likely to report living on their country and report higher levels of cultural knowledge including knowing their dreaming. Despite most living on country, Rangers reported being disconnect from culture slightly more than non-Rangers. Rangers were also more likely to report knowing their mob/tribe.

Figure 2: Cultural characteristics by Ranger status

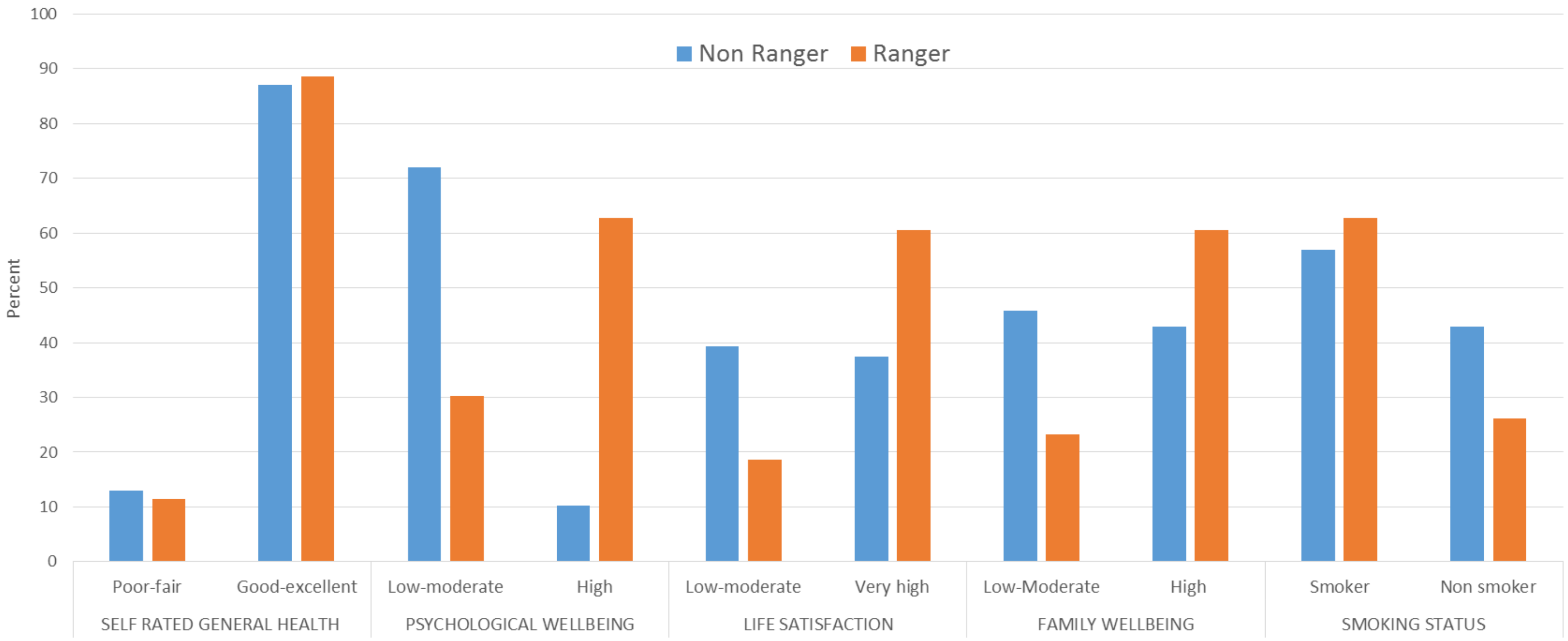


***** (a little, a fair bit, a lot)

Health and Wellbeing

Overall Rangers reported slightly better health, much better psychological wellbeing, moderately better family wellbeing and very high life satisfaction than non-Rangers. Smoking rates were slightly higher amongst Rangers.

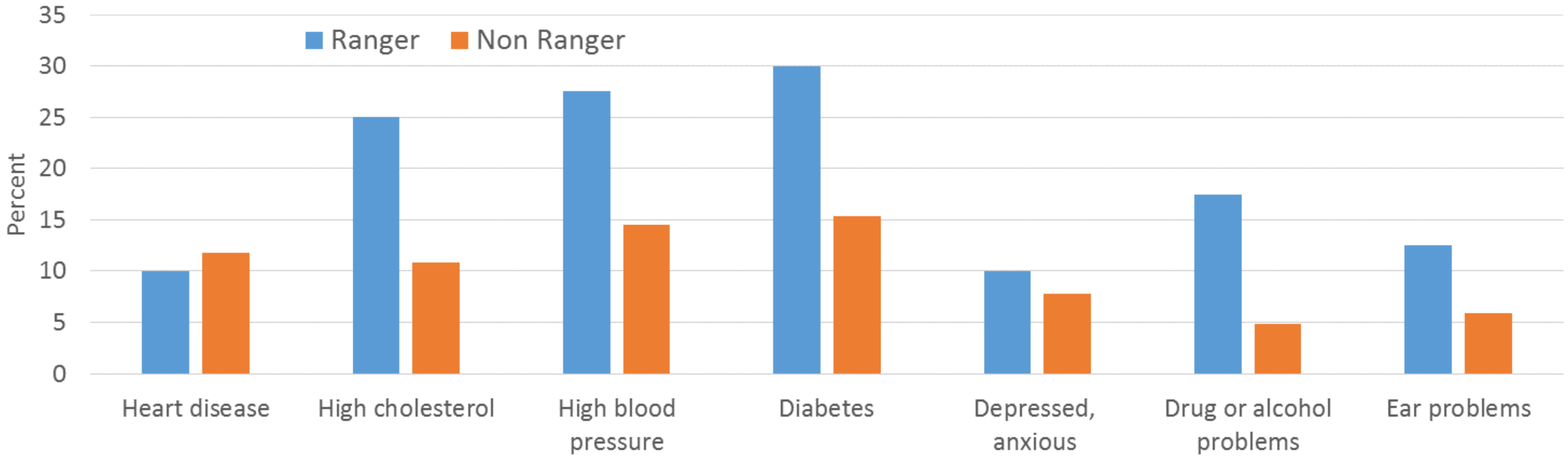
Figure 3: Wellbeing characteristics by Ranger status



Health conditions

Other than heart disease, Rangers reported being diagnosed with health conditions more than non-Rangers. Diabetes was reported at twice the rate (30%) of non-Rangers (15%) and well above the NT rates from the last Aboriginal health survey (12%). This might have occupational implications. For example, if certain types of retinopathy (an eye condition), heavy lifting may not be advisable. Some Diabetics have neuropathy that causes lack/limited sensation in the feet. Wearing steel-toed shoes or boots may put too much pressure on your feet and cause an injury without the person knowing. These are only examples, but CLC should be aware of these.

Figure 4: Health conditions by Ranger status

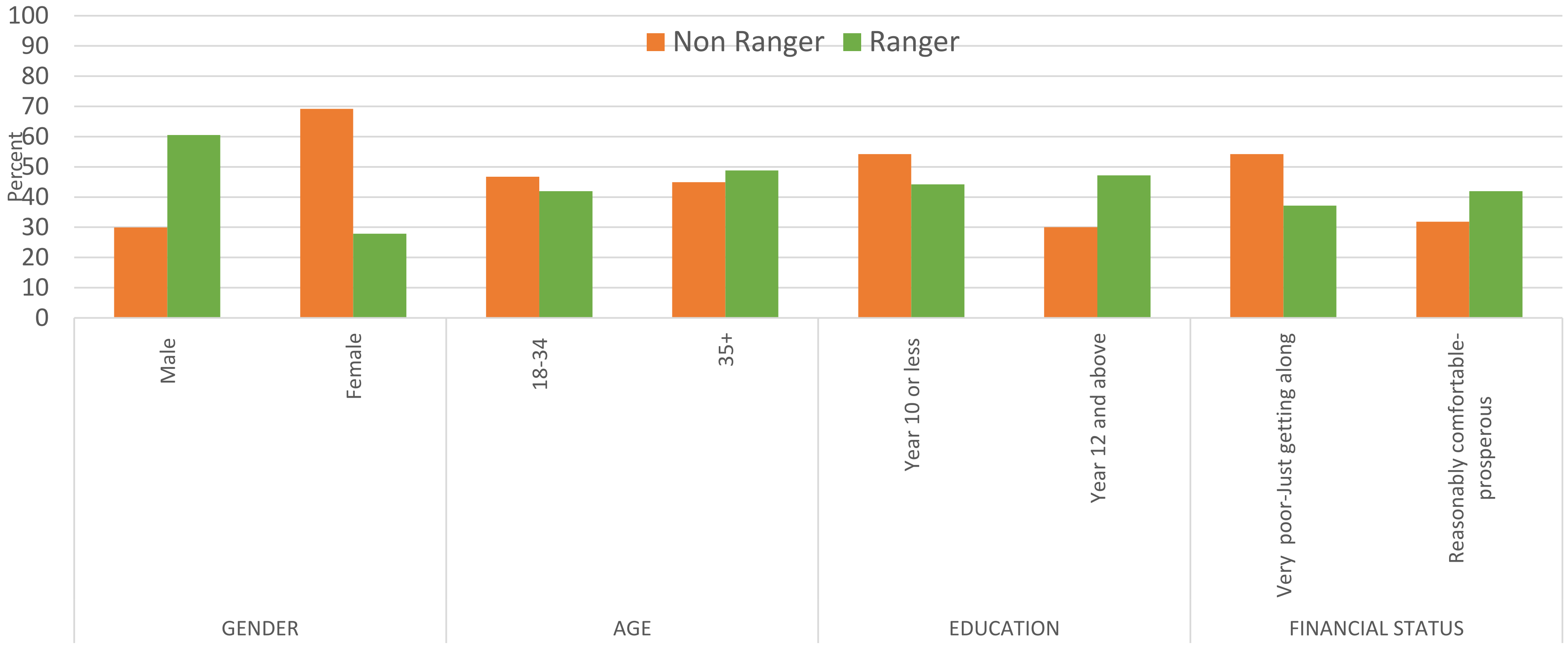


Who took part?

We did not get to speak to all the rangers, but most rangers who were at the camp provided a survey response. Some of the ranger responses were from rangers who do not work with the CLC, including APY Rangers and Wartarrka Rangers.

There were a few differences between the two groups compared in the study (Rangers and non-Rangers). The Ranger group had more male participants than the non-Ranger group. Among Rangers, 30% were female and just over 60% were male. In the non-Ranger group almost 70% were female and just under 30% were male. The age spread was roughly equivalent between the two groups. Rangers were slightly more likely to have school education and trade qualifications. Rangers also reported slightly better financial status, with less reporting that they “were just getting along”. Many of the non-Ranger group were not in employment.

Figure 1: Characteristics of Rangers and non-Rangers



YOUR FEEDBACK:

- **This is preliminary and we are finalising a big report for the CLC.**
- **We'd like to know your response to the report.**
- **Is there something else you would like to know?**
- **We would like to publish these findings in a journal, so that we can share the knowledge of the values of being Ranger and important work the CLC is doing.**

NEXT STEPS:

1. **Finalise report for Peter and the rangers.**
2. **Report at next Ranger camp**
3. **Publish the results in a journal/thesis**
4. **The surveys are feeding into a bigger project that I (and my team) are working on looking at cultural factors for health and wellbeing.**

Australian Bureau of Statistics (2014) *Australian Aboriginal and Torres Strait Islander health survey: updated results, 2012-13 - Australia: table 3.3 [data cube]*. Retrieved 6 June 2014 from http://www.abs.gov.au/AUSSTATS/subscriber.nsf/log?openagent&472705500603.xls&4727.0.55.006&Data%20Cubes&EA7646604E728A2ECA257CEE0010D716&0&2012%9613&06.06.2014&Latest

Appendix 2.15

Preliminary results presentation to Rangers and community members

CENTRAL LAND COUNCIL

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

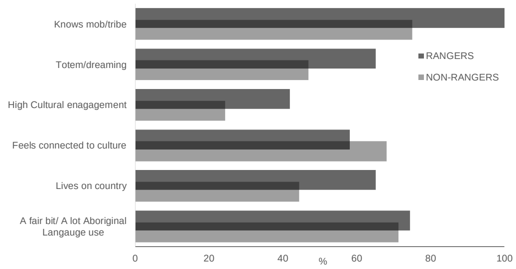
Central Land Council Ranger Wellbeing Survey

Roxanne Jones, Jan Chapman, Katherine Thurber, Alyson Wright, Michael Johnson and Ray Lovett.

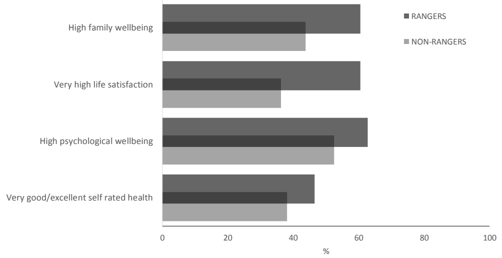
Ranger wellbeing survey

- CLC wanted to see if Ranger work was linked to health and wellbeing.
- The study included data from 43 Rangers and 160 non-Rangers from Central Australia.

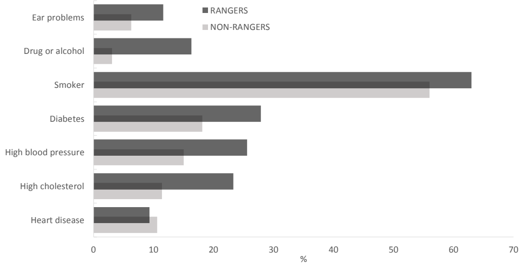
Culture



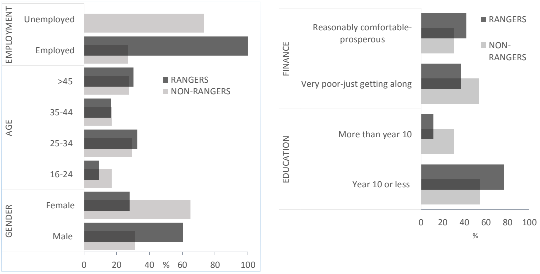
Wellbeing



Health conditions



Other characteristics



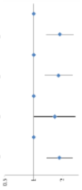
When we compared Rangers statistically to non-Rangers, we found that

- High life satisfaction was twice as common among Rangers
- Very good self-reported health was 50% more common among Rangers
- High family wellbeing was 50% more common among Rangers
- Mental wellbeing between Rangers and non-Rangers was similar

---

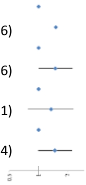
Very high life satisfaction

		Prevalence Ratio (95% CI)
Unadjusted:	Non-ranger	1 (ref)
	Ranger	1.90 (1.35-2.66)
Adjusted education:	Non-ranger	1 (ref)
	Ranger	1.84 (1.32-2.60)
Adjusted employment:	Non-ranger	1 (ref)
	Ranger	1.67 (1.01-2.76)
Adjusted financial status:	Non-ranger	1 (ref)
	Ranger	1.88 (1.37-2.59)



Very good general health

		Prevalence Ratio (95% CI)
Unadjusted:	Non-ranger	1 (ref)
	Ranger	1.51 (1.01-2.26)
Adjusted education:	Non-ranger	1 (ref)
	Ranger	1.50 (1.00-2.26)
Adjusted employment:	Non-ranger	1 (ref)
	Ranger	1.35 (0.78-2.31)
Adjusted financial status:	Non-ranger	1 (ref)
	Ranger	1.49 (0.99-2.24)



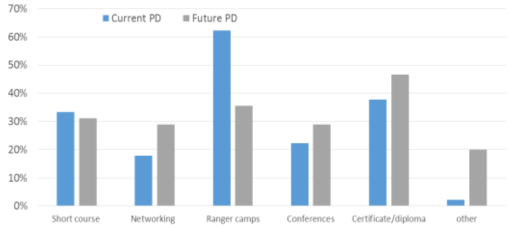
Good mental wellbeing

		Prevalence Ratio (95% CI)
Unadjusted:	Non-ranger	1 (ref)
	Ranger	1.08 (0.83-1.40)
Adjusted education:	Non-ranger	1 (ref)
	Ranger	1.03 (0.78-1.34)
Adjusted employment:	Non-ranger	1 (ref)
	Ranger	1.15 (0.79-1.68)

How we did it?

- Survey questions developed with Rangers (8)
- Our team attended the 2017 Ranger camp
- Surveys done on site
- Surveys done in other communities

Professional development of CLC Rangers



Next:

- Sought Ranger responses to the report (2 x feedback sessions December 2017 and March 2018).
- Publish the findings, so that we can share the knowledge of how being a Ranger helps wellbeing about the important work the CLC Ranger program is doing.
- Rangers (CLC) and research team to present this work to government in Canberra so they see the benefits (July 11 CAEPR Seminar).
- Going back to do the same survey with Rangers so we can see any changes over time.

Questions?

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1800 531600

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Appendix 2.16

Plain language report of final results for Rangers and community members

Central Land Council Ranger Wellbeing Survey

In Short: CLC and researchers (ANU) worked together in 2017 to look at health and wellbeing of Rangers. We used a survey. To see if health and wellbeing was linked to Ranger work, the study compared Rangers with non-Rangers from around the same area (Central Australia). Forty-three Rangers and 160 non-Rangers did the survey. The survey showed:

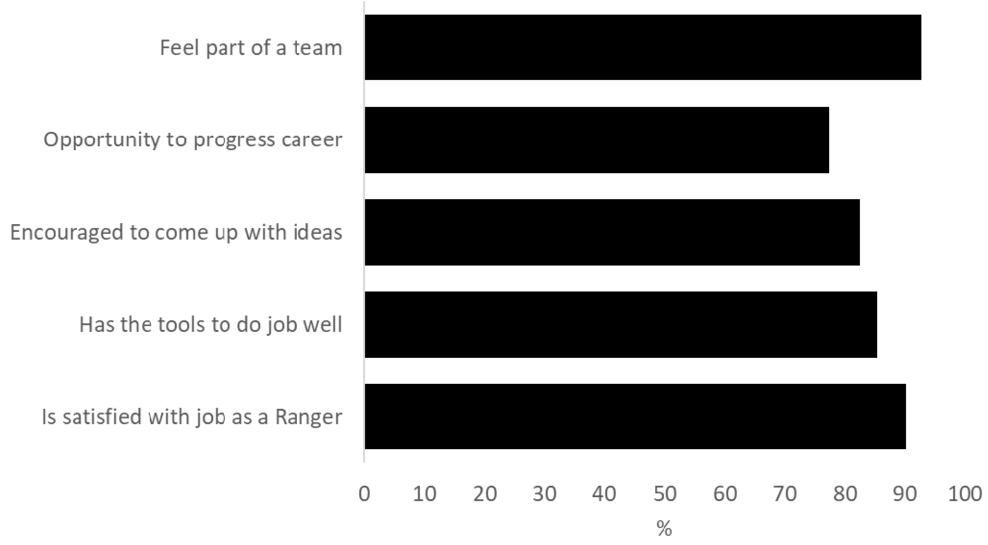
- All Rangers reported being very happy with their job, in particular Rangers enjoyed working on country, contributing to their communities and family, keeping their cultural knowledge strong and pride associated with the job.
- Rangers reported better health, were more satisfied with their life and had better family wellbeing than non-Rangers.
- Rangers were less likely to report financial hardship than non-Rangers.
- Rangers more likely to report access to country, living on country and to have cultural engagement.
- Rangers reported being diagnosed with chronic health conditions (including diabetes, high cholesterol, blood pressure) more than non-Rangers.
- Rangers are interested in PD opportunities

These findings mean that cultural participation (through Ranger work) is linked to better health and wellbeing.

About participants: Rangers completed a survey at the annual CLC training camp in July 2017. Non-rangers did the same survey in August and September 2017.

Ranger Job satisfaction: Rangers report a strong level of satisfaction with their work. Over 90% said they strongly agreed with being satisfied with their job as a Ranger and almost all reported feeling part of a team.

Figure 1: Ranger job satisfaction, 2017

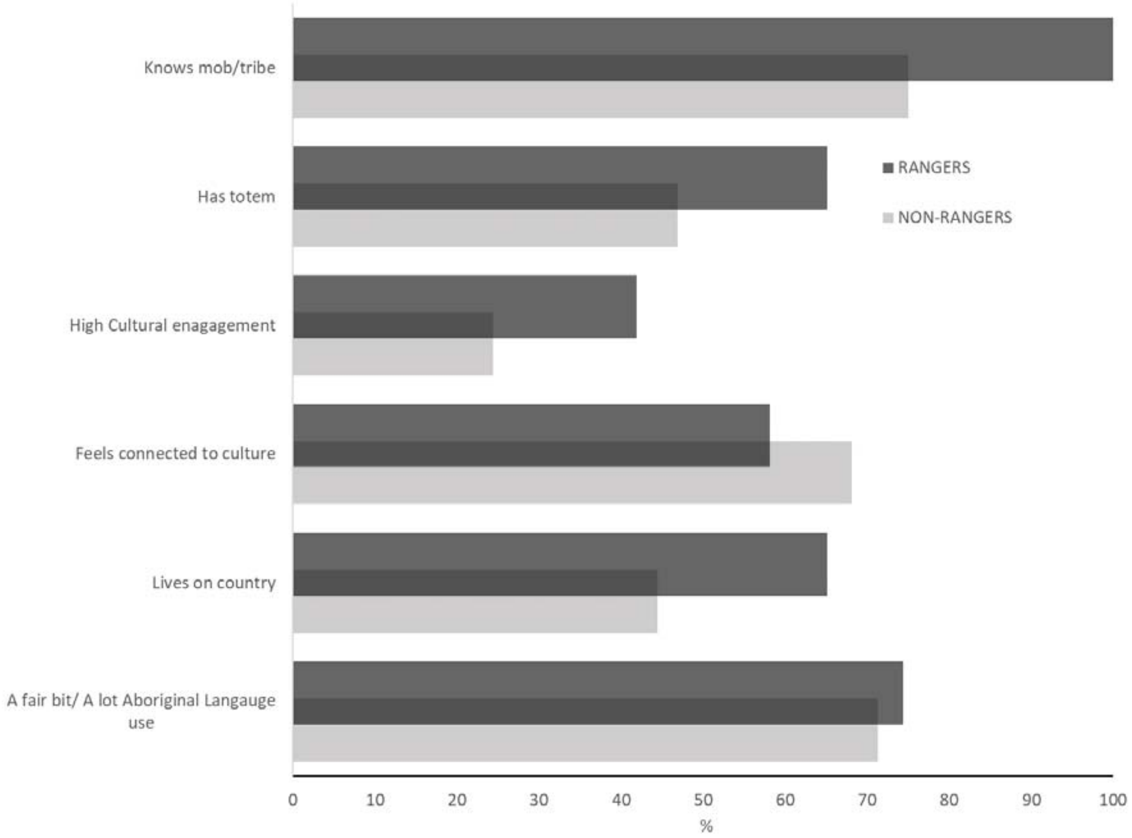


When asked about what impacts being a Ranger had on them many Rangers talked about four main impacts. There was a sense of opportunity the work had created for them including employment, training and money. Many also said that they felt 'better and healthier' from doing Ranger work.

Rangers also identified how looking after country gave them a sense of pride. Rangers also reported on how they were a source of pride within families and the broader community for what they do.

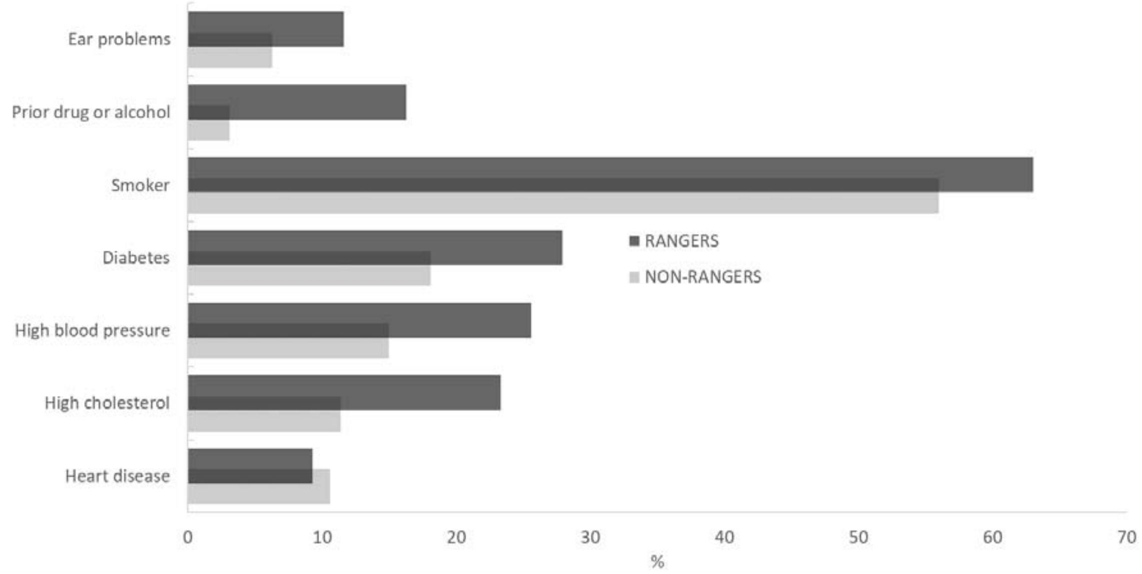
Culture: Rangers answered questions about cultural knowledge and practices (engagement). Many Rangers reported living on country, having high cultural engagement, knowing their totem and knowing which mob they belonged to more commonly compared to non-Rangers. Speaking Aboriginal language was similar between groups.

Figure 2: Culture knowledge and practice of Ranger wellbeing survey participants, 2017



Health and wellbeing of Rangers: Rangers reported less heart disease, but reported more diabetes, high cholesterol and high blood pressure. Rangers reported Diabetes almost twice as much (28%) as non-rangers (18%) and well above the last NT Aboriginal health survey (12%). Rangers were also more likely to report having had drug/alcohol problems (current or past); as well as ear conditions. Smoking tobacco was slightly higher among the Ranger group (63%) than the non-Ranger group (56%).

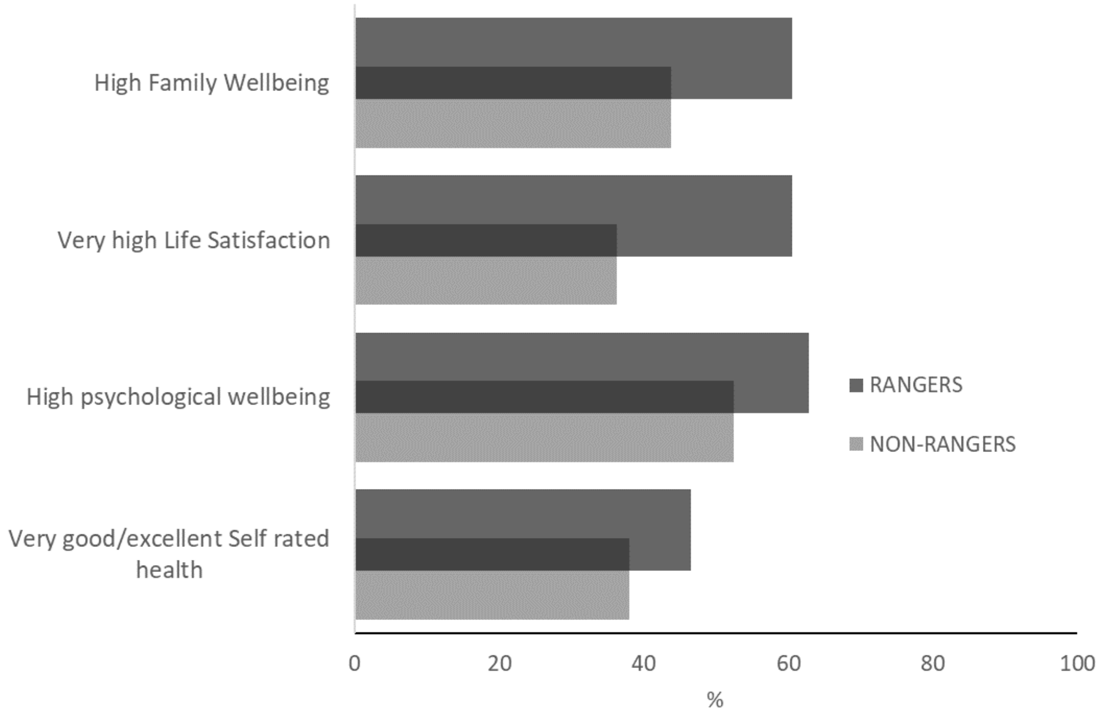
Figure 3: Health conditions and risk factors of Ranger wellbeing survey participants, 2017



Rangers reported more health conditions, but when we compared Rangers to non-Rangers on other wellbeing measures we found:

- High life satisfaction was twice as common
- Very good self-reported health was 50% more common
- High family wellbeing was 50% more common

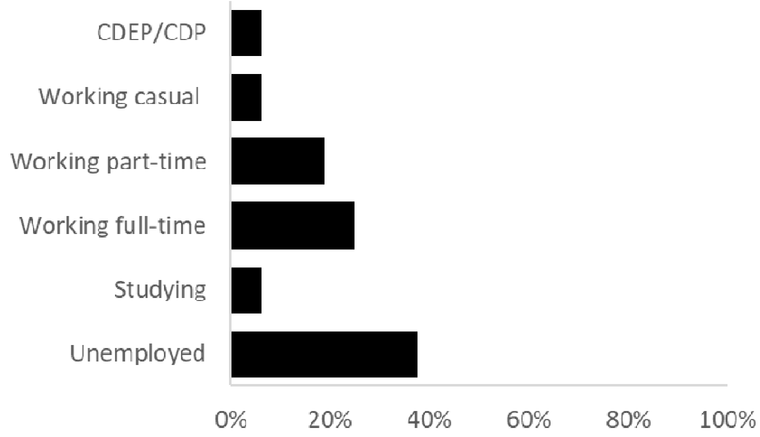
Figure 4: Wellbeing of Ranger survey participants, 2017



These findings further support to the growing evidence that Aboriginal cultural participation (in this case through the Ranger work) is a factor linked to better health and wellbeing.

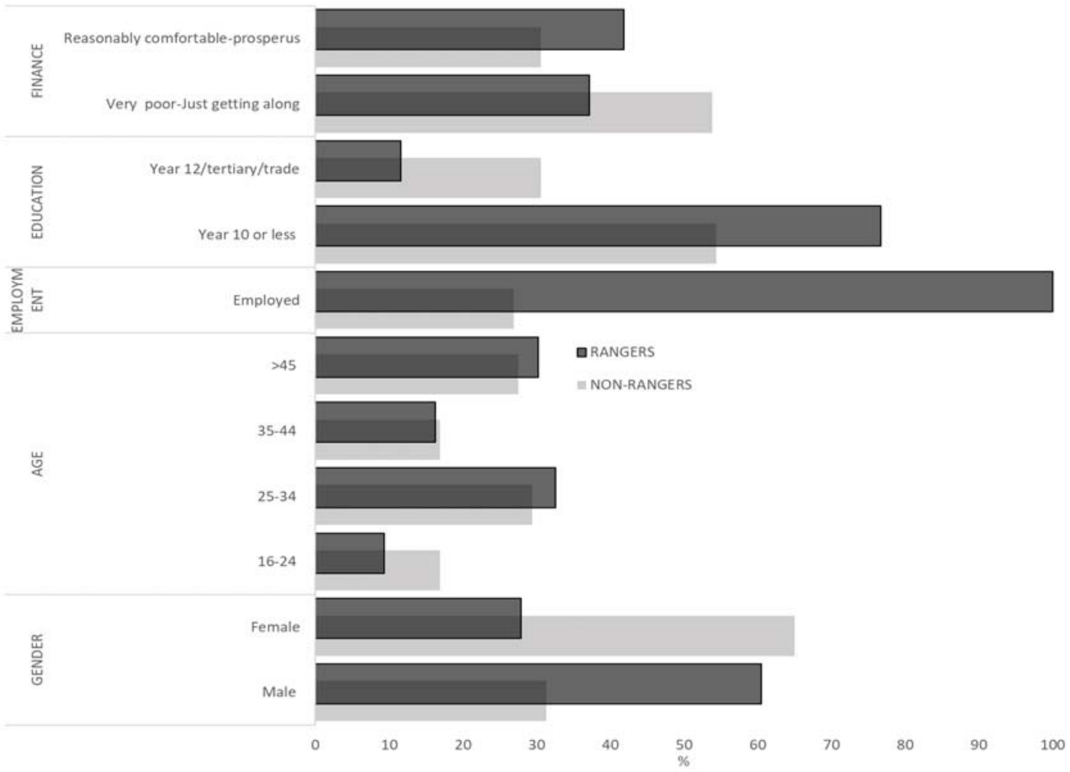
Importantly, higher levels of life satisfaction, general health and family wellbeing among Rangers compared to non-Rangers remained even when education, employment and financial status was taken into account. This suggests that being a Ranger has benefits beyond providing a job and income.

Figure 5: Employment prior to Ranger job



Who took Part: There were some differences between the Rangers and non-Rangers. In the Ranger group 60% were male and 30% were female. In the non-Ranger group: 65% were female and just under 30% were male. Just over half of non-Rangers were unemployed and just over half reported being very poor, poor or just getting along. This was different for Rangers who all reported having a job with just under half reporting they were reasonably comfortable, very comfortable or prosperous financially.

Figure 6: Characteristics of wellbeing survey participants, 2017



Appendix 2.17

Abstract submission for international presentation

(Chiefs of Ontario Health Forum)

Developing a National Indigenous Longitudinal Study (Mayi Kuwayu) in Australia*: Ray Lovett, Jan Chapman, Roxanne Jones, Katherine Thurber*

Culture is a key determinant of health and wellbeing for Aboriginal and Torres Strait Islander peoples in Australia, and for First Nations populations internationally. Cultural factors include (but are not limited to): identity; connection to country, family, and community; history; language; cultural knowledge and practice; and community engagement and empowerment.

Aboriginal and Torres Strait Islander culture is increasingly recognised by communities, organisations and policymakers as a critical, yet under-researched, determinant of health. Despite this, there are currently virtually no data to establish the relationship between culture and wellbeing in the Aboriginal and Torres Strait Islander context, or to identify the mechanisms by which culture impacts on wellbeing. There is a clear need for research that identifies how Aboriginal and Torres Strait Islander peoples navigate the differing cultures in which their lives exist, and how this impacts their health and wellbeing.

The Mayi Kuwayu Study is designed to address this lack of knowledge on a national scale, generating evidence about culture and its relationship to health and wellbeing through a large-scale cohort study of Aboriginal and Torres Strait Islander adults (estimated 16,000-40,000 participants). The Mayi Kuwayu Study will establish an ethical, community-focused and Aboriginal-controlled resource that will contribute to a holistic and contemporary understanding of Aboriginal and Torres Strait Islander culture, health and wellbeing.

The overarching aim of the Mayi Kuwayu Study is to produce robust evidence on drivers of health and wellbeing, with a particular focus on integrating culture with standard risk factors. Specifically, the project will provide: (1) reliable national- and individual-level indicators of Aboriginal and Torres Strait Islander culture; (2) large-scale data on culture and cultural experiences, wellbeing, health behaviours, person-centred outcomes, sociodemographic and other factors, and their inter-relationships, both cross-sectionally and over time; and, (3) a state-of-the-art data resource for investigating Aboriginal and Torres Strait Islander wellbeing, which can also serve as a framework for policy and program planning.

This semnar will cover: the genesis of the Mayi Kuwayu Study; the processes of developing the survey; findings from pilot tests of the survey; and, the next steps in study implementation.

Presenters:
Ray and Roxanne are part of the Aboriginal and Torres Strait Islander Health Program at the National Centre for Epidemiology and Population Health, Australian National University. The team conducts cutting-edge innovative and multidisciplinary large-scale research across the social and cultural determinants of Aboriginal and Torres Strait Islander health and wellbeing. The team's approach is to conduct research in partnership with Aboriginal and Torres Strait Islander individuals, communities, and organisations, and to apply a strengths-based frame to research. Ray Lovett is the Program leader, Roxanne Jones is a student in the Masters of Applied Epidemiology Program.

Appendix 2.18

Presentation slides for international presentation

(Chiefs of Ontario Health Forum)

Mayi Kuwayu

The National Study of Aboriginal
and Torres Strait Islander Wellbeing

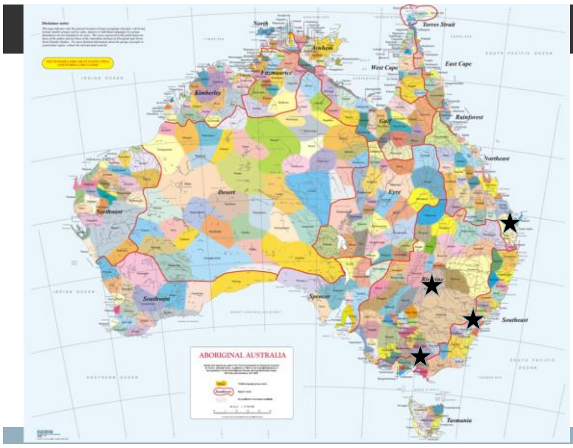
Our Cultures Count

Associate Professor Ray Lovett, Jan Chapman, Roxanne Jones, Dr Katie Thurber
Aboriginal and Torres Strait Islander Health Program
Epidemiology for Policy and Practice
National Centre for Epidemiology and Population Health
Research School of Population Health
The Australian National University
http://nceph.anu.edu.au/about-us/people/ray-lovett

Chiefs of Ontario Health Forum, 28 February 2018

Acknowledgements

- Mayi of this country and Elders
- COO
- Our partners and communities
- Funding: Lowitja & NHMRC



About our work:

The Aboriginal and Torres Strait Islander Health Program conducts research on the social and cultural determinants of Aboriginal and Torres Strait Islander health and wellbeing.

Our approach is to conduct research in partnership with Aboriginal and Torres Strait Islander individuals, communities, and organisations, and to frame our work using a strengths-based approach, where possible.

Context:

- Mayi Kuwayu = Ngiyampaa (Wongaibon) meaning to follow Aboriginal and Torres Strait Islander people over time.
- At least 65,000 years of history within the continent.
- Population of 786,689 in 2016.
- Median age = 22 years.
- 75% regional/urban.
- On average, life expectancy 10 years less.
- Many social and health disparities.

Outline

- Background and rationale
  - Policy and research directions
  - Wellbeing outcomes/Socio-cultural determinants
- Aims
- Methods and Conceptual framework
  - Community engagement
  - Survey domains
  - Survey development
- Proof of concept study results

Broader policy and research directions

- National Health Plan and policies
  - The Centrality of Culture in the Health of Aboriginal and Torres Strait Islander People:

> "We represent an evolving cultural spectrum inclusive of traditional and contemporary practices. **When we are empowered to do this**, and where systems facilitate this reclamation, protection and promotion, we are healthy, well and successful and our communities thrive"
> -- *Professor Ngiare Brown* (2015).

Research directions

- Cultural Determinants of Aboriginal and Torres Strait Islander Health Roundtable, November 2014 (Lowitja Institute)
  1. Half the difference in health outcomes unexplained.
  2. Clarify the cultural determinants.
  3. Consider strategies that could assist in **strengthening culture** as a determinant of Aboriginal and Torres Strait Islander health.

Mayi Kuwayu Study aims

1. Develop appropriate measures of culture and wellbeing **with** Aboriginal and Torres Strait Islander people
2. Look at experiences of culture and wellbeing, and how they relate to each other
3. Make the data available for community benefit

Method and design

- Longitudinal cohort study – follow people over time
- Indigenous governance
- Community indicator development
- Recruit through national database plus through community organisations
- Data linkage

Culture as the 'determinants of the determinants' of health

Review of Australian and international (Canada, US, New Zealand) literature

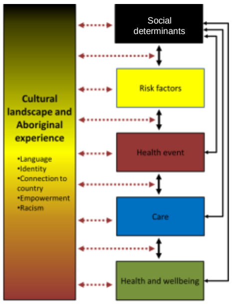
- Knowledges and beliefs
- Cultural expressions
- Country and caring for country (relationship between people and land)
- Language
- Self-determination
- Family, kinship, and continuity

How does culture relate to wellbeing

Questions determined by community

Potential questions:

- Does cultural practice improve education outcomes?
- Does strong connection to country reduce smoking?
- Do those with strong family ties experience fewer mental health problems after stressful life events?



Adapted from framework by Daniel, Lekkas, Cargo, Stankov, & Brown in 'Environmental risk conditions and pathways to cardiometabolic diseases in Indigenous populations'.

Sampling

- Sampling frame:
  - Aboriginal and Torres Strait Islander adults (≥16 years)
  - ≈400,000 people registered with Medicare, 65% of the population
- Mail out survey to 200,000 people from the Medicare list
  - Oversampling some areas
- Additional sampling through community orgs (quota sampling)
- Can complete survey on paper, online or over the phone
- Consent for data linkage and follow up surveys every few years
- Estimated participants: 16,000-40,000 adults

Progress to date

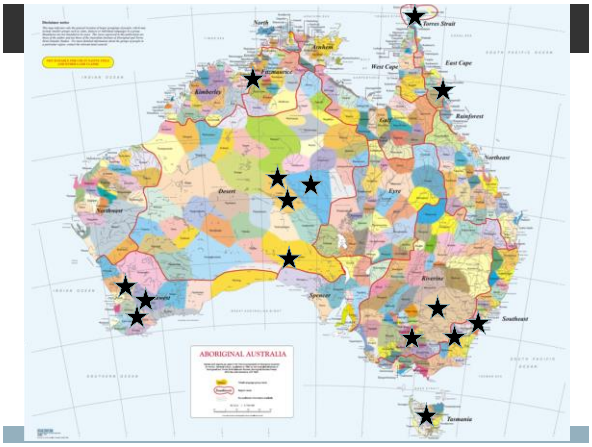
- Literature review
- Grants (NHMRC, Lowitja Institute)
- Ethics (>10)
- Indicator focus groups (24)
- Questionnaire workshops (15)
- 2 “Proof of concept” studies 2015 and 2017
- Study governance group established
- Data Sovereignty built into data processes

Indicator development (>20 groups, 165 people)

- Qualitative process
- Iterative question development and testing
- Proof of concept studies

Focus Groups

- Community org self nomination:
  - Resources provided to run groups
  - Structured according to local preferences
- Structure of groups:
  - Questions about culture and cultural wellbeing
  - Survey testing
- Feedback to groups
- Option to field test survey in community



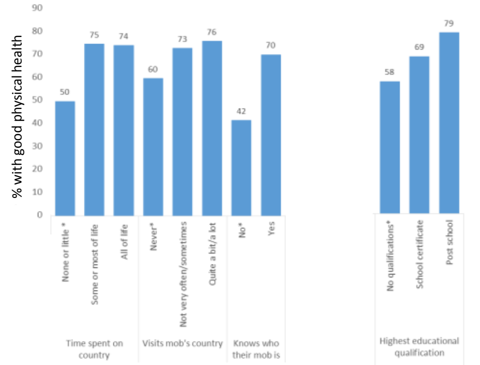
Proof of Concept 1: Murray River, NSW and Victoria 2015.

Regional area NSW/VIC, n=163

Descriptive statistics

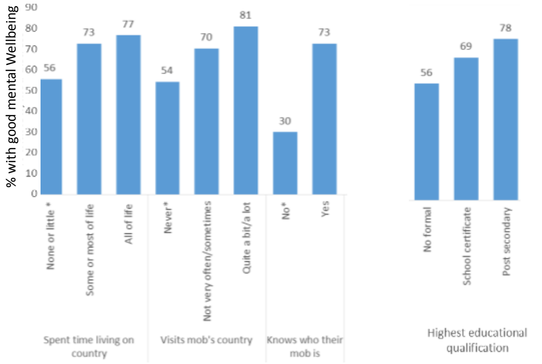
Australian National University

Good physical health



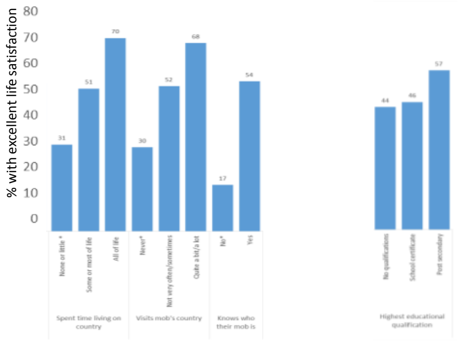
Australian National University

Good mental Wellbeing



Australian National University

Excellent life satisfaction



Australian National University

Proof of Concept 2: Southern Tanami, Northern Territory, 2017.

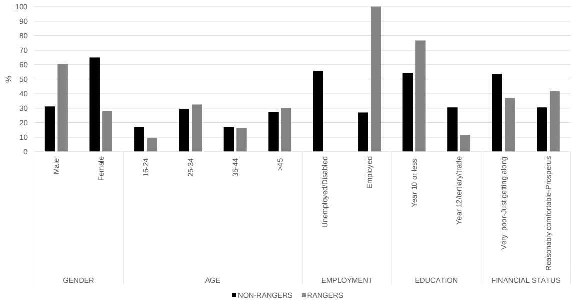
Remote area, n=209

Descriptive statistics

Univariate analysis and adjusted univariate analysis (Logistic regression) expressed as prevalence ratios.

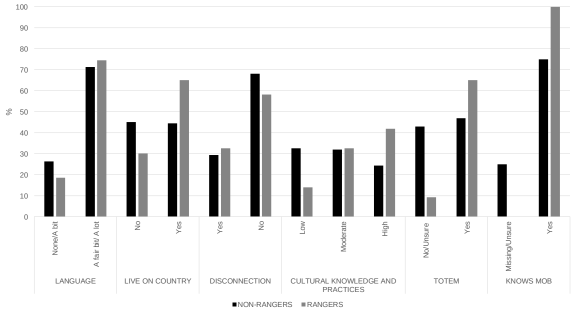
Australian National University

Participant characteristics

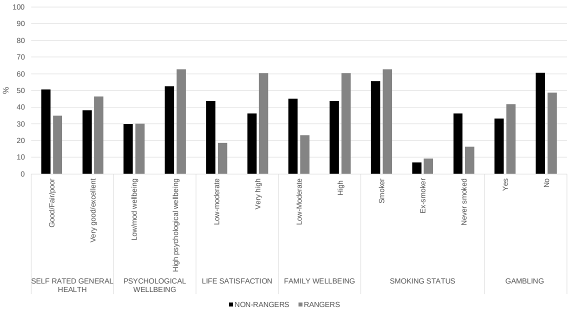


Australian National University

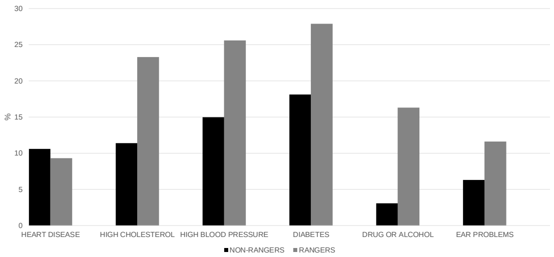
Selected cultural factors



Wellbeing outcomes



Health conditions



Very high life satisfaction

		Prevalence Ratio (95% CI)
Unadjusted:	Non-ranger	1 (ref)
	Ranger	1.90 (1.35-2.66)
Adjusted education:	Non-ranger	1 (ref)
	Ranger	1.84 (1.32-2.60)
Adjusted employment:	Non-ranger	1 (ref)
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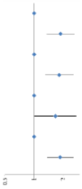
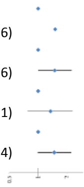
	Ranger	1.88 (1.37-2.59)



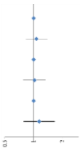
Very good general health

		Prevalence Ratio (95% CI)
Unadjusted:	Non-ranger	1 (ref)
	Ranger	1.51 (1.01-2.26)
Adjusted education:	Non-ranger	1 (ref)
	Ranger	1.50 (1.00-2.26)
Adjusted employment:	Non-ranger	1 (ref)
	Ranger	1.35 (0.78-2.31)
Adjusted financial status:	Non-ranger	1 (ref)
	Ranger	1.49 (0.99-2.24)



Good mental wellbeing

		Prevalence Ratio (95% CI)
Unadjusted:	Non-ranger	1 (ref)
	Ranger	1.08 (0.83-1.40)
Adjusted education:	Non-ranger	1 (ref)
	Ranger	1.03 (0.78-1.34)
Adjusted employment:	Non-ranger	1 (ref)
	Ranger	1.15 (0.79-1.68)



Considerations/limitations

- Sample size
- Proof of concept only (local studies)
- Non-random sample
- What comes first?

Challenges and expectations

- Distance, mobility
- Multiple ethics processes for approval and reporting
- Community priorities
- Ownership / custodianship of data
- Timeframes for consultation
- Community, regional, national reporting and feedback

Next steps

- Formalise Indigenous data governance processes
- Survey design and formatting
- National sampling frame
  - Testing of mail out survey ≈ 20,000 (in early 2018)
  - Medicare mail out ≈ 180,000 (June –December 2018)
- Test if survey questions are meaningful
- Data ready 2019
- Data linkage 2020

Supported by:

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the Lowitja Institute

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

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Questions?

mkstudy@anu.edu.au

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Our Cultures Count

Appendix 2.19

Presentation slides for South East Aboriginal Fire Forum

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Our Cultures Count

Mayi Kuwayu

The National Study of Aboriginal and Torres Strait Islander Wellbeing

Ray Lovett & Roxanne Jones
National Centre for Epidemiology and Population Health
Research School of Population Health
The Australian National University
South East Fire Forum, University of Canberra

http://mkstudy.com.au

Australian National University
The Lowitja Institute

About our work:

The Aboriginal and Torres Strait Islander Health Program conducts research on the social and cultural determinants of Aboriginal and Torres Strait Islander health and wellbeing.

What do we want to know?

1. What is culture?
2. Does cultural expression and practice improve our wellbeing?

Motivations for this work:

- Wanting to know about how strong identity and culture can protect or improve health and wellbeing
- Desire of family and communities to value identity/culture
- Mayi Kuwayu = Ngiyampaa meaning to follow Aboriginal people

How can we answer this?

- Through a survey that you do every few years
- Make sure Aboriginal and Torres Strait Islander people are in control of it
- Make sure Aboriginal and Torres Strait Islander people develop the questions
- Get the survey to as many people as possible

Mayi Kuwayu main question

What is the link between culture and wellbeing?

Our survey questions

Cultural factors

- Identity
- Connection to country/Islands
- Connection to family and community
- How you learn and practice culture
- language
- Control over your life

Wellbeing and History

- Life satisfaction
- Family wellbeing
- Psychological distress
- Health risks/conditions
- Stolen generations
- Racism

How will people do it?

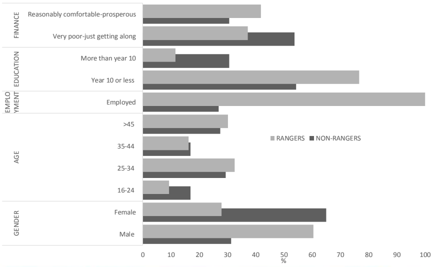
- Later this year we will mail the survey to 200,000 Aboriginal and Torres Strait Islander people across the country
- With researchers in certain areas (North Queensland and Torres Strait): Looking for researchers in community in Western Australia and NT.
- Survey available in hard copy, online and phone
- We think between 16,000-50,000 people will be involved

Rangers in Central Australia

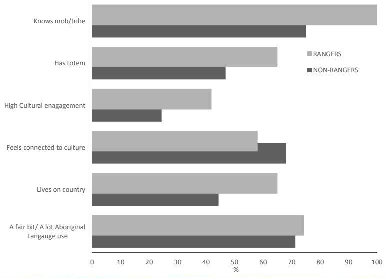
Question: Is cultural participation (Rangers) linked to higher wellbeing?

Looked at 43 Aboriginal Rangers v 160 Non-Rangers

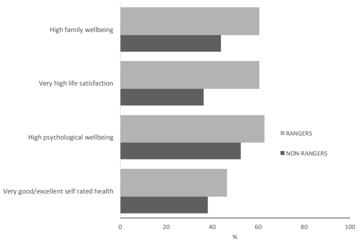
About the two groups

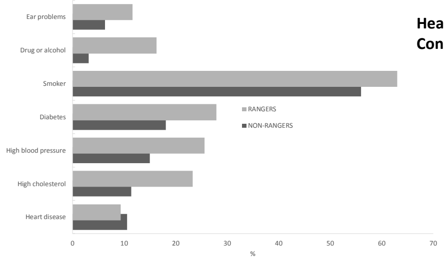


Cultural factors



Wellbeing





Health Risks & Conditions

When we compared Rangers to non-Rangers, we found

- High life satisfaction was twice (X2) as high among Rangers
- Very good self-reported health was 50% higher among Rangers
- High family wellbeing was 50% higher among Rangers

What does it mean: Cultural expression/participation (through Ranger participation is linked to improved wellbeing

---

Thanks

Raymond.lovett@anu.edu.au & Roxanne.Jones@anu.edu.au

mkstudy@anu.edu.au

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Appendix 2.20

Abstract submission for joint seminar with Rangers

CENTRAL LAND COUNCIL

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Aboriginal Ranger jobs and wellbeing outcomes in Central Australia: Proof of concept

Aboriginal Rangers play a crucial role in the care of country. In Central Australia, the Central Land Council (CLC) employs approximately 90 Rangers that work in small regional teams. This seminar will present perspectives from CLC Rangers about how their role and work improves country, ensures continuation of cultural practices and knowledge, and enhances wellbeing. Country and connection to country are important cultural constructs for Aboriginal and Torres Strait Islander peoples across Australia.

Further, this work is supported by new research findings undertaken by researchers at National Centre for Epidemiology and Population Health (NCEPH). The CLC Ranger group participated in the development of a survey, the research team then collected and analysed cross-sectional data and compared health and wellbeing measures from Aboriginal and Torres Strait Islander peoples employed as Rangers (n=43) compared with non-Rangers (n=160). This study explored the link between caring for country, through participation in a Ranger program, and wellbeing.

Ranger participation was significantly associated with very high life satisfaction (PR=1.69,95%CI:1.29,2.20) and high family wellbeing (PR=1.47,95%CI:1.13,1.90); associations remained significant after individual adjustment for education, income, employment, health risk factors and health conditions. The magnitude and direction of associations were similar for very good general health, but results were not significant. We did not observe an association between Ranger participation and psychological wellbeing.

While based on a small sample, these findings support the assertion that participation in the Ranger program is associated with positive health and wellbeing outcomes. This supports the continuation of cultural participation and practice through the Ranger program and therefore has implications for funding, program and policy development.

Presenters

Dione Kelly[1]

Barbara Petrick[2]

Peter Donohoe[3]

Roxy Jones[4]

Ray Lovett[4]

1. CLC North Tanami Rangers based at Lajamanu.
2. CLC Arltarpilta Inelye Rangers based at Atitjere (also known as Harts Range)
3. Central Land Council
4. Aboriginal and Torres Strait Islander Health Program, NCEPH, ANU

Appendix 2.21

Presentation slides for joint seminar with Rangers

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Our Cultures Count

Aboriginal Ranger jobs and wellbeing outcomes in Central Australia: Proof of concept study

Dione Kelly
Barbara Petrick
Peter Donohoe
Roxy Jones
Ray Lovett

CENTRAL LAND COUNCIL

http://mkstudy.com.au

Presentation outline

- About our work
- Development of Mayi Kuwayu
- Proof of concept

About our work:

The Aboriginal and Torres Strait Islander Health Program conducts research on the social and cultural determinants of Aboriginal and Torres Strait Islander health and wellbeing.

Motivations for this work:

- Wanting to know about how strong identity and culture can protect or improve health and wellbeing
- Desire of family and communities to value identity/culture
- Mayi Kuwayu = Ngiyampaa meaning to follow Aboriginal people

---

What do we want to know?

1. What is culture?
2. Does cultural expression and practice improve our wellbeing?

How can we answer this?

- Through a survey that you do every few years
- Make sure Aboriginal and Torres Strait Islander people are in control of it
- Make sure Aboriginal and Torres Strait Islander people develop the questions
- Get the survey to as many people as possible

Mayi Kuwayu main question

What is the link between culture and wellbeing?

Survey development

- **(>20 groups, 165 people)**
- Qualitative process
- Iterative question development and testing
- Proof of concept studies

Our survey domains

Cultural factors

- Identity
- Connection to country/Islands
- Connection to family and community
- Learning and practicing culture
- Language
- Control over your life

Wellbeing and Experiences

- Life satisfaction
- Family wellbeing
- Psychological distress
- Health risks/conditions
- Stolen generations
- Racism

Ranger wellbeing in Central Australia:
a Proof of Concept Study

Question: Is Ranger work linked to higher wellbeing?

Compared 43 Aboriginal Rangers with 160 Non-Rangers

NOTE: Findings under embargo until published. Do not reproduce or distribute.

How we did it

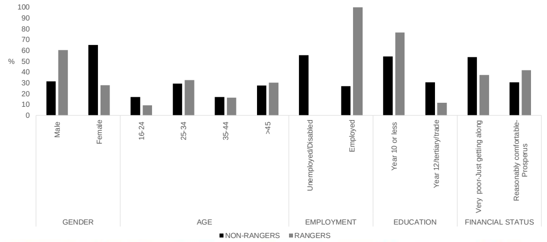
- Survey questions developed with Rangers (8)
- Our team attended the 2017 Ranger camp
- Surveys done on site
- Surveys done in nearby communities

Methods

- Descriptive analysis
- Log binominal models (prevalence ratios)
    - Life satisfaction, self reported general health, family wellbeing and psychological wellbeing
- Individual adjustment for education, financial status, employment, health risk score and health conditions

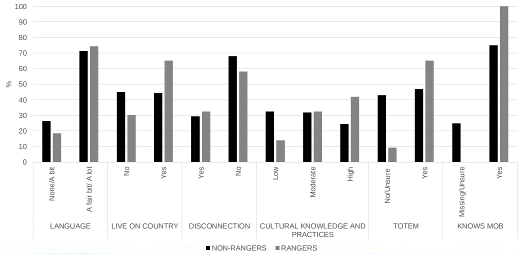
Demographic factors

*RESULTS UNDER EMBARGO



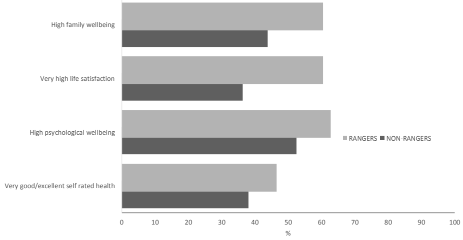
Selected Cultural factors

*RESULTS UNDER EMBARGO



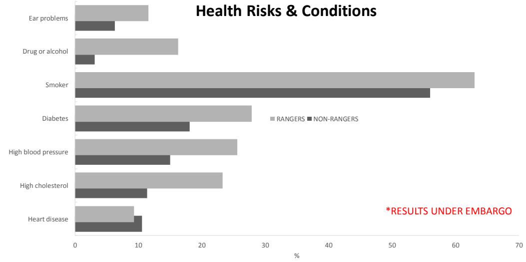
Wellbeing

*RESULTS UNDER EMBARGO



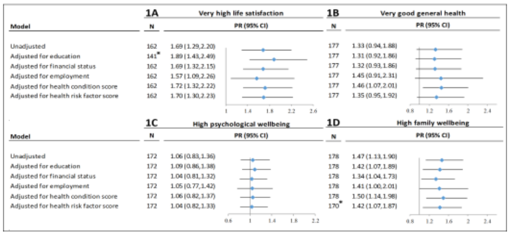
Health Risks & Conditions

*RESULTS UNDER EMBARGO



Associations between Ranger status and wellbeing

*RESULTS UNDER EMBARGO



Model	1A N	Very high life satisfaction PR (95% CI)	1B N	Very good general health PR (95% CI)
Unadjusted	162	1.69 (1.29,2.20)	177	1.33 (0.94,1.88)
Adjusted for education	141*	1.89 (1.43,2.49)	177	1.31 (0.92,1.86)
Adjusted for financial status	162	1.69 (1.32,2.15)	177	1.32 (0.93,1.86)
Adjusted for employment	162	1.57 (1.09,2.26)	177	1.45 (0.91,2.31)
Adjusted for health condition score	162	1.72 (1.32,2.22)	177	1.46 (1.07,2.01)
Adjusted for health risk factor score	162	1.70 (1.30,2.23)	177	1.35 (0.95,1.92)

Model	1C N	High psychological wellbeing PR (95% CI)	1D N	High family wellbeing PR (95% CI)
Unadjusted	172	1.06 (0.83,1.36)	178	1.47 (1.13,1.90)
Adjusted for education	172	1.09 (0.86,1.38)	178	1.42 (1.07,1.89)
Adjusted for financial status	172	1.04 (0.81,1.32)	178	1.34 (1.04,1.73)
Adjusted for employment	172	1.05 (0.77,1.42)	178	1.41 (1.00,2.01)
Adjusted for health condition score	172	1.06 (0.82,1.37)	178	1.50 (1.14,1.98)
Adjusted for health risk factor score	172	1.04 (0.82,1.33)	170*	1.42 (1.07,1.87)

* Missing category for relevant exposure variable was excluded due to zero cells

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Comparing Rangers to non-Rangers…

*RESULTS UNDER EMBARGO

- Rangers were twice (2x) as likely to have high life satisfaction
- Rangers were 50% more likely to have very good self-reported health
- Rangers were 50% more likely to have high family wellbeing

Results were consistent even when taking into account differences in education, employment, financial status, health risk and health conditions (one at a time).

What does it mean?

Ranger participation is linked (associated) with higher wellbeing.

Higher wellbeing among Rangers is *not* just due to the education, employment, or financial benefits.

Thanks

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Peter.Donohoe@clc.org.au
Barbara Petrick
Dione Kelly

CLC Ranger camp 2018, Hamilton Downs.

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

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Australian National University

the Lowitja Institute

Appendix 2.22

Abstract submission for CATSINaM* conference
*Congress of Aboriginal and Torres Strait Islander Nurses and Midwives

ABSTRACT *Our Community Story - Past, Present, Future*

Authors: Roxanne Jones*, Katherine A Thurber*, Jan Chapman, Catherine D'Este, Mark Wenitong, Sandra Eades, Lisa Strelein, Maureen Davy, Wei Du, Anna Olsen, Janet Smylie, Emily Banks, and Raymond Lovett, *on behalf of the Mayi Kuwayu Study Team*

Corresponding author: Roxanne Jones
Address: 54 Mills Road, National Centre for Epidemiology and Population Health, Research School of Population Health, The Australian National University, Acton ACT 2601
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Phone: +61 2 6125 50938

Introduction

Aboriginal and Torres Strait Islander peoples enduring cultures and values are considered critical to health and wellbeing, alongside physical, psychological and social factors. We currently lack large-scale data that adequately represent these experiences. As a result, there is a paucity of robust evidence regarding the drivers of Aboriginal and Torres Strait Islander health and wellbeing; the absence of evidence on cultural practice and expression is particularly striking, given its foundational importance.

Method

Mayi Kuwayu: The National Study of Aboriginal and Torres Strait Islander Wellbeing (Mayi Kuwayu Study) will be a large-scale, national longitudinal study of Aboriginal and Torres Strait Islander adults, with linkage to health-related administrative records. The baseline questionnaire was developed through consultations with communities across Australia, and includes items on: cultural practice and expression, sociodemographic factors, health and wellbeing, health behaviours, experiences and environments, and family support and connection. The baseline questionnaire will be mailed to 200,000 Aboriginal and Torres Strait Islander adults (≥16 years), yielding an estimated 16,000-40,000 participants, supplemented through face-to-face recruitment. Follow-up surveys will be conducted approximately every 3-5 years. The Mayi Kuwayu Study will contribute to filling key evidence gaps, including examination of the contribution of cultural factors to wellbeing, alongside standard elements of health and risk.

Outcomes

The Mayi Kuwayu Study will be an exemplar of Aboriginal and Torres Strait Islander research governance, providing enduring and shared infrastructure to underpin program and policy development, based on measures and values of significance to Aboriginal and Torres Strait Islander peoples. The Study was developed and is conducted in partnership with Aboriginal and Torres Strait Islander organisations across States and Territories. Findings from this Study will be disseminated through various formats with a particular focus on reporting back to communities involved.

Appendix 2.23

Presentation slides for CATSINaM* conference
*Congress of Aboriginal and Torres Strait Islander Nurses and Midwives

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Our Cultures Count

Our Cultures Count: The Mayi Kuwayu Study

Roxy Jones
National Centre for Epidemiology and Population Health
Research School of Population Health
The Australian National University

http://mkstudy.com.au

Acknowledgments:

- CATSINaM
- Research team
- Organisation partners
- Funding providers
- Ethics

Mayi Kuwayu background:

Mayi Kuwayu = Ngiyampaa (Wongaibon) meaning to follow Aboriginal and Torres Strait Islander people over time.

- Culture described as an integral component of health and wellbeing
- No large scale population data available

SA focus group quote:

‘If we don’t have culture, we don’t always have wellbeing’

Mayi Kuwayu aims:

1. Develop appropriate measures of culture and wellbeing **with** Aboriginal and Torres Strait Islander people
2. Look at experiences of culture and wellbeing, and how they relate to each other
3. Make the data available for community benefit

Mayi Kuwayu questions:

1. What is culture?
2. What is wellbeing?
3. What is the link between culture and wellbeing?

Torres Strait focus group quote:

‘Every generation stands on the shoulders of the last generation. So you and me stand up on shoulders of giants. That's why we're here.’

Focus groups:

- Qualitative process of developing cultural and wellbeing indicators
- Semi structured
- >20 focus groups, >200 people

Focus group locations

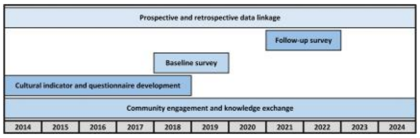
Key domains and measures	
Cultural practice and expression	Country and connection to country, Indigenous beliefs and knowledge, cultural expression, self-determination and leadership, language, family, kinship and community, identity
Sociodemographic factors	Age, sex, housing, education, employment, financial situation, household composition
Health and wellbeing	Life satisfaction, health status, health conditions, medication use, social and emotional wellbeing, functional limitation
Health behaviours	Physical activity, alcohol and tobacco use, health service use
Experiences and environments	Services in the community, experiences of racism, community safety, environmental conditions, life events

---

Mayi Kuwayu Methods

- Longitudinal quantitative survey
- Repeat every 3-5 years
- Mail out survey to 200,000 Aboriginal and Torres Strait Islander adults
- Indigenous governance of data
- Indigenous input throughout the entire survey development
- Data linkage

Bunbury focus group quote:
'If you don't know where you come from, how do you know where you're going?'



Prospective and retrospective data linkage

Follow-up survey

Baseline survey

Cultural indicator and questionnaire development

Community engagement and knowledge exchange

2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024

Maintaining community relationships

- The study has involved multiple trips out to communities in order to maintain relationship with organisations
- Employment and capacity building with community researchers
- Preliminary results presented back to community organisations
- Joint promotion of work with community to policy makers
- Community priorities

Impact

- Provides evidence back to community and partnering organisations
- Spreading community stories
- Capacity building
- Community priorities and relationships
- Published
- Media
- Policy engagement

Thanks

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Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Australian National University

The Lowitja Institute

Appendix 2.24

Abstract submitted for Healing Our Spirits Worldwide

Title: The cultural determinants of health and wellbeing among Aboriginal and Torres Strait Islander peoples in Australia

Presenters: Roxanne Jones, Jan Chapman and Ray Lovett, National Centre for Epidemiology and Population Health, Research School of Population Health, The Australian National University.

Aboriginal and Torres Strait Islander cultural factors are key determinants of Aboriginal and Torres Strait Islander health and wellbeing. These factors include identity, cultural participation and knowledge exchange, connection to country, family and community, language and governance, experiences of racism and discrimination, community engagement and empowerment. There is growing evidence of the association between cultural engagement and positive health and wellbeing outcomes.

This presentation will showcase how our research team has worked with many Aboriginal and Torres Strait Islander people and communities over the last few years to develop questions that best represent Aboriginal and/or Torres Strait Islander cultures and wellbeing. These questions form the basis of the Mayi Kuwayu Study. Mayi Kuwayu means to follow Aboriginal people over time in Ngiyampaa language. The team will present pilot MK Study results.

The Mayi Kuwayu Study aims to provide the first large-scale evidence on cultural factors and their links to health and wellbeing. It will do this by inviting over 200,000 Aboriginal and Torres Strait Islander adults to participate. Participants will be invited to complete follow-up surveys every three-five years.

Data from the Mayi Kuwayu Study will be an Indigenous-controlled collaborative resource for research, conducted in strict accordance with ethical, community and Aboriginal and Torres Strait Islander research standards.

Appendix 2.25

Presentation slides for Healing Our Spirits Worldwide conference

Mayi Kuwayu
The National Study of Aboriginal and Torres Strait Islander Wellbeing

Our Cultures Count

The cultural determinants of wellbeing for Aboriginal and Torres Strait Islander peoples in Australia: Mayi Kuwayu

Jan Chapman, Ray Lovett, & Roxanne Jones
Mayi Kuwayu Study
Aboriginal and Torres Strait Islander Health Program
National Centre for Epidemiology and Population Health, ANU

Healing Our Spirit Worldwide, Sydney 29 | November | 2018

About our work:

The Aboriginal and Torres Strait Islander Health Program conducts research on the social and cultural determinants of Aboriginal and Torres Strait Islander health and wellbeing.
Our approach is to conduct research in partnership with Aboriginal and Torres Strait Islander individuals, communities, and organisations, and to frame our work using a strengths-based approach, where possible.

Outline

- About our work
- Policy and research background
- Aims
- Methods
  - Defining Aboriginal and Torres Strait Islander culture
  - Indicator development
  - Quantifying the link between culture and wellbeing
- Results

Policy Context

- The National Aboriginal and Torres Strait Islander Health Plan 2013-2023 puts culture at the centre of its priorities, stating:
  - Aboriginal and Torres Strait Islander peoples have the right to live a healthy, safe and empowered life with a healthy strong connection to culture and country" (Department of Health, 2013).

Research Context

- Cultural Determinants of Aboriginal and Torres Strait Islander Health Roundtable, November 2014 (Lowitja Institute)
  1. Clarify the cultural determinants
  2. Consider strategies that could assist in strengthening culture as a determinant of Aboriginal and Torres Strait Islander health

---

Defining Culture

- Culture often refers to sets of beliefs, knowledge, attitudes, and behaviours.
- Culture is a fundamental component of, and contributor to, health and wellbeing, through belief systems, knowledge and therefore understanding, attitudes, and behaviours.

Mayi Kuwayu aims

1. Define broad cultural domains
2. Develop appropriate cultural indicators with Aboriginal and Torres Strait Islander peoples
3. Quantify cultural, health risk, health status and other factors, and inter-relationships and any mitigating role of culture in risk factor-outcome relationships
4. Create a collaborative resource for Aboriginal and Torres Strait Islander health research/action

---

Methods 1 – defining cultural domains

1. Establish broad cultural determinant domains
   a) Literature review
      I. Online search
      II. Hand searching
      III. 1997-2017
      IV. Major domains and sub-themes identified
   b) Focus groups
      I. Community self-nomination
      II. Co-facilitation
      III. Recorded and transcribed
      IV. Thematic analysis

Methods 2 - Indicator development

- Results of literature review and insider knowledge
- Conceptualisation of key concepts and how these will be measured
- The process included a descending the *ladder of abstraction*
  - Each subsequent focus group revised wording and re-tested
- Face Validity testing

Cltural Domains Identified through Literature

Discuss Cultural Indicators with Communnity

Develop Questionaire Items from Community Feedback

Face Validity Assessment

Final Questionaire Items

Methods 3– quantifying relationships

- Descriptive analysis
- Log binominal models (prevalence ratios)
  - Life satisfaction, self reported general health, family wellbeing and psychological wellbeing
- Individual adjustment for education, financial status, employment, health risk score and health conditions

---

Results: Cultural Domains

- Previous research and focus groups identified six key cultural domains as identified in the literature. These included:
  - Connection to Country;
  - Cultural Beliefs and Knowledge;
  - Language;
  - Family, Kinship and Community;
  - Expression and Cultural Continuity; and
  - Self-determination and Leadership.

https://openresearch-repository.anu.edu.au/bitstream/1885/148406/5/Defining%20the%20Indefinable_Final.pdf

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Results: Indicators

Domain	Measure
Participant report of family/community environment	
Cultural factors	Identity‡; Cultural knowledge and practice‡; Family wellbeing‡; leadership‡; connection to country‡; language‡
Historical and current exclusion factors	Stolen Generation‡; Family relocations‡; Missions and reserves‡; Racism/Discrimination†
Demographics	Age; sex; education; employment; financial situation‡; height; weight
Family and relationships	Number of children*; family/household structure; service providers‡; community problems‡; caring; Life events†
Participant report of health issues and risk/protective factors	
Health and wellbeing	Global self-rated health*; health conditions*, medication use*; disability †; tobacco, alcohol, health care access, prevention, psychological distress (Kessler-5*); Life satisfaction*;gambling†; exercise‡
Programs and services ‡	Program participation (Deadly choices, FWB, Language programs, NDIS, Native title, Ranger)

*Established tool or instrument. †Modified tool or instrument. ‡Tool or instrument developed through the community consultation process

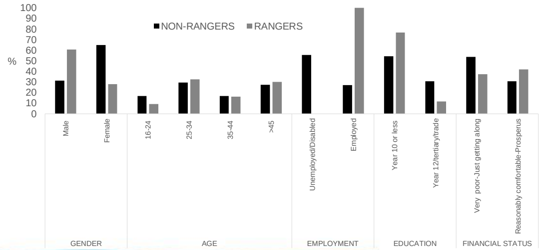
Results of quantifying the relationship between cultural participation and wellbeing: Proof of Concept 2.

Associations between Participation in a Ranger Program and Health and Wellbeing Outcomes among Aboriginal and Torres Strait Islander People in Central Australia: A Proof of Concept Study.

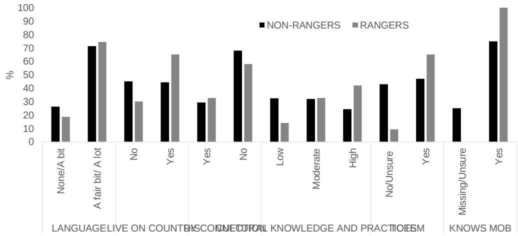
Methods

- Descriptive analysis
- Log binominal models (prevalence ratios)
  - Life satisfaction, self reported general health, family wellbeing and psychological wellbeing
- Individual adjustment for education, financial status, employment, health risk score and health conditions

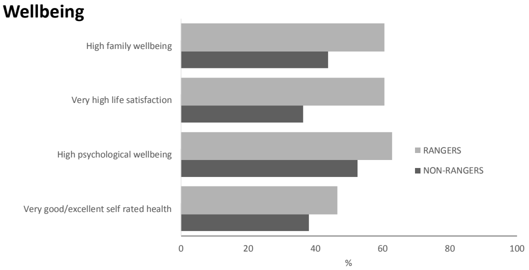
Demographic factors



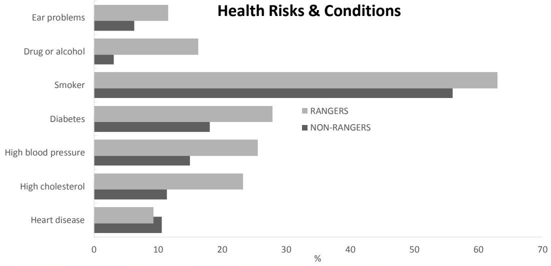
Selected Cultural factors



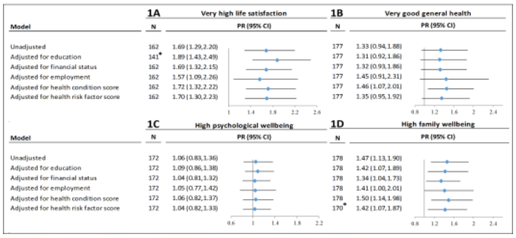
Wellbeing



Health Risks & Conditions



Associations between Ranger status and wellbeing



1A Very high life satisfaction

Model	N	PR (95% CI)
Unadjusted	162	1.69 (1.29,2.20)
Adjusted for education	141*	1.89 (1.43,2.49)
Adjusted for financial status	162	1.69 (1.32,2.15)
Adjusted for employment	162	1.57 (1.09,2.26)
Adjusted for health condition score	162	1.72 (1.32,2.22)
Adjusted for health risk factor score	162	1.70 (1.30,2.23)

1B Very good general health

Model	N	PR (95% CI)
Unadjusted	177	1.33 (0.94,1.88)
Adjusted for education	177	1.31 (0.92,1.86)
Adjusted for financial status	177	1.32 (0.93,1.86)
Adjusted for employment	177	1.45 (0.91,2.31)
Adjusted for health condition score	177	1.46 (1.07,2.01)
Adjusted for health risk factor score	177	1.35 (0.95,1.92)

1C High psychological wellbeing

Model	N	PR (95% CI)
Unadjusted	172	1.06 (0.83,1.36)
Adjusted for education	172	1.09 (0.86,1.38)
Adjusted for financial status	172	1.04 (0.81,1.32)
Adjusted for employment	172	1.05 (0.77,1.42)
Adjusted for health condition score	172	1.06 (0.82,1.37)
Adjusted for health risk factor score	172	1.04 (0.82,1.33)

1D High family wellbeing

Model	N	PR (95% CI)
Unadjusted	178	1.47 (1.13,1.90)
Adjusted for education	178	1.42 (1.07,1.89)
Adjusted for financial status	178	1.34 (1.04,1.73)
Adjusted for employment	178	1.41 (1.00,2.01)
Adjusted for health condition score	178	1.50 (1.14,1.98)
Adjusted for health risk factor score	170*	1.42 (1.07,1.87)

* Missing category for relevant exposure variable was excluded due to zero cells

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Comparing Rangers to non-Rangers...

- Rangers were twice (2x) as likely to have high life satisfaction
- Rangers were 50% more likely to have very good self-reported health
- Rangers were 50% more likely to have high family wellbeing

Results were consistent even when taking into account differences in education, employment, financial status, health risk and health conditions (one at a time).

What does it mean?

Ranger participation is linked (associated) with higher wellbeing.

Higher wellbeing among Rangers is *not* just due to the education, employment, or financial benefits.

Questions?

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The National Study of Aboriginal and Torres Strait Islander Wellbeing

Appendix 2.26

Article submitted and published by Land Rights News

It's the culture: why rangers feel happier and healthier

Jumping for joy: happy rangers at the Ross River ranger camp in 2017.

A NEW study has found that Aboriginal rangers in Central Australia report better health, life satisfaction and family wellbeing than non-rangers.

A study by the Central Land Council, the Australian National University (ANU) and the Tangentyere Research Hub sheds a light on how ranger work improves Aboriginal people's wellbeing.

The researchers compared interviews with 49 rangers and 160 non-rangers and found that rangers report being more satisfied with their lives than non-rangers.

"I really expected that one," commented Tjuwanpa Ranger co-ordinator Craig LeRossignol from Ntaria.

"We do everything with a smile. If you can't smile, you can't work. Every time we come to town, people ask us if there's any jobs out bush. They want to get out of town. Every type of abuse is here [in town] and it's really at an ugly point now."

> **"We do everything with a smile. If you can't smile, you can't work. Every time we come to town, people ask us if there's any jobs out bush."**

The results in life satisfaction remained high even when the interviewees' education, employment and financial situation were taken into account.

This shows that being a ranger has benefits beyond the education, training and income that come with the job.

Rangers also reported a 50 per cent improvement in family wellbeing compared to non-rangers, saying they are proud to be role models for family and community.

"I do this for my grandmother," one ranger told the researchers.

"I am walking in her shoes, she wants me to work on country that she fought to get back and it makes me feel good to know that she is happy."

"It highlights the broader impacts on family and community of programs that combine cultural participation with work", lead researcher Ray Lovett said.

"Many rangers said they felt proud looking after country and the community. They are looked up to in families and by the broader community for what they do," he said.

Dr Lovett presented the findings to the CLC's annual ranger camp at Hamilton Downs in March.

Few rangers were surprised by what they heard and many had stories of personal change.

"I used to be a gambler, but I've changed and go to work every day," a female ranger said. "It's a good job and I really love it. I get up every morning with pride and joy in me."

The study also found that rangers are almost 50 percent more likely to report good health compared to non-rangers.

Mr LeRossignol said staying healthy is important because ranger work can be physically demanding and draining.

"Every complaint we have, physical or mental, it's a requirement to get it checked out. And more than that. It's a cultural requirement. It's very strict," he said.

A lot of people are worried when a problem occurs in the group because we're all together. We understand the repercussions our way."

The researchers believe that rangers feel a greater sense of wellbeing because cultural knowledge is central to their work.

They were more likely to live on their country, be in touch with elders and cultural practices, and more likely to know their mob, languages and dreaming than non-rangers.

The study also identified opportunities to improve ranger health, for example by cutting their high rates of smoking.

"Two hundred years of being paid with tobacco does that to families," Mr LeRossignol explained.

"Out in the bush people were given tobacco as a form of payment and then it became an enjoyable thing and we all became addicted because it was the only form of pleasure for a lot of years and just became the norm unfortunately," he said.

Also, just under a quarter of rangers reported high blood pressure and diabetes, common health concerns across Central Australia that affect the work some individuals can do.

Mr LeRossignol said the CLC has systems in place to keep rangers safe.

"The few fellas I had in my group that had health problems in the past they go to the clinic every Monday and get it checked out," he said.

"It's compulsory before we go out. We can't afford to take that risk of having something go seriously wrong when we are out on country."

Dr Lovett's team plans to revisit the rangers regularly so it can test the growing evidence that Aboriginal cultural participation is linked to better health and wellbeing.

MEET OUR RANGERS

Fraser Oliver

FRASER Oliver from the Ltyentye Apurte Rangers has won the environment category of the Northern Territory Young Achiever Awards.

Mr Oliver travelled from Santa Teresa to Darwin in April, to collect his award.

He is part of the CLC ranger program's digital knowledge group and thinks of himself as an ambassador for the program.

This year, he is tackling a certificate 4 in conservation and land management at Batchelor. He admits he has spent less time with his friends in order to become better at his job.

"My friends need to understand how important my job is to me and that I can spend time with them on weekends. They have since realised how empowered I am and are now constantly trying to obtain a position with the ranger group.

I am considered a role model within the whole ranger program, for my community, for my family and Indigenous people everywhere.

My goal is to inspire the next generation of community leaders to take greater responsibility for their education, their careers and how they would like to achieve their goals.

I am required to leave my family for extended periods of time, which is hard for a young, very culturally strong person, but I learned to balance this and maintain a solid connection with my family, culture, country and employment.

I was a shy person but as soon as this ranger job got me it gave me self confidence. It's about being yourself and still being open to one another."

Chapter three: Evaluation of the Stronger Communities for Children program in Wadeye, NT

Prologue

This chapter comprises of a program evaluation conducted as a MAE core requirement. The evaluation was undertaken for the Stronger Communities for Children (SCfC) program based in Wadeye, Northern Territory.

Appendices

Appendix 3.10 Quantitative survey tool used in this project

Appendix 3.11 Logic model

Acknowledgments

A special thanks to Bobby Maher for her incredible work in coordinating this project and creating the logic model. Thanks also to Ray Lovett and Jan Chapman for their involvement in the project. Thank you to those who generously took the time to participate in the study. Thank you to Palngun Wurnangat Aboriginal Corporation (PWAC), the Kardu Lurruth Ngala Purrungime (KLNP) advisory group and the Stronger for Communities for Children (SCfC) program coordinators.

My role

My role in the study commenced in early 2018. By this stage, other members of the team (Bobby, Jan and Ray) had already established a relationship with the local organisation concerning the project. They had already been to Wadeye on two separate trips, one of these to train local staff in conducting the surveys. Although coming to the project relatively late, I was still able to appreciate the amount of work Bobby had completed and the complexities involved in the project. My role specifically included:

- Field trip: engagement with community members, conducting surveys, conducting focus group, engagement with community organisations
- Data entry
- Data analysis

Lessons learnt

This project gave me great insight into the many strengths (but also the challenges) of conducting ethical community-based research. Given the competing priorities and organisational uncertainty, despite our best intentions and efforts, the project did not go as planned. I feel even more grateful for the responses that we did receive to the survey, and appreciative of the time program participants took to help us. In this situation, I learnt to ‘go with the flow’ and work with what you have. It remains important to do the best by the community and I hope we have done this by continuing with the project and making the most of the data that we did obtain.

Public health impact

This study can serve as the baseline for evaluation of this program into the future. The findings from this study and further research can be used by the community organisation for demonstrating the impact of the program and to monitor further change into the future. This in turn could have positive public health impact, with potential health and wellbeing benefits for the community. The program aimed to improve community health and functioning through revitalisation and participation in cultural activities. This study demonstrates the extent to which program participants were engaged in revitalisation activities and cultural activities at program initiation. Follow up surveys of program participants and non-participants will assist to identify changes in participation over time.

Abstract

Introduction: Community based research and community engagement are essential to conducting ethical research within Aboriginal and Torres Strait Islander communities. The Stronger Communities for Children program engages community in social change initiatives with the aim of creating a safe environment for children to grow up strong and healthy.

Methods: In partnership with a local community organisation, this project was designed to evaluate the SCfC program using a mixed methods approach. A logic model was co-designed with community to guide the evaluation. A quantitative survey was developed and deployed to measure culture, health and wellbeing among adult program participants. Semi structured qualitative interviews were also conducted with program participants to understand how they perceived the program and how the program was improving cultural participation. The primary impact measure was improvement in cultural participation, knowledge and practice.

Results: Initially the evaluation proposed to utilise a pre/post design. However during the process of the evaluation it became clear that the method would need to be modified to a formative (case series) evaluation that was able to provide a baseline from which to work from for the future.

The baseline survey showed that participants reported few barriers to participating in cultural activities and engaged ‘a lot’ some cultural activities (spending time with elders, learning Aboriginal law, bush tucker, learning and passing on cultural knowledge). Common themes were identified in when participants were asked ‘what is Aboriginal culture for you’: family, ceremony/dreamtime, being on country, bush foods, old ways, learning and wellbeing. These themes are identified throughout the SCfC program activities.

Conclusion: Although the methods of this program evaluation changed multiple times due to the complexity of study environment, we were able to measure the culture, health and wellbeing of SCfC program participants. Participants reported high levels of self-rated general health and high levels of cultural knowledge and practice. Due to the limitations of this evaluation we cannot ascertain whether this is due to the SCfC program or other factors. Further repeat surveys are recommended in the future.

Introduction

This program evaluation was conducted in partnership with the Palngun Wurnangat Aboriginal Corporation (PWAC), the Kardu Lurruth Ngala Purrungime (KLNP) advisory group and the Stronger for Communities for Children (SCfC) program coordinators. An Aboriginal research team from the National Centre of Epidemiology and Population Health at the Australian National University undertook the fieldwork and data collection over a six-month period in 2017. The study was conducted in Wadeye, Northern Territory.

Community context

Wadeye is a remote Aboriginal community 320km southwest of Darwin. It has a population of approximately 3000 people and is one of the largest Aboriginal communities in the Northern Territory [1]. Wadeye was formerly known as Port Keats and is located in the Thamarrurr region. Thamarrurr means ‘coming together as one people’ in the local language Murin-patha [2]. Up to nine traditional languages are spoken in Wadeye and Murin-patha represents the main language spoken in town. English is often the second, third, fourth or fifth language spoken by locals.

The history of the Thamarrurr region is complex and its history has been well documented [3, 4]. In 1935 Wadeye became the site of a Catholic Mission, which saw up to 20 distinct clan groups within the region moving together upon one geographical site [1]. For many decades, Wadeye has endured government interventions and policies. Although the impact by government intervention led to widespread community disempowerment, culture remains strong. To this day Wadeye maintains ceremonial and cultural structures that underpin the community environment. Ceremonial groups, language groups and clan groups remain prominent in the community and continue to influence day-to-day life of the region.

Stronger Communities for Children Program (SCfC)

The Stronger Communities for Children (SCfC) program is an Australian Government initiative aimed at supporting community development through provision of communities having a ‘real say in what services they need and how they are delivered’ [5]. The SCfC is funded by the Department of the Prime Minister and Cabinet (PMC) and provides resources to support local Aboriginal community boards to lead social change. The SCfC uses place-based funding, which enables programs and services to be tailored to each individual community’s needs. The program is currently implemented in the following communities throughout the NT: Wadeye, Galiwin’ku, Santa Teresa, Ntaria, Ngukurr, Utopia Homelands, Lajamanu, Gunbalanya, Maningrida, and Atitjere (Including Engawala and Bonya) [1].

The intended outcomes of the SCfC are to support Aboriginal children and young people to grow up strong and healthy. Although the intended outcomes of the program have changed over time, the four key target areas remain: schooling and children; culture and capacity; safety and wellbeing; and jobs, land and economy. Some of the individual intended outcomes include: nurturing young children; getting children school ready; supporting school attendance; cultural participation opportunities; safer communities; increased Indigenous organisations capacity; and community capacity to lead, plan and prioritise services. In Wadeye, the aim is to achieve these outcomes through seven separate programs all run in the community: women's cultural program, men's shed, youth leadership program, AFL program, early childhood program, healthy homes, after hours program.

Table 1. SCfC program activities and outcomes

Program	Activity	Primary outcome
Women's cultural program	Bush Wok Women's culture camp Weaving, art, sewing	Cultural connections and participation
Early childhood program	Ceremony, language, cultural knowledge Respect elders and family	Children to grow up with a strong cultural identity
Men's shed	Capacity building Health and wellbeing Cultural activities	Cultural connections and participation
Healthy homes	Healthy living practices Reducing hazards Assistance with damaged property	Safe, healthy home environment
Youth leadership program	Employment training Workshops and life skills Interstate travel	Identifying and developing future leaders
After hours program	Drop in Youth centre Out of school holiday programs Cooking classes/cultural classes	Youth support, mentoring and opportunities
AFL program	Training and local matches Travelling to regional matches Community development officers	Encouraging healthy lifestyles, leadership skills and community cohesion

Community organisations involved

The SCfC program in Wadeye is facilitated by the Palngun Wurnangat Aboriginal Corporation (PWAC) and guided by the Kardu Lurruth Ngala Purrungime (KLNP) advisory group. There are a number of other organisations that are involved in the delivery of certain program activities and these are listed in Table 2.

Table 2. Organisations involved in program activities

Palngun Wurnangat Aboriginal Corporation	Thamarrurr Development Corporation	Thamarrurr Youth Indigenous Corporation	Australian Football League Northern Territory
Women's cultural program	Men's shed	Youth leadership program	AFL program
Early childhood program	Healthy homes	After hours program	

Methods

Methodology

Community based participatory research underpins the methodological approach this evaluation has taken[6]. Research internationally has shown that Indigenous research has traditionally been done ‘on’ Indigenous communities, not ‘with’ Indigenous communities[7]. Ethical research within Aboriginal and Torres Strait Islander communities should be conducted in conjunction with community members, in alignment with their wishes, values and priorities.

Community based participatory research aims to facilitate inclusivity and knowledge exchange between community members and researchers[8]. This method values the reciprocal exchange of knowledge and seeks to empower those participating in the research. This approach seeks to understand community member priorities and adjusts the research methodology to facilitate co-production of meaningful results for both researcher and community members[9]. Communication throughout the entire research process is important to ensure continued meaning for both researchers and community[10]. For example, shared interpretation of results can add meaning behind figures, lead researchers to find areas of significance for community priorities and seek to ensure the results of the study have meaning and use for everyone involved[11].

This study involved a significant amount of community partnerships and consultation with PWAC and the KLNP committee. PWAC approached ANU researchers in 2017 for assistance with the evaluation of the SCfC programs and a relationship commenced shortly thereafter. The researchers consulted with PWAC and the KLNP to identify areas in which they sought feedback and evaluation, and quantitative measures were identified and refined in order to measure program outcomes. Feedback from PWAC and KLNP was sought at all time periods and items were adjusted accordingly. The relationship between PWAC, KLNP and the researchers was forged over multiple trips to the community and regular communication. In order to be most culturally appropriate in this community, researchers trained local PWAC staff in conducting evaluation data collection. The logic model which forms a basis of the evaluation was constructed and modified according to the identified community needs. The survey used in this study was adapted from a preliminary Mayi Kuwayu Study[12] survey and additional community feedback.

Evaluation design

Initially, the aim of this evaluation was to conduct a pre and post survey in order to determine changes in outcomes over time, at baseline and at six months. The aim was to compare changes observed among those involved in the program to changes observed among those not involved in the program. That is, program non-participants were intended to serve as a control group. However, due to a number of factors (time constraints, competing community priorities, sorry business, program funding changes, and the political context) it was not possible to conduct repeat surveys -- only one data collection was possible. We moved to a cross sectional design where program participants and non-program participants would still be compared, just at one point in time. However, it was deemed not possible to survey program non-participants because program coordinators and staff were concerned about asking non-program participants to complete the surveys, so the sample includes only persons who participated in one or more of the programs.

The evaluation design was adapted to fit within these constraints, with the aim of still providing useful information for the community. In the revised evaluation design, the aim of this initial data collection was to provide a baseline quantitative measurement on cultural, health and wellbeing factors among SCfC participants. The baseline data could then be used to support ongoing monitoring and evaluation of the SCfC programs. For example, the survey could be repeated among program participants every six months to monitor changes in outcomes over time. Unfortunately, the lack of the comparison group (the intended group of program non-participants) means that with this design, it will not be possible to determine the extent to which any observed changes are attributable to program participation.

A qualitative component was included in the evaluation design to enable contextualisation of the quantitative data. This triangulation of data sources could provide additional insight into whether observed changes in program participants were likely to be linked to their program participation. This mixed methods approach included facilitating semi-structured interviews with program participants at the time of baseline data collection. Findings from the focus group informed interpretation of the quantitative results in this study, and detailed analysis of the qualitative data is provided detailed elsewhere[13]. The qualitative component I have incorporated is an assessment of the cultural indicators in the survey against what respondents said was culture from the free text responses to the question ‘What is Aboriginal culture for you?’

The research team worked with program staff to develop a logic model (Appendix 3.13) to guide the evaluation process. From this logic model, culture was deemed to be a critical component of the programs, and as such our survey instrument and analysis was tailored to focus on cultural variables.

Participant recruitment

Study participants were Aboriginal and/or Torres Strait Islander adults living in the Wadeye region, who have participated in one (or more) SCfC programs. The ANU research team trained the SCfC program coordinators in each program area to administer the survey. Participants could self-complete the survey or complete the survey with assistance from the SCfC staff in English or their language. Participation in the survey was voluntary. All those involved in the SCfC programs were eligible to participate during the study period. Participants were provided a plain language information sheet and consent form prior to undertaking the survey.

Data and variables

All quantitative data presented and utilised in this study are based on responses to the survey. Both self-administered and community researcher administered surveys are included in the analysis. All participants who took part in the survey have been included in the analysis.

Sociodemographic variables

Age was calculated based on reported date of birth and date of survey completion, and categorised as: 18-34, 35-49, or 50 years and over. Highest level of education was measured based on responses to the survey question ‘What is the highest education you have completed’. Response options included: no school; primary school; year 10 (school or intermediate certificate); year 12 (higher school, leaving certificate, college); certificate or diploma (e.g. childcare worker, mechanic); or university.

Financial status was measured based on responses to the survey item, ‘which words best describe your family’s money situation’. Responses were categorised as low financial status (‘we are spending more than we get’ or ‘we run out of money before payday’), moderate financial status (‘we have just enough to get us to the next payday’) or high financial status (‘we can save now and then’ or ‘we have a lot of savings’). Employment status was categorised as (casual, part-time or full-time); unemployed; and other (includes other, retired, disabled/sick, unpaid carer, studying).

Cultural factors

SCfC ***program participation*** was measured based on responses to two combined survey questions: ‘have you ever participated in…’ and ‘have any of the children in your care and under the age of 16 years, participated in…’ For both questions, respondents could select all of the seven programs that they and/or their children had been involved with. Responses were categorised into two groups: one program; or two or more programs according to the total number of programs a participant indicated involvement with.

Cultural knowledge and practice was measured according to responses to 'How much time do you spend…' [list nine cultural practice items]. For each item, participants responded 0 (want to but can't), 1 (not at all), 2 (a little bit), 3 (a fair bit), or 4 (a lot). Items were explored individually, and in addition, a total score was created as an overall measure of cultural knowledge and practice. In calculating the total score, 'want to but can't' was recoded to 1 and treated the same as 'not at all'. The responses to the nine questions were summed (range: 9-36) and this sum was categorised into four groups. Participants were categorised as having low (score 9), a little (score 10-18), a fair bit (19-27) or a lot (score 28-36). Responses to the nine questions were summed for participants with complete data only; participants missing responses to any of the questions were coded as missing the total score.

Health and wellbeing variables

Five health and wellbeing variables were included in the survey: life satisfaction, general health, psychological wellbeing, family wellbeing and community wellbeing.

Life satisfaction was measured according to responses to the modified question, 'How satisfied are you with your life?' [14]; on a scale from 1 (not at all) to 4 (a lot). Scores were categorised as low to moderate life satisfaction (score 1 or 2 [not at all or a little bit]) or high to very high life satisfaction (score 3 or 4 [a fair bit or a lot]).

General health was measured according to the question, 'How would you rate your general health?' [15]; response options were 'poor, fair, good, very good or excellent'. Responses were categorised into two groups: poor to fair general health (poor or fair) and very good general health (good, very good or excellent).

Psychological wellbeing was measured using a modified Kessler-5 Psychological Distress (K5) scale[16]. Responses to the five questions were summed; participants were categorised as having low/moderate (score 5-11) or high/very high levels of distress (score 12-25), according to established K5 cut-offs[16]. Scores were only calculated for participants with complete data on the five items. For the analysis, those with 'low/moderate distress' were defined as having high psychological wellbeing; those with 'high/very high distress' were defined as having low/moderate psychological wellbeing.

Family wellbeing was measured using a modified version of the Western Australian Aboriginal Child Health Survey family functioning scale [17]. The scale includes a set of nine questions each with response options of 'not at all' (1) to 'a lot (4). Responses to the nine questions were summed (range: 9-36) for participants with complete data only; participants missing responses to any of the questions were coded as missing. Participants were categorised as having low (score 9-18), moderate (score 19-27) or high family wellbeing (score 28-36).

Community wellbeing was measured according to responses to a set of 17 community cohesion questions each with response options of ‘not at all’ (1) to ‘a lot (4). Responses were summed (range 17-68) for participants with complete data only; participants missing responses to any of the 17 questions were coded as missing. Participants were categorised as having low (score 17-34), moderate (score 35-51) or high community wellbeing (score 52-68).

Statistical methods

Descriptive analysis

A descriptive analysis of the sociodemographic factors, cultural factors, and wellbeing outcomes for the sample was conducted. In order to protect participant’s privacy, small cells (n≤3, with the exception of ‘missing’ data) are confidentialised. Stata 15 was used for all analysis.

Ethics

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

Results

Sociodemographic factors

In total, 37 program participants completed a survey; 46% (n=17) identified as male and 51.4% (n=19) identified as female. The age range of participants was 20 to 69 years. A substantial percentage (40.5%, n=15) were missing a response to age or were unsure of their age. The percentage of participants missing data was lower for other variables (range 2.7% to 10.8%). Thirty-five percent (n=13) of participants were employed and 27% (n=10) indicated they were unemployed. This left 32.4% (n=12) indicating 'other' employment (retired, studying, unpaid carer or disabled/sick).

Over half (56.8%, n=21) of participants reported having low financial status. Over three-quarters (83.8%, n=31) of participants reported sleeping in the same house each night. Seventy-three percent of participants (n=27) responded yes to the question 'Are there any days you don't have enough food and feel hungry'. Of those who responded yes: 37% (n=10/27) reported that this occurring more than once a week; 51.9% (n=14/27) reported this occurring once a week and 11.1% (n=3/27) reported this occurring once a month.

Table 3: Sociodemographic factors

Sociodemographic factors	**%**	**N=37**
Gender		
Male	46	17
Female	51.4	19
Missing	2.7	1
Age group (years)		
20-34	21.6	8
35-49	18.9	7
50 and over	18.9	7
Missing/unsure	40.5	15
Employment status		
Unemployed	27.0	10
Employed	35.1	13
Other*	32.4	12
Missing	5.4	2
Highest level of education		
Primary school	29.7	11
Year 10	21.6	8
Year 12	35.1	13
Cert/diploma	10.8	4
Missing	2.7	1
Financial status		
Low	56.8	21
Moderate	21.6	8
High	13.5	5
Missing/unsure	8.1	3

Sociodemographic factors	%	N=37
Are there days when you don't have enough food and feel hungry?		
Yes	73.0	27
No	16.2	6
Missing/unsure	10.8	4
If yes, how often does this happen? (N=27)		
More than once a week	37.0	10
Once a week	51.9	14
Once a month	11.1	3
Do you sleep in the same house each night?		
No	10.8	4
Yes	83.8	31
Missing	5.4	2
Have you ever been to prison or youth detention?		
No	70.3	26
Yes	24.3	9
Missing	5.4	2

*other includes: other, retired, disabled/sick, unpaid carer, and studying.

SCfC participation

Forty-three percent (n=16) of participants were involved with one SCfC program and 48.7% (n=18) were involved with two or more SCfC programs.

Cultural factors

With the exception of the one missing response (2.7%, n=1), nearly all participants indicated that their first language was an Aboriginal language (97.3%, n=36). Similarly, nearly all participants knew their totem (97.3%, n=36) and knew who their mob were (94.6%, n=35).In response to the set of cultural practice and knowledge variables: 35% (n=13) scored a fair bit and 50% (n=17) scored a lot. The variables in this scale are shown individually below in table 4.

Table 4: Cultural characteristics

Cultural characteristics	%	(n)
Program participation		
One program	43.2	16
Two or more programs	48.7	18
Missing	8.1	3
Aboriginal first language		
No	0	0
Yes	97.3	36
Missing	2.7	1
Currently live on country		
No	67.6	25
Yes	29.7	11
Missing/unsure	2.7	1
How much of your life have you lived on country		

Cultural characteristics	%	(n)
None/a little bit	46.0	17
A fair bit/ a lot	18.9	7
All of my life	24.3	9
Missing/unsure	10.8	4
Have you ever felt disconnected from culture		
Yes (a little, a fair bit, a lot)	35.1	13
No	56.8	21
Missing/unsure	8.1	3
Cultural practice and knowledge		
None/Want to but can't	0	0
A little bit	≤8.11	≤3
A fair bit	35.1	13
A lot	50.0	17
Missing	10.8	4
Knows mob		
No	0	0
Yes	94.6	35
Missing/unsure	5.4	2
Do you know your totem?		
No	0	0
Yes	97.3	36
Missing/unsure	2.7	1
How often do you eat bush foods?		
Not at all/a little bit/want to but can't	18.9	7
A fair bit/a lot	73.0	27
Missing	8.1	3

Cultural knowledge and practices are shown individually in Table 5 and Figure 1. For most of the items, no participants responded 'want to but can't'; this response was provided by ≤8.1% (n= ≤3) participants for the two items: 'spending time participating in social events' and 'spending time contributing to your community'. Around thirty-five percent reported feeling some level of being disconnected from culture.

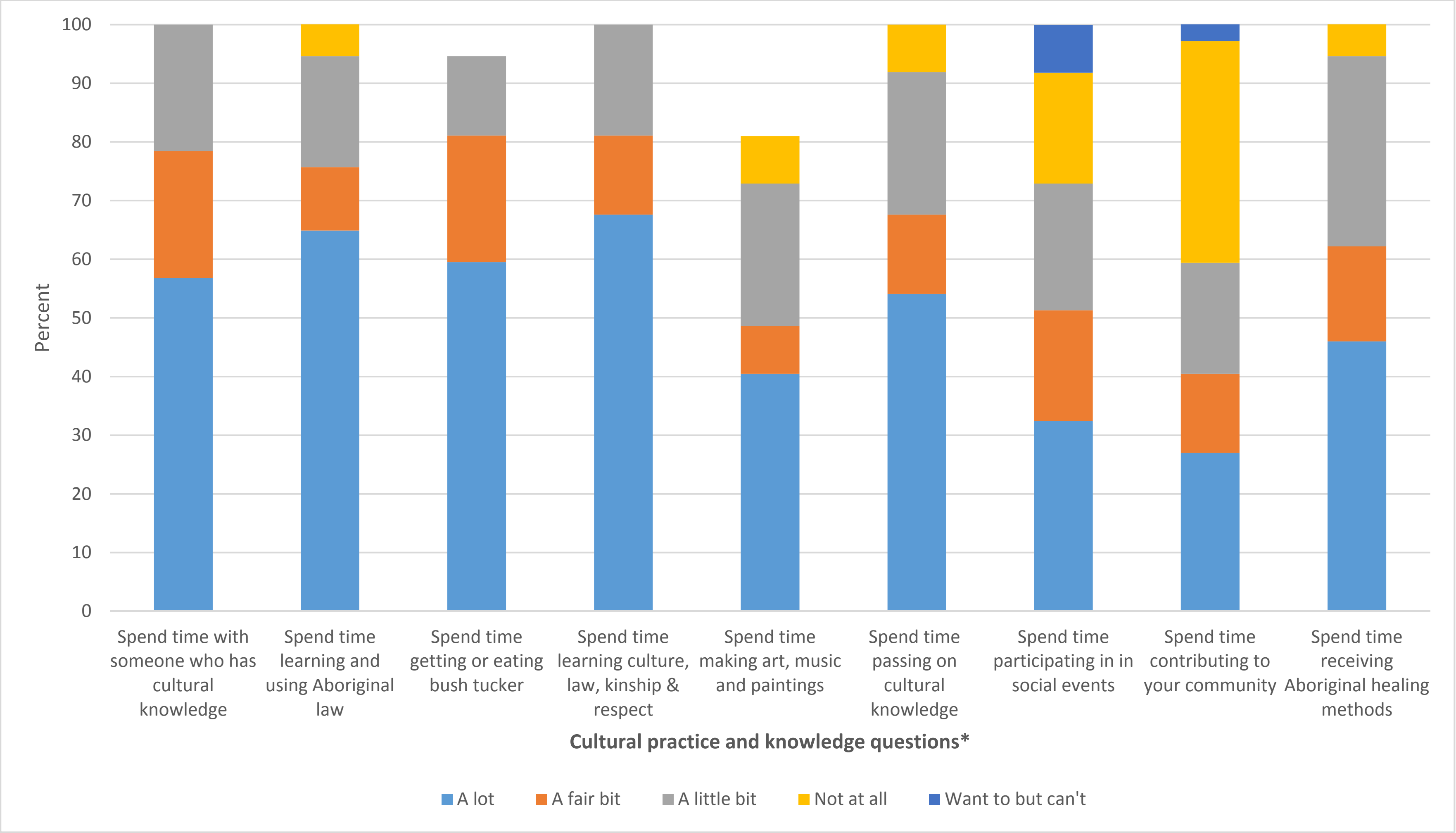
Table 5: Cultural knowledge and practices

Cultural practices and knowledge	%	(n)
C1. Spend time with someone who has cultural knowledge (i.e. Elder)		
Want to but can't	0	0
Not at all	0	0
A little bit	21.6	8
A fair bit	21.6	8
A lot	56.8	21
Missing	0	0
C2. Spending time learning and using Aboriginal Law		
Want to but can't	0	0
Not at all	≤8.1	≤3
A little bit	18.9	7

Cultural practices and knowledge	%	(n)
A fair bit	10.8	4
A lot	64.9	24
Missing	≤8.1	≤3
C3. Spending time getting or eating bush tucker		
Want to but can’t	0	0
Not at all	0	0
A little bit	13.5	5
A fair bit	21.6	8
A lot	59.5	22
Missing	5.4	2
C4. Spending time learning culture, law, kinship and respect		
Want to but can’t	0	0
Not at all	0	0
A little bit	18.9	7
A fair bit	13.5	5
A lot	67.6	25
Missing	0	0
C5. Spending time making art, music and paintings		
Want to but can’t	0	0
Not at all	35.1	13
A little bit	16.2	6
A fair bit	≤8.1	≤3
A lot	40.5	15
Missing	≤8.1	≤3
C6. Spending time passing on cultural knowledge		
Want to but can’t	0	0
Not at all	≤8.1	≤3
A little bit	24.3	9
A fair bit	13.5	5
A lot	54.1	20
Missing	≤8.1	≤3
C7. Spending time participating in social events		
Want to but can’t	≤8.1	≤3
Not at all	18.9	7
A little bit	21.6	8
A fair bit	18.9	7
A lot	32.4	12
Missing	≤8.1	≤3
C8. Spending time contributing to your community		
Want to but can’t	≤8.1	≤3
Not at all	37.8	14
A little bit	18.9	7
A fair bit	13.5	5
A lot	27.0	10
Missing	≤8.1	≤3
C9. Spending time receiving Aboriginal healing methods		
Want to but can’t	0	0
Not at all	≤8.1	≤3
A little bit	32.4	12

Cultural practices and knowledge	%	(n)
A fair bit	16.2	6
A lot	46.0	17
Missing	≤8.1	≤3

Figure 1: Cultural knowledge and practices



*missing data excluded from graph

Self-reported health and wellbeing

Over half (56.8%, n=21) of participants reported having very good self-rated general health. Similarly, 59% (n=22) of participants also reported having very high life satisfaction. High psychological wellbeing was reported by just under half (48.7%, n=18) of participants. The missing category for psychological wellbeing was higher (19.9%, n=7) compared to the missing categories for self-rated general health and life satisfaction (5.4%, n=2; and 8.1% n=3, respectively), which reflects that the psychological wellbeing score was missing if data were missing on any of the five included items.

High family wellbeing was reported by 64.9% (n=24) of participants. High community wellbeing was reported by 51.4% (n=19) of participants. The missing category was higher for community wellbeing (24.3%, n=9) compared to family wellbeing missing only ≤8.1% (n=≤3). Almost three-quarters (73%, n=27) of participants responded that they felt they had 'a fair bit/a lot' of control in their life. In response to the question 'Are you woken up at night?' 51% (n=19) reported not at all/a little bit compared to 43% (n=16) reporting a lot/a fair bit.

Table 6: Wellbeing characteristics

Wellbeing characteristics	%	N = 37
Self-rated general health		
Poor-fair	37.8	14
Very good	56.8	21
Missing	5.4	2
Psychological wellbeing		
Low/Moderate wellbeing	32.4	12
High psychological wellbeing	48.7	18
Missing	19.9	7
Life satisfaction		
Low-moderate	32.4	12
Very high	59.5	22
Missing	8.1	3
Family wellbeing		
Low	≤8.1	≤3
Moderate	21.6	8
High	64.9	24
Missing	≤8.1	≤3
Community wellbeing		
Low	0	0
Moderate	24.3	9
High	51.4	19
Missing	24.3	9
How much are you in control of your life		
Not at all/a little bit	18.9	7

A fair bit/a lot	73.0	27
Missing	8.1	3
Are you woken up at night?		
A lot/ a fair bit	43.2	16
Not at all/ a little	51.4	19
Missing	5.4	2
Have you had a health check in past 12 months?		
No	10.8	4
Yes	54.1	20
Missing/unsure/not relevant	35.1	13

Free text responses

In response to the question *'What is Aboriginal culture for you?'* participants were able to provide free text responses. Common themes were identified (see Table 7).

Table 7: Free text responses to 'What is Aboriginal culture for you?'

Theme	Example quote
Family	*'Being with family'* *'Listening to parents'* *'Stories from family'* *'Passing on to family'*
Ceremony/dreamtime	*'Ceremony'* *'Dance and art'* *'Totem and dreaming'*
Being on country	*'Going out on country'* *'Time on our land'* *'Country'*
Bush foods	*'Eating bush food'* *'Food from land'* *'Bush ways'*
Old ways	*'Learning old ways'* *'Old stories'* *'Old way'* *'Old songs'*
Learning	*'Learning songlines'* *'Learning country'* *'Learn about Grandfathers land'*

Wellbeing	*'Culture is good for me'* *'Everything'* *'Keep you strong'* *'Special for me'*

Discussion

The design of this evaluation changed a number of times in response to the complexities of undertaking community-based research in a complex setting. We adapted the evaluation design to work with what data we were able to collect. The adaptation of the design was primarily in response to PWAC having time pressures to demonstrate the impact of their program of work despite limited time to implementation. Initially, the study design would have included a ‘pre and post’ survey in order to measure change associated with being involved in the program over time. When time would not permit this, we moved to a cross sectional design where program participants and non-program participants would be compared to see if program participants were more likely to report higher levels of cultural practice and/or wellbeing measures. However, we were unable to survey non-program participants so instead this study design focuses specifically on program participants.

It is important to consider the context in which interventions are implemented to and ensure appropriate design considerations[18]. There is also the need to be responsive to community organisation wishes[19]. The type of intervention and (social and behavioural interventions) at the community level may require different methodological considerations based on the context for which they are being designed and have important ethical aspects to consider[18].

The intended outcomes for the Stronger Communities for Children program have changed over time, and as such it was unclear what the facilitating partner were aiming to ‘measure’ initially. In consultation with the facilitating partner (PWAC), including through developing the logic model, it was decided that cultural participation be the primary outcome of interest. The SCfC programs in Wadeye were targeted at increasing cultural participation, facilitating knowledge exchange and helping children to grow up with a strong cultural identity. Members from PWAC and the KLNP committee expressed views that cultural engagement was central to social change and importantly, children growing up strong. Therefore, this evaluation was targeted to focus on the cultural variables measured in the survey and contextualising how cultural participation made people feel.

The historical, community, organisational and policy contexts were important to be mindful of in this environment. In order to conduct ethical community based research, partnerships were an essential component of this study[20, 21]. As such, involvement was sought from all partners throughout the entire study process.

Cultural knowledge and practices

The set of cultural knowledge and practice variables was an effective tool in this evaluation. The instrument appears to have been able to measure variation within the participant’s responses. While a number of participants did say “a lot” across each of the cultural practice variables, there remained variation across response options. This instrument provides an understanding of the level of engagement across multiple cultural practice areas and has been used in this evaluation to guide the community organisation to areas in which there are high participation and also where program areas could target to increase participation.

Overall, Table 4 demonstrates minimal responses of “want to but can’t” across most activity areas. This is a positive finding and suggests that participants are not facing significant barriers to participating in these activities. This may suggest that the SCfC program is supporting access to these activities. It could also suggest that these cultural practices were already well established within the community before the SCfC program began. This is a survey item that would benefit from resurvey in the future to better our understanding of where the SCfC program may have contributed to increased participation. This would also add to the robustness of the evaluation.

There was two questionnaire items that did receive responses of “want to but can’t”: ‘spending time participating in social events’ and ‘spending time contributing to community’. These two questionnaire items also reported the highest levels of “not at all” (18.9% (n=7) and 37.8% (n=14)). This suggest that future SCfC programs could incorporate opportunities to increase social engagement and create opportunities to contribute to the community. It might also indicate that people feel unable to spend time participating and contributing to the community. There may be cultural reasons for this or because at times safety within the community is an issue. Additional investigation would be required to understand this in the future.

There are a number of questionnaire items that showed a majority of responses that they were engaged “a lot” in the activity (spending time with elders, learning Aboriginal law, bush tucker, learning and passing on cultural knowledge). This is another positive finding. This suggests that there are very high levels of engagement with these cultural activities. Given that some SCfC programs target these specific activities (see Table 1), this could be a positive reflection on the impacts of the SCfC program. However given the limitations of this study design it remains unclear whether this is reflective of SCfC program involvement or whether these activities already had high levels of engagement in the community.

Health and wellbeing

Over half (56.8%, n=21) of participants in this study reported having very good self-rated general health which is above the national estimate of 39.7% of Aboriginal and Torres Strait Islander adults reporting very good self-rated general health[22]. A recent study also undertaken in the Northern Territory found that forty-seven percent of Aboriginal adults who were participating in a Ranger program reported very good general health compared to 38% of those not involved in the program[23]. Thirty two percent (n=12) of participants reported having low-moderate psychological wellbeing which is similar to the national results of high/very high psychological distress reported by 31% of adults who participated in the 2008 National Aboriginal and Torres Strait Islander Social Survey[16, 24].

Free text responses

In addition to the qualitative components of the evaluation that have been detailed elsewhere[13], the free text responses to ‘What is Aboriginal culture for you’ provide further insight into how culture is viewed by participants. The themes identified from the free text responses provide further evidence to support the use of the cultural knowledge and practices question item. The themes that participants identified in the free text responses correlate to themes asked within the questionnaire item. For example, a question in the cultural knowledge variable ‘Spending time getting or eating bush tucker’ was a theme identified in the free text responses: “*Eating bush food*”, “*food from land*” and “*bush ways*”. Additionally the variable ‘spending time passing on cultural knowledge’ can be seen in the free text responses: “*Passing on to family”, “stories from family”* and *“learning old ways”.*

The free text responses are also a useful tool in this evaluation to provide insight into whether the SCfC programs are capturing the themes that participants have reported are important to them. Are the cultural themes identified by participants reflected in the SCfC program activities? Given that culture is our outcome of interest it is important to highlight what culture means to the participants and evaluate whether the SCfC programs are targeting these areas. When viewing the SCfC program activities (Table 1) and the free text responses (Table 7) it is clear that the themes identified by participants are largely present in the program activities. For example: family, ceremony, art and bush foods are activity themes present in both the Women’s Cultural Program and the Early Childhood Programs. Wellbeing is an integral part of the Men’s Shed program and its importance demonstrated by participates quotes: “*Keep you strong”, “Good for me” and “everything”.*

Strengths and limitations

The small sample size and the modified evaluation design limited our ability to conduct statistical analysis of the data. Regardless, this evaluation has been useful to the community in providing a baseline picture of cultural participation and wellbeing among program participants, enabling future evaluation. Although this was a small size in statistical terms, it was a sizeable data collection for the community researchers within a relatively small timeframe. This gives strength to the feasibility of re-survey by community researchers in the future.

There is a potential limitation of the survey being based on self-reported measures. Wherever possible, validated measures were utilised in the survey. This includes utilising the K5 scale, which has specifically been validated for use in Aboriginal and Torres Strait Islander communities [16]. Survey items were adapted throughout the survey design phase as requested by the KLNP committee, to include clarifying statements or simplified wording. This process (face validity) is useful in assessing if measures were interpreted correctly meaning participants were able to understand the questions. The high response rate to questionnaire items may demonstrate that the survey questions were considered "acceptable" by participants. This is likely at least partially due to the fact that the survey instrument was co-designed with local partners.

A strength of this research has been the collaboration between the facilitating partner (PWAC), the KLNP committee and the ANU. This has ensured that the results of the study are relevant for the community and meet their priorities while also meeting program evaluation requirements. The community members trained in conducting the data collection were an asset to this project. The completeness of data is worthy of note and the ability to translate to the local language was invaluable for this success of the data collection and thus the project.

The organisational and funding uncertainty had a significant impact on the progress of this study. The organisation was provided with limited information about the continuation of the program into the future and this factored into the required speed of the project. Data collection was hampered by staff and organisational uncertainty around why data were being collected and Sorry business on one field trip.

It is recommended that re-survey occurs in the future to enable evaluation of change over time for those involved in the SCfC programs. Ideally this would involve re-surveying those involved in this study, in addition to non-program participants. If feasible, new program participants could also be surveyed prior to their commencement in any program.

Conclusion

The Stronger Communities for Children (SCfC) program is an Australian Government initiative aimed at supporting Aboriginal and Torres Strait Islander communities to implement programs aimed at supporting Aboriginal children and young people to grow up strong and healthy. The SCfC program in Wadeye has program activities that run in several parts of the community and engages multiple community organisations. Despite Wadeye having a historically complex past, culture remains an integral component of everyday life for the community. Although the methods of this program evaluation changed multiple times due to the complexity of study environment, we were able to measure the culture, health and wellbeing in a number of SCfC program participants. Participants reported high levels of self-rated general health and high levels of cultural knowledge and practices. Due to the limitations of this evaluation we cannot ascertain whether this is due to the SCfC program or other factors. Further repeat surveys are recommended to measure change over time in addition to pre and post surveys for future SCfC participants. The qualitative component of this evaluation providing insight into what culture means for participants and serves a reminder of how integral culture is to health and wellbeing of Aboriginal and Torres Strait Islander people. “*Culture is everything”.*

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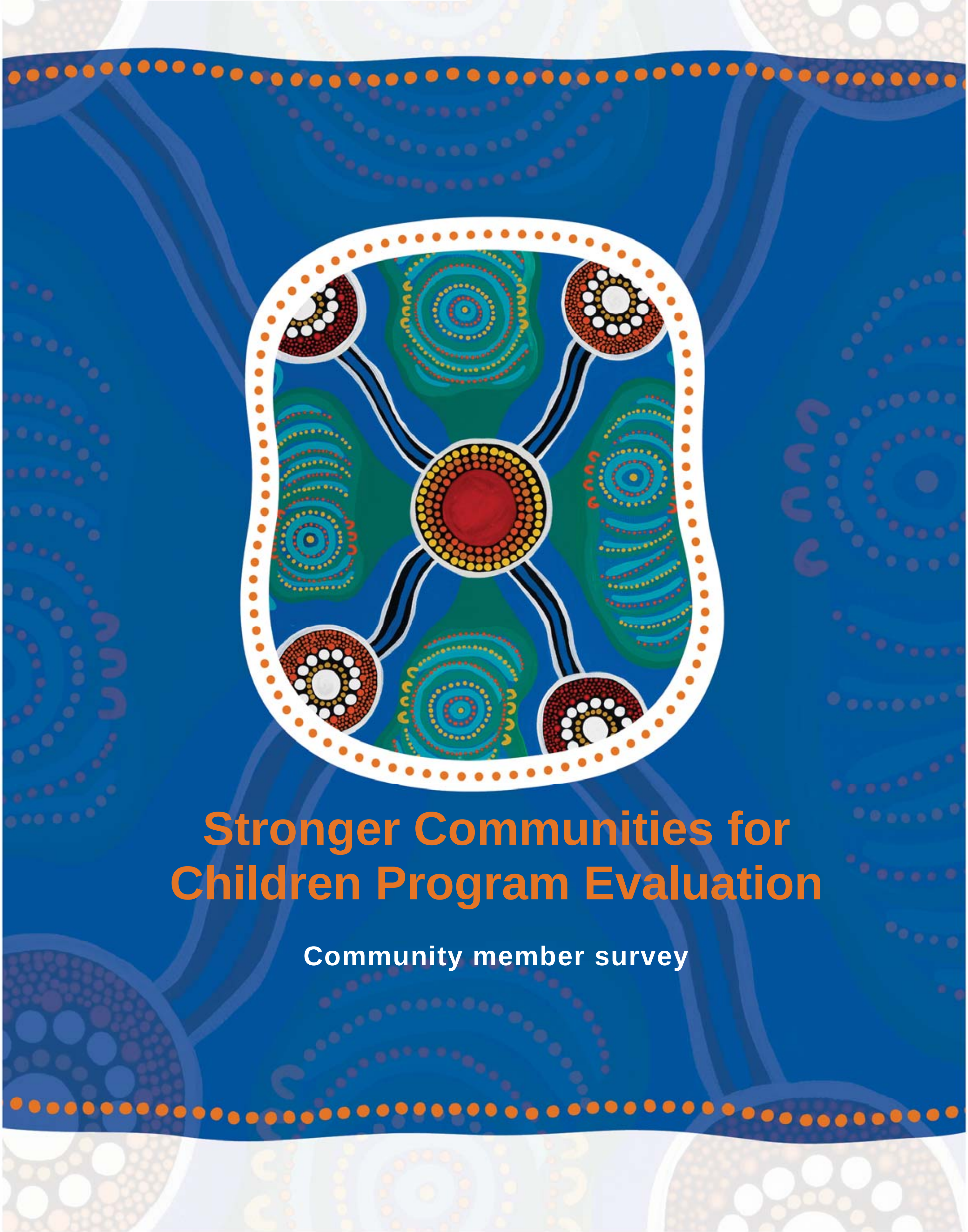
Appendix 3.10

Quantitative survey tool used in this project

Palngun Wurnangat Aboriginal Corporation

Australian National University



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)? *You can list multiple answers.*	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? *This includes all country you follow.*	○ 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</u>, how often do you visit? *Skip this question if you currently live on your tribe's/mob's country.*	○ None ○ A little bit ○ A fair bit ○ A lot ○ Unsure ○ Want to but can't
Whose country(s) are you connected with? *Select all that apply.*	○ Mother's ○ Father's ○ Mother's & father's ○ Other country ○ None ○ Unsure
Do you have special cultural responsibilities for country? *Select all that apply.*	○ 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, corroborree, 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 <u>yes</u>, how old were you when you had your <u>first</u> 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 Aunty(ies) or Uncle(s) ☐ Other family ☐ Other friends or visitors
What <u>best</u> 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? ***Select all that apply.***	○ No ☐ Yes, prison ☐ Yes, youth detention
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

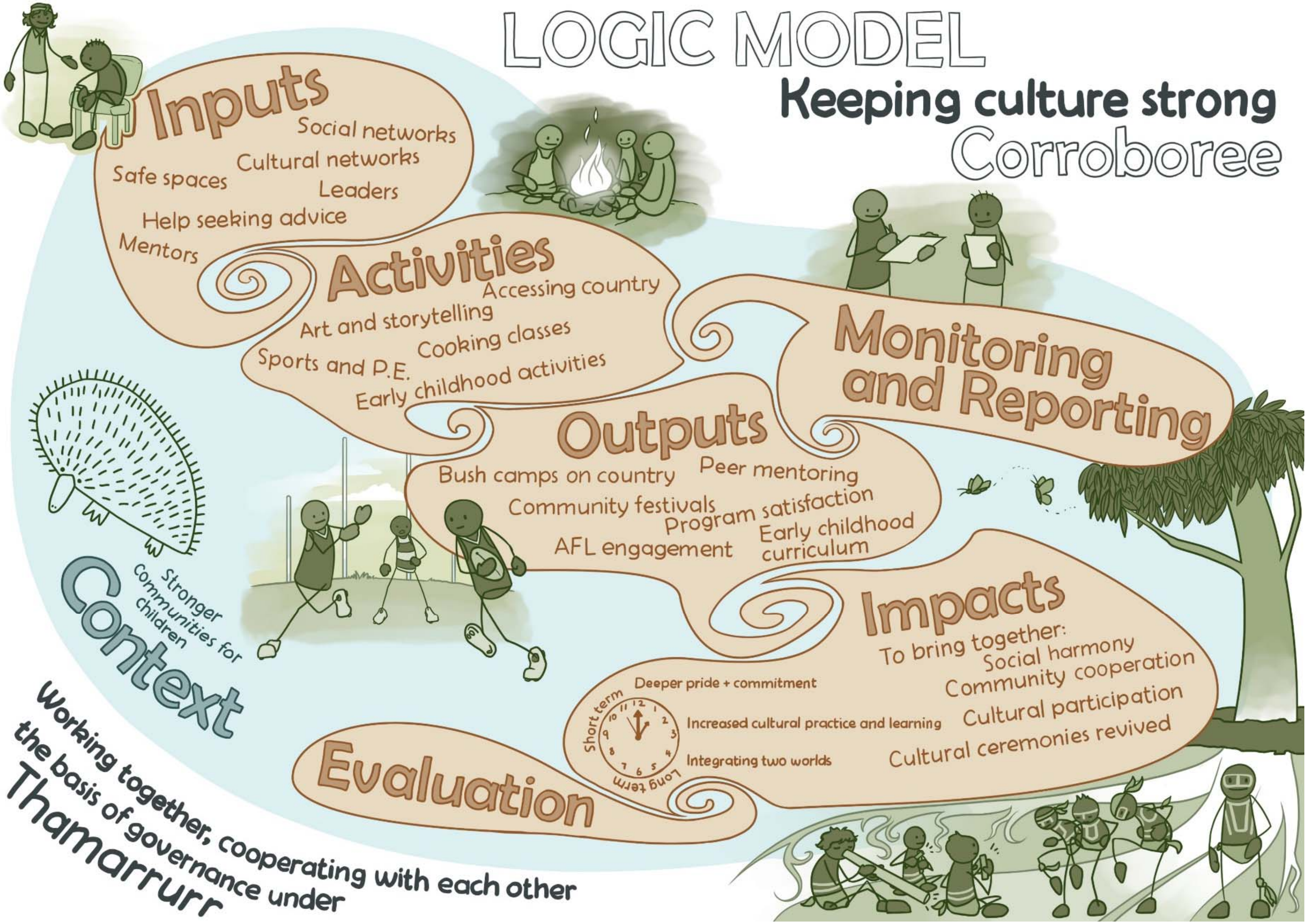
In my family…	Not at all	A little bit	A fair bit	A lot
1. We get on together and cope in the hard times.	○	○	○	○
2. We like to remember and celebrate special days/events.	○	○	○	○
3. We talk with each other about the things that matter.	○	○	○	○
4. We are always there for each other.	○	○	○	○
5. We manage 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 3.11

Logic Model created by Bobby Maher

Appendix 3.11: Logic model created by Bobby Maher



A cluster of *Salmonella* Typhimurium with a unique MLVA pattern in Canberra, ACT

Prologue

On the 16th of May 2018 I was contacted by the National Centre for Epidemiology and Population Health (NCEPH) to assist with an investigation through the Australian Capital Territory (ACT) Health Protection Service (HPS). HPS had identified three cases of salmonellosis with a novel Multiple Locus Variable-number Tandem Repeat Analysis (MLVA) strain that had not previously been seen in the ACT. Cases reported consumption of eggs from the same producer in their food histories. My involvement as an MAE scholar started when the Epidemiologist and Environmental Health Officer from the HPS commenced the investigation.

Investigation team

ACT Health Protection investigation team included the following:
Lead Epidemiologist: Timothy Sloan-Gardner
Environmental Health Officer: William Mude
Microbiologist: Deborah Denehy
MAE scholar: Roxy Jones

Background

In 2017 I spent a week at the HPS as an overall introduction into the service, learning the processes within the Unit, including what activities were involved in outbreak investigations. I also learnt about the overall communicable disease surveillance in the ACT. I spent some time entering routine notification data into their system and then assisted with calling people notified to the HPS for routine follow-up of salmonellosis notifications. The placement helped me to become familiar with how a disease surveillance unit ran and how to be part of an outbreak investigation team.

My role in the current investigation

My role in the investigation of the 2018 cluster of *Salmonella* Typhimurium commenced with the environmental investigation at a farm (Farm X). I assisted the team with collecting specimens, inspecting the premises and speaking with the farm manager. We spent several hours at Farm X taking samples from multiple chicken pens, investigating the buildings and facilities and assessing their farm processes and practices. Following the environmental inspection and investigation, I prepared the draft 'Outbreak summary report' for HPS. I then collated all of the information available, including the line list of notifications, field investigation reports, environmental health reports, food histories and *Food Act* 2001[1] Improvement Notice and all lab data to prepare the final investigation report.

Lessons learnt

I had a steep learning curve when I became involved in this investigation. With no prior experience in foodborne outbreaks, I felt quite out of my depth. During the process of this study I have learnt so much about *Salmonella*, the egg industry, environmental health and how public health units are run. I have learnt the importance of working in a team, as this successful investigation would not have been possible without each individual's input. And although there were a small number of cases, I was struck by how unwell the patients became and how long symptoms lasted. It highlighted to me the importance of foodborne investigations and how public health interventions can impact on disease in the community.

Public health impact

An Improvement Notice was issued under the *Food Act* 2001[1] resulted from this investigation, which was revoked once the farm had met all requirements. The *Public Health Act* 2007 covered the collection of data by authorised officers from an individual with a notifiable condition. Observations and details of the *Food Act* 2001[1] Improvement Notice are detailed later in this chapter. The impact of this enforcement was to ensure all actions were taken to reduce the risk associated with salmonellosis at Farm X.

Acknowledgments

Thank you to Tim Sloan-Gardner for your patient guidance throughout the entire investigation. You helped me to navigate the unfamiliar territory that I found myself in and were always forthcoming with my 'silly' questions. Thanks also to the rest of the investigation team from HPS, you all made me feel very welcome and I couldn't have been a part of this investigation if it weren't for you.

Abstract

Background: HPS conduct routine surveillance of samlonellosis notifications. A unique *S.* Typhimurium MLVA type, not previously seen in the ACT, was identified through routine notifications.

Methods: Descriptive epidemiology and environmental investigation of three cases of a novel strain of *Salmonella* identified by MLVA was conducted to identify the source.

Results: The novel MLVA pattern 03-10-10-09-496 strain was isolated from three people and was also found on an egg processing farm during the environmental investigation. Issues at Farm X were identified during the environmental investigation; an enforcement notice was issued and subsequently revoked once the farm addressed the issues.

Conclusion: A unique aspect of this investigation was finding the same *Salmonella* MLVA strain during the environmental investigation and from samples collected from people infected with the bacteria. Though this cluster was small in numbers, it is a good example of when cases can be both epidemiologically and laboratory linked to a common source.

Introduction

Salmonella enterica is a pathogen of concern worldwide, and is the most common bacterial source of gastroenteritis in humans [2]. *Salmonella* infection (salmonellosis) typically manifests as gastroenteritis, though meningitis and hepatitis are also possible. Salmonellosis can warrant hospitalisation for intravenous rehydration and, rarely, death can occur [3]. Although *Salmonella* can be transmitted to humans via a number of routes (food, water, soil, animals) *Salmonella* in Australia is most commonly transmitted via contaminated foods. Outbreaks of salmonellosis are often linked to ingestion of contaminated eggs, poultry (and other) meats, dairy, nuts, seafood and fresh produce [4].

There are more than 2500 different serotypes of *Salmonella* and laboratory testing is required to identify serotypes. Salmonellosis is a notifiable condition in all states and territories in Australia. In addition, all laboratory confirmed cases of *Salmonella* infection in Australia are required to be reported to the National Notifiable Disease Surveillance System (NNDSS)[5, 6]. The public health importance (and subsequent requirement for notification) is due to the potential for widespread illness and the ability to place control measures to prevent further illness [7].

In Australia, *S.* Typhimurium is the most common serotype to cause infection in humans [4], with egg consumption being a major contributing factor [4, 8]. Reference laboratories in Australia commonly undertake MLVA for *S.* Typhimurium isolates to assist in the investigation of disease outbreaks [9]. MLVA has been especially useful in trace-back investigations of egg associated *S.* Typhimurium [10]. Whole genome sequencing (WGS) is a relatively new technology that has had a significant impact on the laboratory capabilities related to outbreak investigations. The improvements in technology allow for salmonellosis cases to be traced back to specific sources as it has been proven to be more discriminatory than other testing types such as MLVA [9]. When combined with epidemiological data, WGS was both sensitive and specific and was able to attribute a source with higher precision than MLVA [9]. The ACT Government Analytical Laboratory lacks the facilities to ascertain the MLVA of a specimen, therefore specimens can be sent interstate for testing.

This study investigates a cluster of cases with a novel MLVA strain of *S.* Typhimurium that had not been seen before in the ACT. The ‘ten steps to an outbreak investigation’ [11] have been used to guide this investigation.

Aim

To conduct a retrospective investigation of a salmonellosis cluster in the ACT to reduce the burden of disease related to *Salmonella.*

Methods

Epidemiological investigation

In May 2018, the HPS identified a cluster of cases with the same MLVA strain. Subsequent epidemiological, environmental, and microbiological methods were determined based on the initial results from this epidemiological investigation, and are described below.

Through the conduct of routine salmonellosis food histories, the HPS noted that all three cases reported eating eggs from two brands of eggs, originating from one farm (Farm X). An investigation team was established and an environmental investigation to Farm X was scheduled.

Upon identifying these three cases, the investigation team then looked for similar MLVA types in past salmonellosis notifications in the ACT. Three 2016 cases with a very similar MLVA strain were identified. One of those cases reported consuming eggs from Farm X.

Environmental investigation

The investigation team conducted the environmental investigation in accordance with the *Food Act, 2001* [1]. The farm manager was interviewed regarding farm practices, cleaning schedules and egg handling practices. A number of environmental samples were taken for microbiological analysis. Boot covers were worn when inspecting the egg processing area and subsequently taken off and sent for microbiological analysis. A sample of clean and dirty eggs were collected, in addition to egg wash waste water and chicken faeces samples. Swabs were taken from a number of locations including the egg processing chain.

Microbiological investigation

A total of 15 samples were collected at Farm X and sent for microbiological analysis. The 15 samples were initially sent to ACT Government Analytical Laboratory, with any positive isolates of *Salmonella* sent to the Melbourne Diagnostic Unit (MDU) for further characterisation.

Data collection

As part of routine disease surveillance, all salmonellosis cases that are notified to ACT Health are followed up (phone call) and a food history taken. A modified *Salmonella* hypothesis generating questionnaire was used. A line list was created upon identification of this new MLVA cluster in May.

Case definition

For the purposes of this thesis, a confirmed case is defined as any case with MLVA pattern 03-10-10-09-496 that reported eating eggs from Farm X.

For the purposes of this thesis, an unconfirmed case is defined as any case in the ACT with MLVA pattern 03-10-09-09-496 in 2016 that does/does not report eating eggs from Farm X.

Ethics

This study was conducted with ethics approval from the ANU Human Research Ethics Committee (Approval: 2017/909) which allows for a blanket waiver for outbreak investigations to be performed under the *Public Health Act* 2017. A confidentiality agreement was signed with HPS and only de-identified data has been used as part of this investigation.

Results

Epidemiological investigation results

Person, place and time

There were three notifications from April 18 to May 7 2018 of *S.* Typhimurium MLVA 03-10-10-09-496; all reported egg consumption from Farm X. This pattern had not been seen in the ACT previously. The investigation team then retrospectively examined notifications of a similar MLVA pattern and found three cases in 2016 with MLVA 03-10-09-09-496. One reported eating eggs from Farm X.

Case summaries

Confirmed cases (2018, n=3): All confirmed cases reported diarrhoea, fever, nausea and headache, with additional symptoms of vomiting, lethargy, joint/muscle pain and abdominal pain varying. All confirmed cases presented to the emergency department with two cases being admitted to hospital. Ages ranged from 10 to 57 years old, all identified as non-Indigenous. All cases reported eating eggs from Farm X. Reports of symptom duration ranged from 7-14 days. Median incubation period was not able to be determined due to insufficient data (incomplete questionnaires). No cases reported travel outside the ACT prior to illness and no food premises were linked between cases.

Unconfirmed cases (2016, n=3): All unconfirmed cases reported diarrhoea and lethargy, with additional symptoms of vomiting, nausea, fever varying between cases. One unconfirmed case was admitted to hospital. Unconfirmed cases included both adults and children; all identified as non-Indigenous. The median duration of symptoms was 6 days (range 3-10 days). Median incubation period was not able to be determined due to insufficient data. No cases reported travel outside of ACT prior to illness and no food premises were linked between cases.

2018 cases:

Case 1:

***Salmonella* Typhimurium MLVA pattern 03-10-10-09-496**

- Onset date: 29/04/18 (fever)
- Specimen date: 04/05/18 (stool)
- Fever, diarrhoea, nausea, vomiting, headache, lethargy, joint/muscle pain
- No travel outside of ACT prior to illness
- Ambulance: 01/05/18
- Emergency Department visit: 04/05/18
- Days admitted to hospital: 1 day
- Duration of illness: 7 days of diarrhoea, still ill at time of report (ATOR)
- Reported eating eggs Farm X

Case 2:

***Salmonella* Typhimurium MLVA pattern 03-10-10-09-496**

- Onset date: 21/04/18 (fever)
- Specimen date: 01/05/18 (stool)
- Fever, diarrhoea, nausea, headache, abdominal pain
- No travel outside of ACT prior to illness
- Emergency Department visit: 25/04/18
- Duration of illness: 2 weeks, still ill ATOR
- Reported eating eggs Farm X

Case 3:

***Salmonella* Typhimurium MLVA pattern 03-10-10-09-496**

- Onset date: 11/04/18 (fever)
- Specimen date: 18/04/18 (stool)
- Fever, diarrhoea, nausea, vomiting, headache, lethargy, joint/muscle pain
- No travel outside of ACT prior to illness
- Emergency Department visit: 04/05/18 & 16/04/18
- Days admitted to hospital: 1 day
- Duration of illness: 9 days, still ill ATOR
- Reported eating eggs Farm X

2016 cases:

Case 1:

***Salmonella* Typhimurium MLVA pattern 03-10-09-09-496**

- Onset date: 08/09/16 (fever)

- Specimen date: 13/09/16 (stool)
- Fever, abdominal pain, diarrhoea, nausea, vomiting, lethargy, joint/muscle pain
- No travel outside of ACT prior to illness
- Duration of illness: 5 days, still recovering ATOR
- Played with chickens at school 07/09/16

Case 2:

***Salmonella* Typhimurium MLVA pattern 03-10-09-09-496**

- Onset date: 09/09/16
- Specimen date: 17/09/16 (stool)
- Fever, diarrhoea, nausea, lethargy
- No travel outside of ACT prior to illness
- Duration of illness: 10 days, still ill ATOR

Case 3:

***Salmonella* Typhimurium MLVA pattern 03-10-09-09-496**

- Onset date: 06/04/18
- Specimen date: 09/04/18 (stool)
- Diarrhoea, lethargy, abdominal pain
- No travel outside of ACT prior to illness
- Emergency Department visit: 07/04/16
- Days admitted to hospital: 5 days
- Duration of illness: 3 days
- Reported eating eggs Farm X

Environmental investigation results

A number of breaches were identified at Farm X, and a *Food Act* 2001 [1]Improvement Notice was issued by the Environmental Health Officer. Of immediate note was that the farm was not located at the place the business traded at. The environmental investigation identified a lack of hand washing facilities at Farm X. Further observations from the environmental investigation and summary of the *Food Act* 2001[1] Improvement Notice are detailed below.

The *Food Act* 2001 [1] Improvement Notice was revoked once all requirements had been met.

Microbiological investigation results

A total of 15 specimens were collected during the environmental investigation including a variety of egg samples, waste water samples, swabs of cleaning chain and boot covers from the egg processing area. Two samples returned positive for *Salmonella* spp. From these samples four isolates (one from a boot cover and three from the waste hose water) were sent to MDU for further characterisation. All four isolates returned with *S.* Typhimurium MLVA pattern 03-10-10-09-496, the same novel MLVA as the three 2018 cases.

Legislative actions

Details of the legislative actions and environmental investigation are detailed in Table 1.

Table 1. Summary of *Food Act* 2001 [1]Improvement Notice, issues identified at Farm X environmental investigation

Issues/personal reflections from Farm Visit	**Contravention/Breach**	**Requirement under *Food Act* 2001 [1] Improvement Notice**	**How the Farm addressed the issues identified**
1. Business was not located at the premises which it was registered 2. Two different trading names	Food Act 2001 Section 97 Section 2 (a &b)	A proprietor of the food business commits an offence if: a) There is a change in the particulars, or the operation of the food business, b) The proprietor does not, as soon as practicable 1. Give a written notice of the change to the chief health officer; and 2. If the change affects particulars shown on the certificate of registration	Unknown at time of report (ATOR)
1. No hand wash basins on the farm (including in the egg processing areas or bathroom facilities) 2. Witnessed hand washing with a hose (no basin, no soap, no hand drying)	Food Safety Standards 4.2.5 Clause 6(1&2) Food Safety Standards 3.2.3 Clause 14(2)	1. A person involved in egg production must exercise personal hygiene and health practices that do not make the eggs unsafe or unsuitable 2. An egg processor must take all reasonable measures to ensure that personnel and visitors exercise personal hygiene and health practices that do not makes the eggs unsafe Hand washing facilities must be permanent fixtures, connected to, or otherwise provided with, a supply of warm running potable water, of a size that allows easy and effective hand washing; and clearly designated for the sole purpose of washing hands, arms and face	Farm X installed a hand wash basin for staff to utilise within 3 days of being advised to do so. Hand washing practices documented in new staff guidelines
Staff were unable to provide conclusive egg handling and cleaning guidelines. - Recently changed over from manual egg washing to automated egg washer - Chlorine measured by 'smell' - No guidelines on how often egg processor, floors or transport vehicle was cleaned - Wash water left to drain on the ground only	Food Safety Standards 4.2.5 Clause 19(b)	An egg processor must keep premises, equipment and transportation vehicles effectively cleaned, sanitised and in good repair to ensure the eggs or egg products are not made unsafe or unsuitable	Workplace Induction Checklist created for staff including cleaning, health and safety information Egg process washing and packing procedure guidelines Egg machine and room washing procedure guidelines Transport vehicle cleaning guidelines Egg food safety assessment Egg food safety processes Staff to pressure clean the egg processing floor each day

Issues/personal reflections from Farm Visit	**Contravention/Breach**	**Requirement under *Food Act* 2001 [1] Improvement Notice**	**How the Farm addressed the issues identified**
No food safety statement	Food Safety Standards 4.2.5 Clause 13(1-3)	An egg processor must: 1. Systematically examine all of its processing operations to identify potential hazards and implement control measures to address those hazards 2. Also have evidence to show that a systematic examination has been undertaken and that control measures for those identified hazards have been implemented 3. Operate according to a food safety management statement that sets out how the requirements of this Division are to be or are being complied with	Unknown ATOR
Chickens were not properly contained in their yards which resulted in birds roaming free around the egg processing site. The doors to the egg processor were left open and birds were inside the processing station	Food Safety Standards 4.2.5 Clause 19 (a)	An egg processor must ensure that premises, equipment and transportation vehicles are designed and constructed in a way that minimises the contamination of the eggs or egg products, allows for effective cleaning and sanitisation and minimises the harbourage of pests and vermin.	Unknown ATOR

Discussion

In this cluster investigation, we were able to identify the same MLVA pattern on Farm X that was present in human salmonellosis cases. Combining the epidemiological evidence of confirmed cases all reporting eating eggs from Farm X, in addition to matching the MLVA identified at farm X during the environmental investigation suggests that the source of the cluster is Farm X.

Although *Salmonella* cannot be entirely eliminated from chicken flocks [12], there are preventative measures that can be put in place to reduce risk of transmission [13, 14]. Safe egg handling practices are known to reduce the risk of infection of *Salmonella* [15]. These preventative measures extend to home food handling practices [16]. Raw or undercooked eggs present a high risk. This can be mitigated by ensuring the eggs are cooked thoroughly to kill any bacteria that is present [15]. It is unclear how all of the cases reported eating their eggs, however it provides an opportunity to provide education on safe egg cooking and handling practices.

Within the unconfirmed cases in 2016, there may have been evidence of person-to-person transmission. These two cases lived together and became ill shortly after one another. It is also possible transmission was related to handling of live chickens. These chickens could not be linked to Farm X. This remains another opportunity for educating the public on ways to mitigate transmission of disease.

MLVA is commonly used in Australia in *Salmonella* outbreaks due to its ability to enable early detection of cases and therefore facilitate rapid public health response [17]. In the ACT, outbreaks or clusters of disease are usually first identified through routine food history screening, with additional laboratory testing being undertaken as required. The relatively new technology of whole genome sequencing is considered the gold standard in outbreak investigations for its accuracy and specificity. Whole genome sequencing can be useful in confirming outbreaks where environmental (and clinical) data are available for testing [18]. While the MLVA pattern associated in the 2018 cluster of cases has not been seen previously before in the ACT, it is possible to see microbial mutations [10, 19]. Microbial evolution is an ever persistent challenge. For *S.* Typhimurium, this is particularly so due to its ability to persist in varying environments [10].

We were able to use legislation available to HPS to require Farm X to implement strategies to improve egg processing at Farm X, aimed at reducing the risk of transmission of bacteria to humans. Specifically, the positive samples were located in the wash water and egg processing area, indicating that the farm needed to improve their cleaning practices of the egg processing chain. An Improvement Notice was issued in accordance with the *Food Act* 2001 [1]. *Salmonella* contamination at various stages of production is a complex issue. It is important to ensure that the eggs are processed, and stored in appropriate conditions and not re-exposed to *Salmonella* post washing. Additionally, regular cleaning of the egg washing machine is an essential activity to ensure no recontamination occurs [12, 13]. In addition, as a result of this investigation HPS report they will be developing a consumer guide to safe egg handling practices.

Strengths and limitations

We identified three confirmed cases in this cluster, and three potential linked cases, according to the definitions used in the current analysis. Only 1 in 5 patients with gastroenteritis symptoms present to a general practitioner for treatment [3]. Therefore, it is possible there were more cases in this cluster that HPS did not get alerted to. It is also possible that due to the severity of disease present in this cluster investigation, cases may have been more likely alerted to the HPS due to being severely ill and seeking hospital treatment. Small numbers limited the study design and analysis that could be performed as typically it is noted that case control or cohort studies are utilised in outbreak/cluster investigations. Despite the small case numbers, we were still able to find the exact MLVA pattern within two samples from Farm X. A number of control measures/ interventions were put in place to help prevent further risk of disease. For the purposes of this chapter, a consistent case definition has been used throughout. It is noted that this case definition has its limitations and is not reflective of a broader case definition that may/may not be used outside of this project.

Conclusion

This chapter reports on a cluster investigation of a novel MLVA strain of *S.* Typhimurium in the ACT. Three confirmed cases were identified with an additional three unconfirmed cases being possibly linked to the investigation. Farm X was identified to have been a common link in all confirmed cases and an investigation was undertaken. As a result, an Improvement Notice was issued as part of efforts to ensure no ongoing risk of contamination to the public. The identification of the exact strain of MLVA in samples taken from Farm X confirmed the epidemiological link between cases and the farm. Given that eggs are a common source of *Salmonella* infections in Australia, ongoing vigilance through routine surveillance systems and notifications is important to ensure public safety. The prompt nature of this investigation ensured that the source of infection was identified in a timely manner and appropriate interventions ensued.

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Chapter five: Teaching

Prologue

The MAE program requires scholars to complete a teaching component in the form of 'Lessons from the Field' (LFF) and teaching the first year MAE cohort. In addition to these requirements, I was also involved in delivering a lesson at the National Indigenous Science and Engineering Summer School.

Appendices

Appendix 5.10 Lessons from the field – *Intro to Qualtrics*

Appendix 5.11 Teaching first years – *Writing tips*

Appendix 5.12 Teaching first years – *MAE top tips*

Appendix 5.13 National Indigenous Science and Engineering Summer School – *'Disease detectives: how epidemiologists find the cause of an outbreak'*

Acknowledgments

I would like to thank all of those involved in preparing, participating and delivering the lessons in this chapter. The group of students in my Lessons from the Field were very supportive and provided great constructive feedback. Thanks Gabby, Ximena and Bobby for taking the time to go through my lesson and also sharing great lessons yourselves.

Thanks to Gabby, Natalie and Bernadette for making our session with the first years fun and insightful. The MAE top tips was an amalgamation of ideas from each of us in the cohort on how to survive the MAE journey. Thanks everyone for your amusing perspectives.

Thanks to Dr Katie Glass and Professor Martyn Kirk for the opportunity to be involved in presenting a class to the Indigenous summer school kids. I have a passion for helping young people and I very much enjoyed being involved.

Lessons learnt

I discovered that I really enjoy teaching. I found that it helped to cement my knowledge of the topic in preparing the lessons and through answering questions from peers/students. I like being able to help others to problem solve and work through the lessons. I sometimes find it easier to help others problem solve and break down tasks than I find doing it myself. I hope to continue teaching periodically throughout my career and begin supervising other students.

Appendix 5.10

Lessons from the field: lesson plan
Introduction to Qualtrics

Lessons from the field: Intro to Qualtrics

Schedule

Email lesson: 20th July (sorry, I know I'm late with this)

Responses due: 3rd August

Teleconference: 10th August

Feedback sent out: 27th August

Learning objectives

In this lesson you will learn the basic principles for operating Qualtrics.

Specifically, you will learn to:

- Create a survey using multiple question types
- How to distribute your survey
- Enter data using Qualtrics
- Export data for analysis

What is Qualtrics?

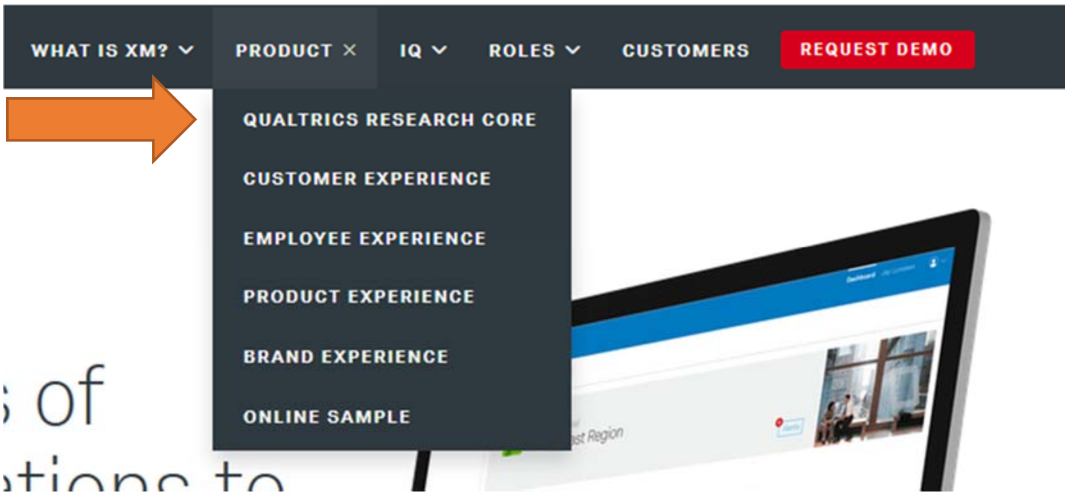
Qualtrics (research core) is an online tool used to create surveys, distribute surveys, collect data and export data for analysis. Think survey monkey – but far more sophisticated.

*disclaimer: I am not a massive whiz with Qualtrics, but it is a fairly easy tool to use and has been really helpful for my data entry. You can use Qualtrics to do all kinds of fancy looking surveys, but for the purposes of this lesson it is to only learn to basics. So be prepared for your surveys to look ugly at the end. ☺

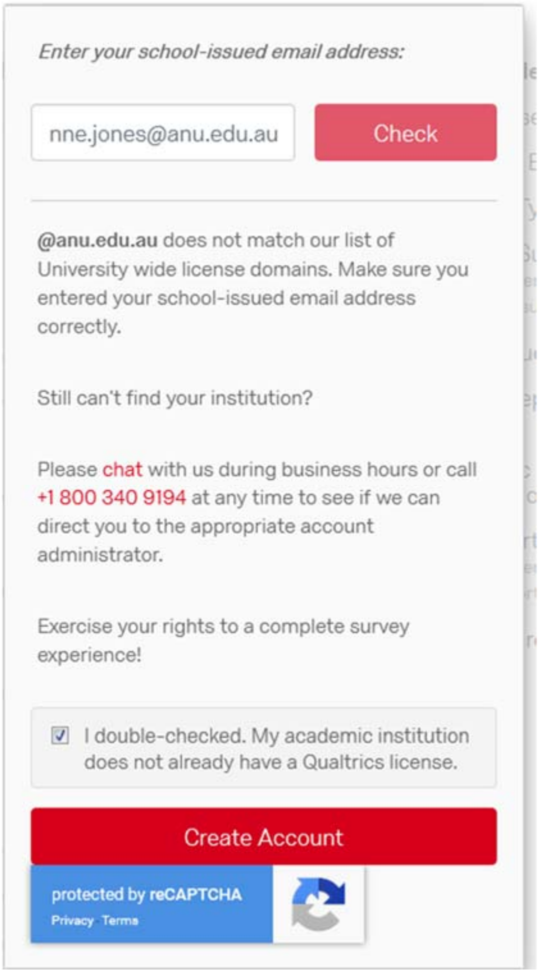
Instructions

Create Qualtrics account

1. Go to www.qualtrics.com
2. On the top right hand side of page to go *Product* then click on *Qualtrics Research Core*



3. Click on *Free account*
4. Fill out details and click *Create Account*
5. *It may ask you to check if your institution already has a license but don't stress about this. Continue on and click ~*I double checked. My Academic institution does not already have a Qualtrics license.*~



Enter your school-issued email address:

nne.jones@anu.edu.au

@anu.edu.au does not match our list of University wide license domains. Make sure you entered your school-issued email address correctly.

Still can't find your institution?

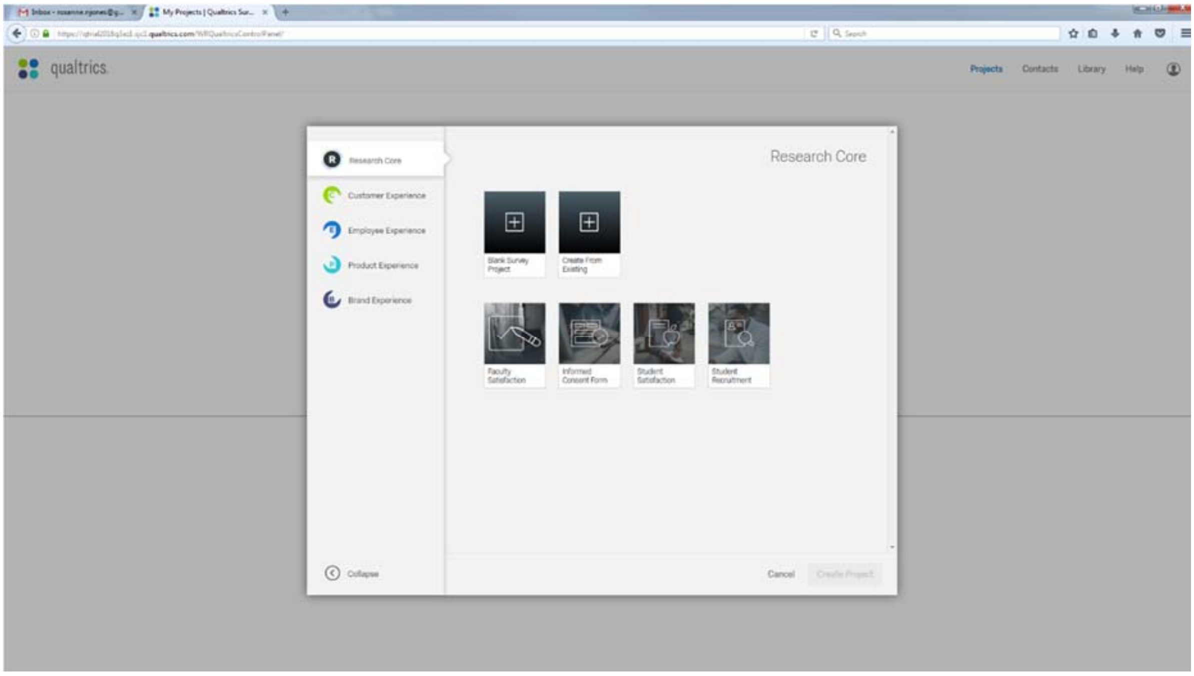
Please chat with us during business hours or call +1 800 340 9194 at any time to see if we can direct you to the appropriate account administrator.

Exercise your rights to a complete survey experience!

☑ I double-checked. My academic institution does not already have a Qualtrics license.

6. Once you’ve clicked create account you should see a *Terms of Service* page. Click accept.

7. You should now be at this page. Leave this page open and open a new tab in your internet browser and watch https://www.youtube.com/watch?v=_hSo-ldj19k (don’t worry, it’s only 10 minutes)



By this page you will have created a Qualtrics account and watched the beginner tutorial on YouTube. We will now go through the scenario and create our own survey.

Scenario

We are coming up to the final months of our thesis writing and we are becoming concerned about how the stress is impacting on our cohort’s mental health. It isn’t just MAE’s – we constantly hear how ‘normal’ it is for HDR students experience some form of “mental breakdown” within the last 6 months of thesis writing.

We decide to send out a simple, 5-10-minute survey to get an overall ‘picture’ of what is happening among HDR students who are within 6 months of submitting their thesis. This will be open to both MPhil and PhD students at the ANU. *(Not really an ideal study design but it will do for the purposes of this exercise)*

To measure psychological distress we will use the K10 scale. Hopefully we are all familiar with this scale – but if not – have a read of http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4817.0.55.001Chapter92007-08

This shows how the scale is usually set out: https://s3.maic.qld.gov.au/files/K-10.pdf

Exercise 1

When creating your survey please think about some questions that will get you the following data:

- demographic information (age, sex)
- study information (confirm they're in their final 6 months of candidature)
- K10 scale
- Free text question (something they can answer freely into a text box. Ie. An open ended question)

There are no right or wrong questions to put in your survey, and there are no right or wrong variables to measure. I just want you to go through the process of developing different question styles in Qualtrics. We will all have surveys asking different things and that is totally fine. I want you to explore how to use Qualtrics, not focus on the questions themselves. Please ensure you've made at least 5 questions in your survey though.

Tips

You may need to watch the video again while you are in the process of developing your first survey items. I want you to think about what styles of questions (multiple choice, yes/no, open text) are best suited to what you are asking.

When creating your K10 scale – think about how the data will export. See from 8mins in the video tutorial. ~~RECODE VALUES~~ you may consider recoding the variables now, so that you don't have to do it later in Stata (trust me, do it now rather than later).

Exercise 2

Once you have finished creating your survey I want you to email me your direct survey link. To do this go to the distributions tab, and copy and paste the distribution link into an email and send it to me.

Next, I want you to enter a dummy response in for yourself – so that you can test your own surveys. I have found this to be really beneficial – because you can pick up on your own mistakes before sending links out to participants. Go through and complete your own survey now.

Exercise 3

Exercise 3 will be in the teleconference and we will do this all together. I will enter some dummy answers into each of your links so that when we have our teleconference, we can learn how to view and export our data.

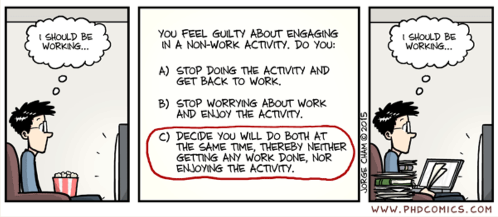
That's it! So at the end of this LFF the only thing you need to do is send me your survey link. Then we will have some fun during our teleconference! Also if you get stuck anywhere, write it down and we will go through it together in the teleconference.

Appendix 5.11

Teaching first years – Writing tips

WRITING TIPS

Gabi Willis, Bernadette Kenny, Natalie Strobel, Roxy Jones



Learning objectives

- Provide ideas on how:
  - *To write effectively*
  - *Manage large documents*
  - *Respond to reviewers/supervisors comments*
- Discuss formatting conventions for tables and graphs
- Let you know where to find help

How to write effectively

http://elvindantes.com/post/117698995545/the-pomodoro-technique-heres-one-way-to-organize

Other ways to be effective

- Swear now and again
- Write as though you're telling a story to a 5 year old
- Draft your outline and dot point what you want to say
- Mind maps

Managing large documents

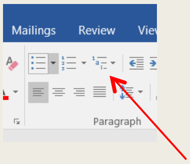
- Version control
  - *Date and time – consider your international co-authors*

    e.g. 2/4/2018 or 2Mar2018
- Endnote is your friend
- Back up your work!


"THAT'S TO BACK UP MY DATA. AND THAT'S TO BACK UP THAT DEVICE. THAT'S TO BACK UP THE DEVICE THAT'S BACKING UP THAT DEVICE. THAT'S TO BACK UP THE DEVICE THAT'S BACKING UP THE DEVICE THAT'S..."

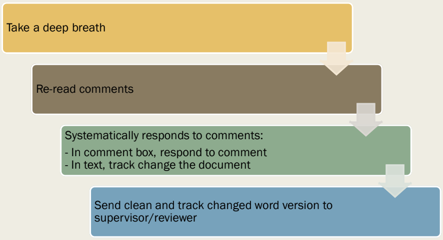
Managing large documents

- Word is also your friend!
  - *Use headings, captions, and styles for easy formatting and automatic table of contents, list of tables/figures etc*
  - *Cross-reference*
  - *Consider using a Master document for your bound volume.*
- https://www.youtube.com/watch?v=2G7lr_7qqkc



Don't forget this button, it's the most important one!

Responding to comments


Take a deep breath

Re-read comments

Systematically responds to comments:
- In comment box, respond to comment
- In text, track change the document

Send clean and track changed word version to supervisor/reviewer

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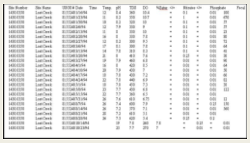
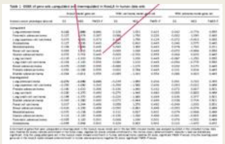
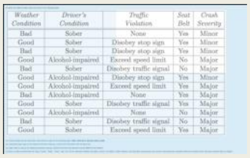
A.



B.



C.



Weather Condition	*Driver's Condition*	*Traffic Violation*	*Seat Belt*	*Crash Severity*
Bad	Sober	None	Yes	Minor
Good	Sober	Disobey stop sign	Yes	Minor
Bad	Sober	Disobey stop sign	Yes	Minor
Good	Alcohol-impaired	Exceed speed limit	No	Major
Bad	Sober	Disobey traffic signal	No	Major
Good	Alcohol-impaired	Disobey stop sign	Yes	Minor
Good	Alcohol-impaired	Exceed speed limit	Yes	Major
Bad	Alcohol-impaired	None	Yes	Major
Good	Sober	Disobey traffic signal	Yes	Major
Good	Alcohol-impaired	None	No	Major
Bad	Sober	Disobey traffic signal	No	Major
Good	Sober	Exceed speed limit	Yes	Major

D.

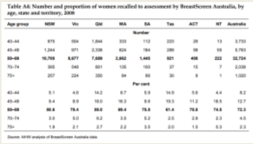
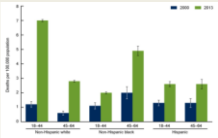


Table A4: Number and proportion of women recalled to assessment by BreastScreen Australia, by age, state and territory, 2006

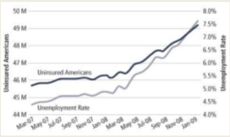
Age group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
					Number				
40–44	675	504	1,844	333	112	223	29	13	3,733
45–49	1,244	971	2,338	624	184	280	58	55	5,763
50–69	**10,700**	**8,877**	**7,689**	**2,662**	**1,445**	**921**	**408**	**222**	**32,724**
70–74	395	540	801	135	100	37	15	7	2,030
75+	257	224	350	84	66	30	8	1	1,020
					Per cent				
40–44	5.1	4.6	14.2	8.7	5.9	14.9	5.6	4.4	8.2
45–49	9.4	8.9	18.0	16.3	9.6	19.3	11.2	18.5	12.7
50–69	**80.6**	**79.4**	**59.0**	**69.4**	**75.8**	**61.4**	**78.8**	**74.5**	**72.3**
70–74	3.0	5.0	6.2	3.5	5.2	2.5	2.9	2.3	4.5
75+	1.9	2.1	2.7	2.2	3.5	2.0	1.5	0.3	2.3

Source: AIHW analysis of BreastScreen Australia data.

A.



B.



C.

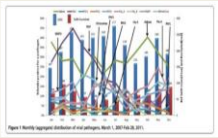


Figure 1 Monthly (aggregate) distribution of viral pathogens, March 1, 2007-Feb 28, 2011.

D.

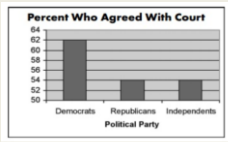


Table and chart formatting

Tables

- Avoid vertical lines
- Avoid too many horizontal lines
- Consistent alignment
- Enough space between rows
- Avoid colours/shading unless absolutely necessary
- Always use sans-serif font
- Use footnotes

Charts

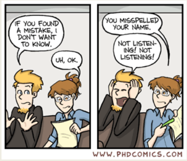
- No gridlines
- Use a legend
- Consider black & white printing
- Use fine lines and small font (but not too small!)
- Avoid too much data in one chart

Writing help

- Library workshops
  - *Endnote, formatting long docs, word help, maintaining consistency*
- ANU Academic Skills and Learning Centre
  - *Available for one-on-one appointments, workshops, self help resources*
- PARSA
  - *Shut up and write*
  - *Thesis boot camp*
- Statistical consulting unit
  - *Available for one-on-one appointments, workshops, self help resources*
- ANU Aries ethics training
- ACSPRI courses

Our last word for the day…

- Bound volume – maximum word count 60,000
  https://policies.anu.edu.au/ppl/document/ANUP_012815
- Abbreviations
- Check to see if there is a corporate style in your workplace
- If you need a laugh PhD comics – there's one for every situation
  http://phdcomics.com/



Appendix 5.12

Teaching first years – MAE Top tips

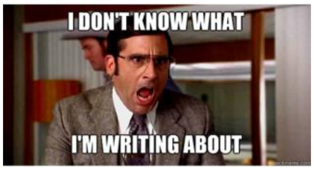
How to survive and thrive in the MAE

Top tips from those that have been in your shoes!

If all that you achieve in the first week of your placement is finding the best coffee shop around – you're doing well

Roxy Jones – Aboriginal and Torres Strait Islander Health Program; NCEPH, ANU.

Write early and often



Kaitlyn Vette, Office of Health Protection, Canberra

"Keep in mind the present you are constructing, it should be the future you want"

(Alice Walker, author of 'The Colour Purple')

Bernadette Kenny, SA Health CDCB

You will undoubtedly have hard days, but they will pass

Kelley Meder, National Centre for Immunisation Research and Surveillance, Sydney

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Planning is Key for the MAE

plan projects… but also plan how to stay alive

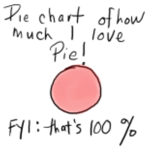
food… exercise… holidays!

Aurysia Hii NHMRC CRE Integrated Systems for Epidemic Response, Sydney

Rely on your fellow MAE's. They're only a **WhatsApp** away!

Gabi Willis, Communicable Disease Prevention Unit, Hobart

Remember to make time for the people and things you love…



Brigitta Osterberger – Office of Health Protection, Australian Government of Health, Canberra

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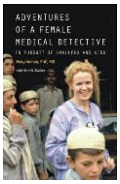
Getting ready for deployment

- Join ARM (Australian Response MAE network) http://arm.org.au/#join
- Join Yammer ARM https://www.yammer.com/arm-australianresponsemaenetwork/#/home
- Complete WHO GOARN online courses https://openwho.org/channels/goarn



Ximena Tolosa, WHO Collaborating Centre for Reference & Research on Influenza, Melbourne

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Don't be a victim of 'grass is always greener' syndrome- but if there is no grass, say it loud and say it early.

Jana Sisnowski, Kirby Institute, Sydney

Don't stress and try to get 4 perfect super exciting projects. You have the rest of your life as an field epidemiologist to do all those exiting things

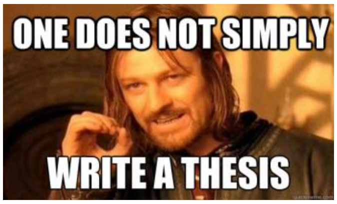
Pat Andersson, Office of Health Protection, Canberra

Trust yourself, back yourself, and advocate for yourself.

Sophie, The Kirby Institute, Sydney.

Build your networks…..you could get an outbreak out of it

Bobby Maher, Department of Prime Minister & Cabinet, Canberra



Have holidays!

Julia Maguire, National Centre for Immunisation Research and Surveillance, Sydney

Spend time enjoying the program and take advantage of the opportunities

Cushla Coffey, Health Protection Branch, Queensland Health, Brisbane

Just do it!

(You can do it!)

Nat Strobel, Improving health services for Aboriginal and Torres Strait Islander Children, Perth

Appendix 5.13

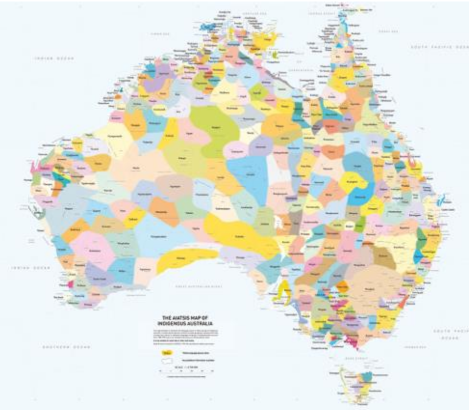
National Indigenous Science and Engineering Summer School 2017
‘Disease detectives: how epidemiologists find the cause of an outbreak’

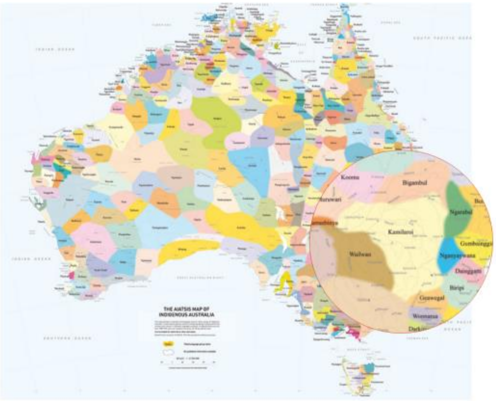
Australian National University

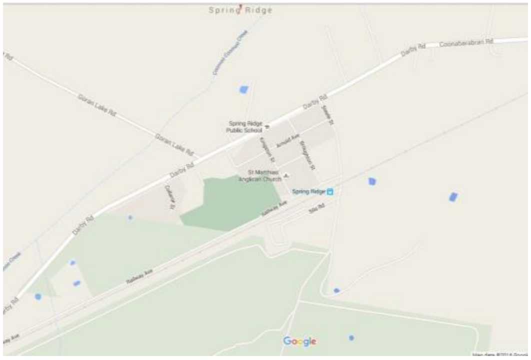
Disease detectives: how epidemiologists find the cause of an outbreak

Katie Glass, Charlee Law, Bobby Maher,
Roxanne Jones, Martyn Kirk, Katrina Roper

Research School of Population Health,
Australian National University

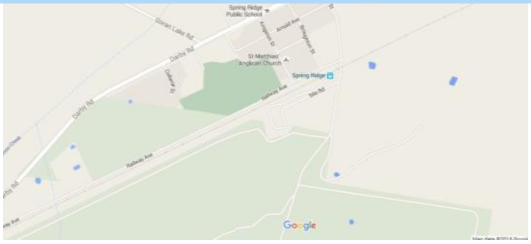






Every year in the Western Pacific Region, unsafe food causes

125 MILLION ILLNESSES | 50,000 DEATHS | DEATH IN 7000 CHILDREN UNDER FIVE



Every year in the Western Pacific Region, unsafe food causes

125 MILLION ILLNESSES | 50,000 DEATHS | DEATH IN 7000 CHILDREN UNDER FIVE

Population: 23 million

125 MILLION ILLNESSES

125 MILLION ILLNESSES

What happens in Australia?

Each year in Australia there are:

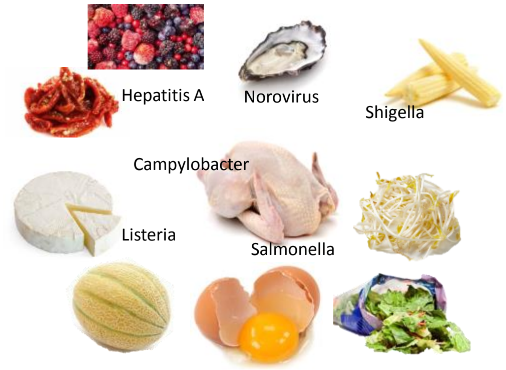
- 15.9 million episodes of gastroenteritis
- 4.1 million of these are due to food
- 30.6 thousand hospitalizations due to foodborne gastroenteritis

Common causes of illness and hospitalization include:

- *Campylobacter*
- *Salmonella*
- Norovirus

Some illnesses are part of outbreaks.

Disease outbreaks due to food



Scientists that detect outbreaks

- Epidemiologists: interview sick people, develop hypotheses, analyse data
- Environmental Health Officers: examine kitchens, take samples from food and the environment
- Microbiologists: test samples, identify pathogens
- Food safety experts: develop laws, oversee food recalls

Our mock outbreak investigation

- Chicken sandwich
- Beef sandwich
- Cheese sandwich
- Egg sandwich

- Spring roll
- Bacon quiche
- Rockmelon
- Strawberries

Your roles

Sick person

Well person

Interview each other about food eaten

Environmental Health Officer

Interview premises manager

Which role do you have?

What food do you suspect?

What did we find out?

- Report from the Environmental Health Officers
- Summary sheet – what foods were commonly eaten by sick people?
- Results of the lab tests…
  - Samples from the preparation benches and a bowl used to prepare mayonnaise were positive for *Salmonella*

What went wrong?

Fill in your workbook:

- What bug do you think is responsible for the illness?
- What food do you think carried this bug?
- What could the person in charge of the food premises do differently in the future to prevent another outbreak?

Why outbreaks are challenging..

- How well could you remember what you ate for lunch two weeks ago?
- Would you remember whether your sandwich contained mayonnaise?
- How can we distinguish between foods that are always eaten together?
- What happens if the kitchen is cleaned thoroughly before we know about the outbreak?
- What should we do if we are not confident we know what food was responsible?

Chapter six: Other work

Prologue

During the MAE program I participated in a variety of other work, some projects worth noting are attached as appendices to this chapter.

Appendices

Appendix 6.10 Study proposal – *Development of a national database of paediatric Human Parechovirus (HPeV) cases*

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Study proposal – *Development of a national database of paediatric Human Parechovirus (HPeV) cases*

My role

In May 2018 I was approached by staff of the MAE program as to whether I would be interested in being involved in a paediatric human parechovirus outbreak. At this time I was also undertaking my Salmonella outbreak investigation in Canberra, but nonetheless I was very interested in being involved because of my previous experience being a paediatric intensive care nurse (and nursing babies with parechovirus). The attached study proposal (Appendix 6.10) details why this investigation was important, the aim of the project and how I was to be involved. This was a multi-state outbreak and I was collaborating with, and organising meetings with, specialists from around Australia. I became deeply involved in the project as it was of high interest to me personally and professionally. It was a very large project that I had to narrow down significantly, as my capacity to be involved in all aspects of the project was simply unrealistic. In addition to the development of the national database/line list (which I would be undertaking), there was also interest from some states as to the neuro-developmental outcomes of children who had been ill with parechovirus, the clinical features of the disease and whether it should be included as a National Notifiable Disease. It was a challenging project from the start, as each state specialist seemed to have competing priorities as to what should be looked at first. To consolidate the study proposal (which states had agreed to) and refine the principles of the project, in June 2018 I spent a week at the Infection Management and Prevention Service (IMPS), at Queensland Children’s Hospital (QCH). Despite the visit being planned with all relevant parties, and the specialists involved were aware of the plan (and the four month turnaround timeline), the visit to QCH was where the project fell apart.

The study proposal included three key questions that needed to be answered during the visit to QCH for this project to go forward. What were the ethics requirements, the data sharing agreements between hospitals and the time frame that these would take to establish? In retrospect, I should have answered these questions before I made the effort to travel to Queensland. However I was led to believe that our ANU blanket ethics approval for outbreak investigations would cover the project. On the second day in Queensland I met with their research ethics officer who very quickly answered my ‘key questions’. It was unfeasible. The ethics approval from ANU would not be accepted, there are formal data sharing agreements that need to be put in place (and applied for) months in advance in order to take data offsite (which I would have to do, given I was supposed to be coordinating and collecting multijurisdictional data from my base in Canberra).

Upon my return to Canberra we did attempt to keep the project going. Some of the MAE staff were hopeful of getting assistance from CDNA with regards to the data sharing across jurisdiction issues, and whether the national line list could be collated under the public health act. However in the end I had to withdraw from the project because it simply was no longer feasible for me to contribute in such a short timeframe.

Public health impact

I sincerely hope that this project was able to continue after I stepped away. It has great public health importance for Australian children. It is an emerging disease that is affecting vulnerable children all around Australia, resulting in critical illness and possibly long term negative neurodevelopmental outcomes. There was talk of the illness being placed on the National Notifiable Disease Surveillance System (NNDSS) which would greatly enhance our understanding of the disease, and provide reliable data on the incidence, patterns and severity of the illness. Without being placed on the NNDSS we have no way of quantifying the extent to which the illness affects children on a national scale. The public health importance of my project specifically was to replicate a basic version of the NNDSS and create a national line list. This would at least give a baseline understanding of the disease over the past year. The aim would then be to improve the dataset to capture more information and enhance our understanding in other areas (such as neurodevelopmental outcomes). Although some states appear to be developing state-based line lists of their own, it is important to be able to combine the results to create a national picture. There is great potential in this project having a tangible impact in our understanding of the disease and it’s significance nationally. I hope that the project continued after I had to step away, I was very excited to be involved in a project of this importance.

Lessons learnt

The greatest lessons I learnt during my short (but intense) time involved in this project were around managing expectations and how challenging project management can be. I would have loved to jump into the project with everything that I had, but that was not possible given the nature of the MAE program and my impending submission date. Trying to convey this to a group of senior academics whom I admire and who had no grasp on the nature of the MAE project was incredibly challenging. If it were a different time in my MAE journey, or after completion of the MAE I could see myself really enjoying the project and being in a very different place (logistically and time wise) to be able to participate. This was disappointing on a personal level, but also very challenging to navigate in practice. I knew what my limits were and enforcing those limits was difficult. In the end I did have to walk away and I continue to believe that was the right thing to do.

Project management was a surprisingly difficult and time consuming task. I found coordinating teleconferences with various (incredibly busy) researchers was near impossible. I found the additional mental load of managing communications and managing the project in general to be quite overwhelming. It was a taste of what is to come in my PhD, and while it excites me I also hope it gets less overwhelming with time. The output of research (ie. Papers) shows such a small amount of the overall picture. It is quite amazing the workload, hours and resources that are behind each paper.

Acknowledgments

This was a large project and many people were involved at various stages in it's creation. My sincerest thanks extend to all involved and I look forward to being involved in projects with you in the future.

Dr Meryta May

Associate Professor Julia Clark

Dr Philip Britton

Professor Kristine Macartney

Rebecca Doyle

Associate Professor Luregn Schlapbach

Dr Seweryn Bialasiewicz

Dr Tambri Housen

Professor Ross Andrews

Dr Ben Polkinghorne

Appendix 6.10

Study Proposal
Development of a national database of paediatric Human Parechovirus (HPeV) cases

Study Proposal

Roxanne Jones

Development of a national database of paediatric Human Parechovirus (HPeV) cases

Background:

There is evidence that HPeV in young children has rapidly emerged in Australia since 2013, with outbreaks identified periodically across state jurisdictions. HPeV infections mostly cause mild symptoms of gastroenteritis or influenza-like symptoms but can manifest in severe disease with sepsis-like presentations, acute abdomen, meningoencephalitis and seizures. Treatment options are limited to supportive measures and management of complications. Severe HPeV infections can cause adverse neurodevelopmental outcomes. In order to describe and understand the epidemiology of HPeV in Australia there is a need to establish a national database of cases.

Aim:

The aim of this project is to collate multi-jurisdictional data on documented cases of HPeV from tertiary paediatric hospitals in QLD, NSW, VIC, WA into a national line list for the period 1st June 2017- 1st June 2018.

Methods:

Paediatric admissions meeting the case definition for Parechovirus will be included in the database.

Variables in the national data set will include (where available)

- Demographic characteristics of the case: unique ID, gender, age at gestation, date of birth, ATSI status, postcode, state
- Illness characteristics: date of onset, symptoms, diagnosis, co-infections, immunocompromised, date of presentation, hospitalized (Yes/No), ICU admission (Yes/No), duration of illness, date of discharge, outcome
- Laboratory data: specimen collection date, specimen type, isolated pathogen, genotype

Timeline

- Visit LCCH June 25-29th
- Review the QLD HPeV data

- Finalize variables for inclusion in the line list
- Decide on the best way to collate data (Redcap, excel, Qualtrics, ODK?)
- Collate QLD data as starting point
- Latter part of July: Contact other jurisdictions and hospitals, obtain permissions and access data.
- August: Compile national data, clean and code database, construct data dictionary
- September: Draft descriptive analysis and circulate for feedback
- October: Construct final report and circulate

Key Questions:

Is approval from one or more ethics review boards required?

Requirement for data sharing agreements?

Key contacts for each jurisdiction and hospital

Deliverable:

A national parechovirus database (QLD, NSW, VIC, WA) that can become an ongoing resource for jurisdictions to add to in the future

Descriptive analysis of June 2017-June 2018 data.

MAE requirements that will be met

- Obtain preliminary information and describe the nature of the problem and epidemiology
  - Information obtained in our teleconference and initial investigations (as well as this brief proposal) will form part of my thesis chapter
- Establish what level of investigation is necessary
  - Emphasis on investigation with the intention of building an ongoing resource
- Participate in an outbreak response team,
  - Define objectives and scope of investigation, design and conduct field investigation
  - Count cases and characteristics of outbreak by time, place, person, clinical and lab characteristics
- Write a report and recommendations
  - Descriptive analysis of above, build ongoing data resource
  - Recommendations to improve the database and extend it to include further details in the future

Appendix 6.11

PhD Proposal

The epidemiology and experiences of Aboriginal and Torres Strait Islander children admitted to tertiary Paediatric Intensive Care Units in Australia

PhD Research Proposal
Roxanne Jones

The epidemiology and experiences of Aboriginal and Torres Strait Islander children admitted to tertiary Paediatric Intensive Care Units in Australia

Background:

There is limited research conducted to date that explores the epidemiology and experiences of Aboriginal and Torres Strait Islander children admitted to tertiary Paediatric Intensive Care Units (PICU) in Australia. We are yet to understand the national picture of the trends in PICU admissions for Aboriginal and Torres Strait Islander children across Australia. Ostrowski et al. (2017) explored the burden of invasive infections in critically ill Indigenous children in PICU. They found that the admission rate for invasive infections was several times higher for Indigenous children compared to non-Indigenous children (47.6 *v* 15.9 per 100 000 children per year). This study is the largest study of Indigenous children admitted to PICU to date, and provides robust evidence of inequality experienced by critically ill Indigenous children. This publication received significant media attention, yet no resulting changes to policy or practice have been implemented. The article only focused on one specific admission type (invasive infections), and therefore does not provide a clear understanding of the overall nature of admissions across Australia. This proposed PhD research will seek to quantify trends at the national level, and enhance our understanding of the experiences of Aboriginal and Torres Strait Islander children and families admitted to PICU, in order to provide evidence to implement policy change.

Aims:

1. To quantify trends in Aboriginal and Torres Strait Islander child admissions to PICUs in Australia, and variation by key factors.
2. To give voice to Aboriginal and Torres Strait Islander families and their experiences of admission to PICU.

Methods:

I intend to use a participatory, mixed methods approach for my thesis which will comprise of two major components. The quantitative component will utilise the Australian and New Zealand Paediatric Intensive Care Registry (ANZPICR) data to explore the epidemiology of Aboriginal and Torres Strait Islander children admitted to tertiary PICUs in Australia. I will describe: admission characteristics (admissions by state, year, age, remoteness, retrieval status); illness characteristics (severity, outcomes, risk factors, duration of stay, ventilation and intubation status); and investigate how these figures have changed over time.

The qualitative component will comprise semi structured interviews/focus groups to explore the experiences of parents of Aboriginal and Torres Strait Islander children admitted to PICUs in Australia. In addition to parental experiences, I will also seek to understand the experiences of health professionals providing care to these children and their families. This research design supports ongoing engagement and collaboration with Aboriginal and Torres Strait Islander children, families and health professionals

Outputs and dissemination:

This research will form part of a thesis by publication, aiming for up to 5 peer-reviewed journal articles. I will actively engage with those involved in the entire research process, learning from their experiences, and providing feedback and recommendations at relevant intervals. In addition to PhD related research, I would like to become involved in teaching within the Master of Philosophy in Applied Epidemiology program. I hope to continue to build skills in areas such as writing small grant applications; media engagement; travel and present at conferences; attend additional short courses in statistics; become a peer mentor and serve on a board/committee.

Priorities for first two years:

- Initial scoping discussions/build reference group
- Ethics applications and literature review
- Data access applications
- Data analysis plan(s) and research plan
- Build relationship with health services
- Preliminary analysis
- Knowledge exchange
- /feedback sessions
- Thesis proposal review

References:

Ostrowski, J. A., MacLaren, G., Alexander, J., Stewart, P., Gune, S., Francis, J. R., . . . Schlapbach, L. J. (2017). The burden of invasive infections in critically ill Indigenous children in Australia. *Med J Aust, 206*(2), 78-84.

Appendix 6.12

‘Telling our story… Creating our own history’: caregivers’ reasons for participating in an Australian longitudinal study of Indigenous children

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

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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, Aunty, 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 analysists 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

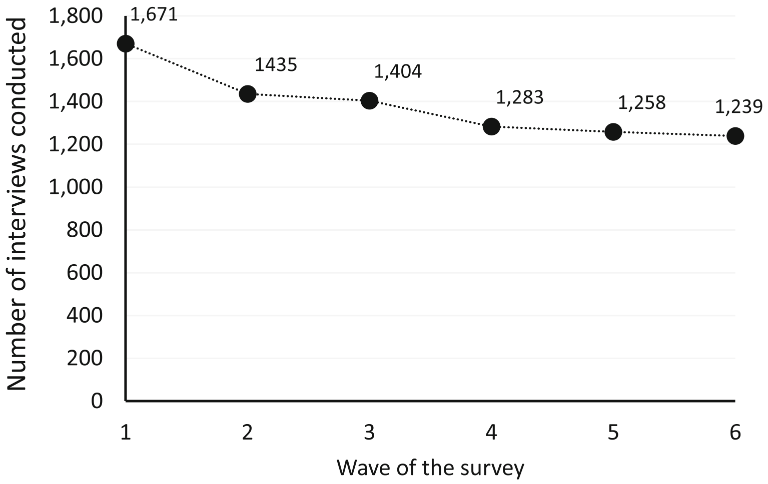

Fig. 1 Number of participating families in Waves 1 to 6 of *Footprints in Time*. * Numbers refer to interviews with the primary caregiver. The total sample of 1759 families includes 1671 Wave 1 (baseline) participants and 88 new entrants who joined the study in Wave 2

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

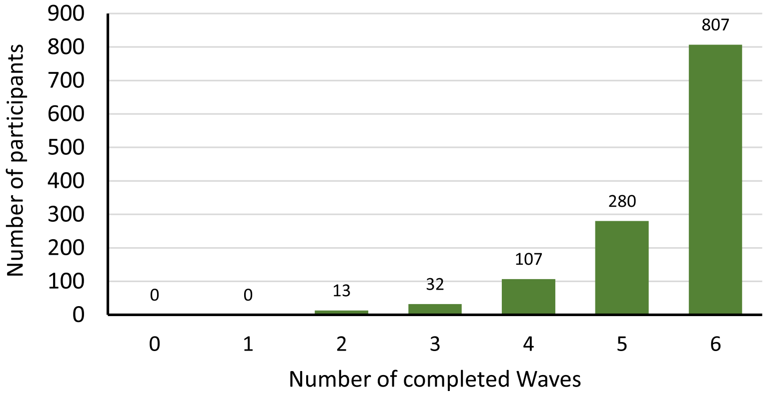

Fig. 2 Number of *Footprints in Time* interviews completed by Wave 6 participants. * Numbers refer to interviews with the primary caregiver. This graph presents the number of LSIC interviews completed by families participating in Wave 6 of the study. The minimum number of completed interviews is two 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.*

Table 2 Themes, definition and frequency

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

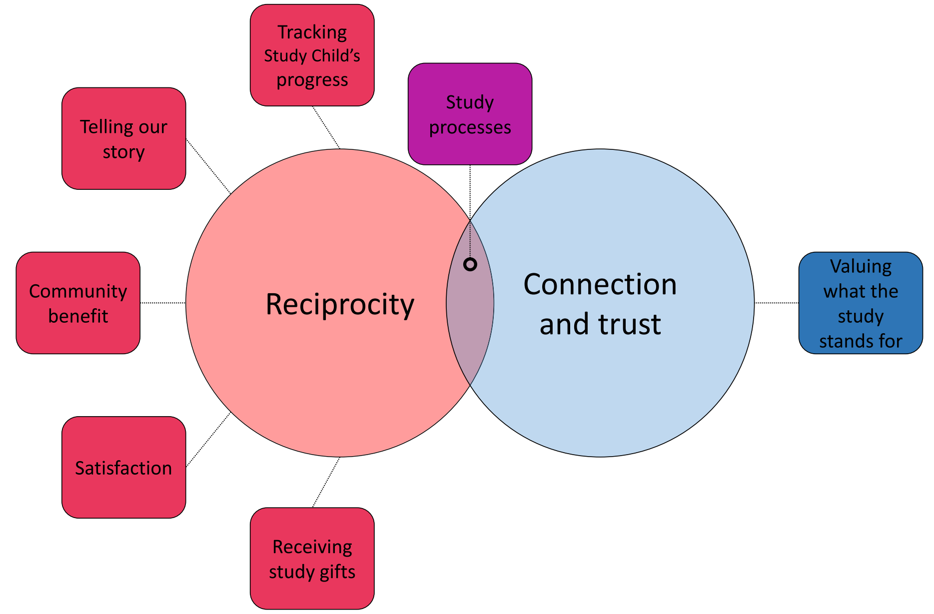

Fig. 3 Relationships between themes and meta-themes

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 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 response; 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 6.13

Closing the Gap in child mortality: Ten years on
SBS Article

Closing the Gap in child mortality: Ten years on. Available from: https://www.sbs.com.au/nitv/article/2018/02/13/closing-gap-child-mortality-ten-years

Article · February 2018

4 authors, including:

Ray W Lovett
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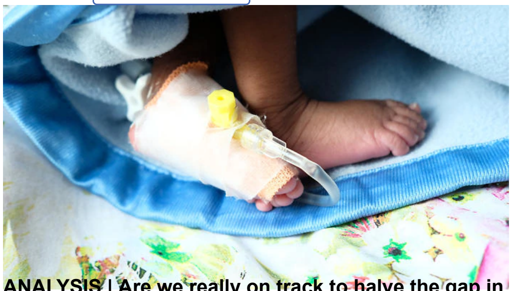
#WalkWithUs
Grace Beside Me
Indigenous Science

SBS sbs.com.au

15 FEB 2018 - 10:53AM

Closing the Gap in child mortality: Ten years on

Tweet Recommend 97



In 2008, the Rudd Government set a target to halve Indigenous child mortality rates in 10 years. (Getty/Towfiqu Photography)

ANALYSIS | Are we really on track to halve the gap in mortality rates for Indigenous children under five within a decade?

By
Ray Lovett, Katherine Thurber, Roxanne Jones, Emily Banks

13 Feb 2018 - 8:42 AM UPDATED 15 Feb 2018 - 10:53 AM

Tweet Recommend 97
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Disclaimer: This analysis discusses statistics of children's deaths which some readers may find distressing.

In 2008, the Council of Australian Governments committed to ‘Closing the Gap’ between the health of Indigenous and non-Indigenous Australians. One of the key targets under this strategy was to halve the gap in mortality rates of Indigenous children under 5 years of age, within a decade. Now in 2018, 10 years on, it’s now time to reflect on this ambitious target.

Child mortality and Closing the Gap

The death of any child is devastating to parents, families and the community.

Australia has made some progress in reducing Aboriginal and Torres Strait Islander child mortality, but more work needs to be done.

General studies measure how common child death is by calculating the child mortality rate, which is the number of children dying in a given time period. We then divide this number by the total population of children at that time. Mortality rates are reported as the number of deaths per every 100,000 children in a given time period.

We can compare the mortality rate of two populations (such as the Aboriginal and Torres Strait Islander population and the non-Indigenous population) using measures such as the ‘mortality rate difference’ and the ‘mortality rate ratio’. These measures look at how Aboriginal and Torres Strait Islander child mortality is changing *relative to* non-Indigenous child mortality. These are the key indicators used to measure progress against the 'Closing the Gap' 2018 target.

Ten years on: what have we achieved?

The amount of progress the country has made in reducing Aboriginal and Torres Strait Islander child mortality depends on how you look at the data.

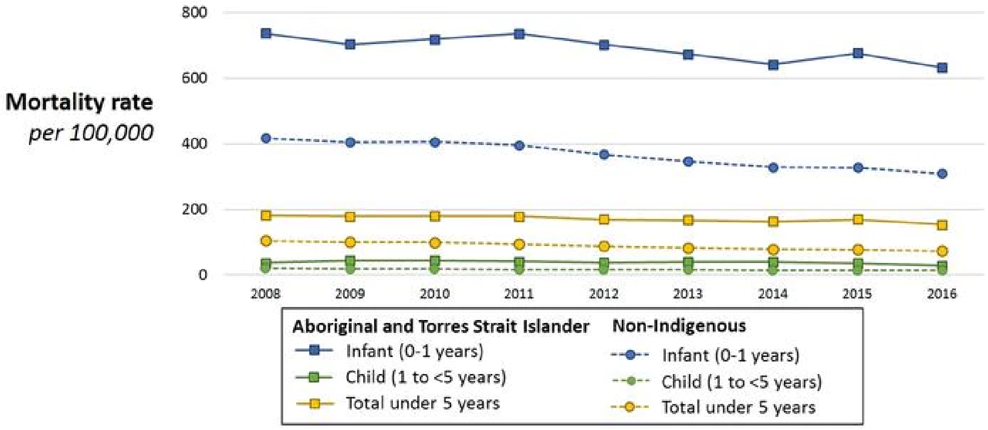
We compared data from 2008, when the Closing the Gap strategy was announced, to the most recent available data, from 2016. The mortality rate for Aboriginal and Torres Strait Islander children under 5 years decreased between 2008 and 2016, and so did the mortality rate for non-Indigenous children overall. However, even when the Aboriginal and Torres Strait Islander under 5mortality rate is decreasing, the ‘gap’ will increase if the non-Indigenous mortality rate is decreasing faster.

When we focus on the ‘gap’ alone, we can lose sight of progress that is occurring.

Aboriginal and Torres Strait Islander child deaths account for more than 10% of all child deaths in Australia, despite the fact that Aboriginal and Torres Strait Islander peoples only make up around 3% of the total population. In 2008, there were 125 deaths of Aboriginal and Torres Strait Islander children under 5 years and 935 deaths of non-Indigenous children under 5 years. In 2016 there were 113 deaths and 726 deaths, respectively.[1]

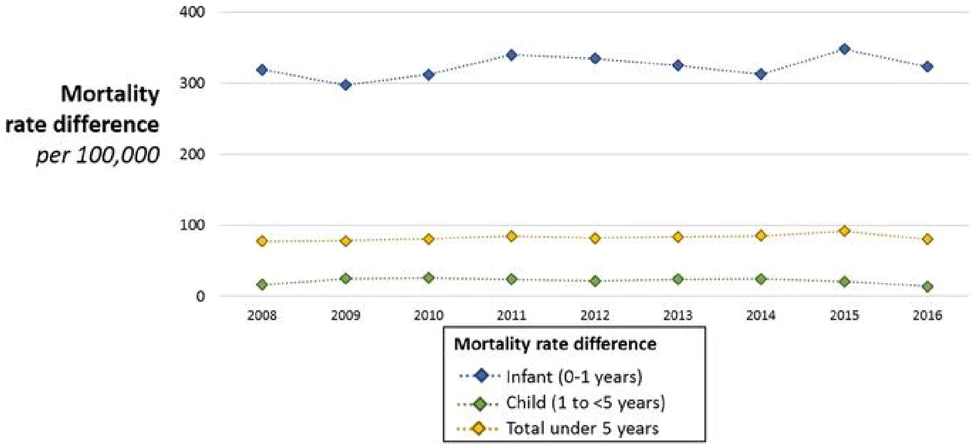
If we look at the Aboriginal and Torres Strait Islander data on its own, we see that the mortality rate for Aboriginal and Torres Strait Islander children under 5 years changed from 181.6 deaths per 100,000 in 2008 to 153.6 deaths per 100,000 in 2016 (Figure 1). This means the under 5 mortality rate was 28.0 deaths per 100,000 population lower in 2016 compared to 2008.

The non-Indigenous under 5 mortality rate was 104.4 deaths per 100,000 in 2008 and 73.2 deaths per 100,000 in 2016. This means the non-Indigenous under 5 mortality rate decreased by 31.2 deaths per 100,000 population lower in 2016 compared to 2008.

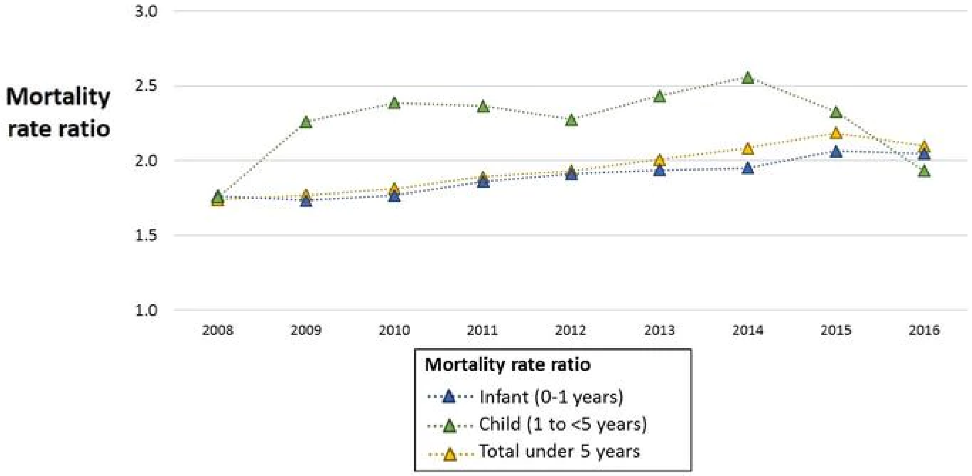


This means that the child mortality rate decreased for Aboriginal and Torres Strait Islander children and for non-Indigenous children. The decrease was similar for non-Indigenous children and Aboriginal and Torres Strait Islander children.

When we look at the absolute difference in mortality rates for Aboriginal and Torres Strait Islander children compared to non-Indigenous children under 5 years, we see that the mortality rate difference was 77.2 deaths per 100,000 in 2008 (181.6 *minus* 104.4) and 80.4 deaths per 100,000 (153.6 *minus* 73.2) in 2016 (Figure 2).



When we look at the mortality rate ratio for Aboriginal and Torres Strait Islander compared to non-Indigenous children under 5 years, we see that the mortality rate ratio was 1.7 in 2008 (181.6 *divided by* 104.4) and 2.1 in 2016 (153.6 *divided by* 73.2) (Figure 3).



When we focus on these measures of the 'gap' in child mortality, it looks like things are not improving. The 'gap' remains similar or, if anything, is getting wider – it is certainly not narrowing.

Why haven't we seen more progress in child mortality?

Our use of a single measure of under 5 child mortality makes it difficult to see progress where it is occurring.

Current Closing the Gap targets are based on mortality rates for those under 5 years of age which combines infants (0 to 1 year old) with children (1 to less than 5 years old). This is problematic because we see a different story for infant mortality compared to child mortality.

Most of the deaths that happen in the first years of life are infant deaths. For example, in 2016, 98 out of the 113 (87%) Aboriginal and Torres Strait Islander deaths under 5 years were infant deaths.[1] Aboriginal and Torres Strait Islander infant mortality rates have decreased substantially over the past decade (Figure 1), and this is what is largely driving the decrease we see in total under 5 mortality.[2] [3] However, when we combine infants and children together, we dilute the reduction in infant mortality rate, and we overstate the reduction in child mortality rate.

If we look at deaths in the first year of life only, we see that the Aboriginal and Torres Strait Islander infant mortality rate has decreased substantially, from 736.1 deaths per 100,000 in 2008 to 631.8 deaths per 100,000 in 2016 (decrease of 104.3 deaths per 100,000). There was a similar decrease in the non-Indigenous infant mortality rate during that time (416.9 to 308.7, decrease of 108.2 deaths per 100,000).

In contrast, we see a much absolute smaller reduction in child (aged 1 to 5 years) mortality rates during that time period. The Aboriginal and Torres Strait Islander child mortality rate dropped from 37.4 deaths per 100,000 in 2008 to 29.0 deaths per 100,000 in 2016 (decrease of 8.4 deaths per 100,000). The non-Indigenous child mortality rate dropped from 21.3 deaths per 100,000 to 15.0 deaths per 100,000 (decrease of 6.3 deaths per 100,000).

> By grouping all causes of death together, we lose sight of areas where progress is being made, and areas where more attention is needed.

In addition, current Closing the Gap targets are based on deaths due to all causes, but mortality rates and trends vary for different causes of death. By grouping all causes of death together, we lose sight of areas where progress is being made, and areas where more attention is needed. For example, the Aboriginal and Torres Strait Islander infant mortality rate due to sudden infant death syndrome (SIDS) dropped by half between 2002-06 and 2008-11. This drop in SIDS was responsible for a quarter of the total drop in the infant mortality rate for that time period.[3] We have seen less progress in other causes of infant deaths, such as respiratory diseases and injury/poisoning,[3] which may require additional policy and program focus.

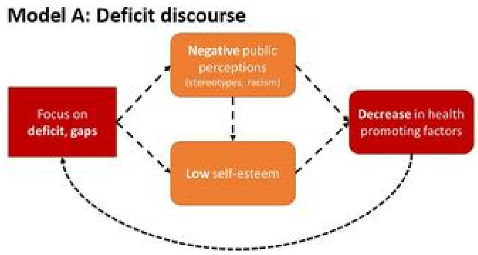
How we talk about Closing the Gap matters

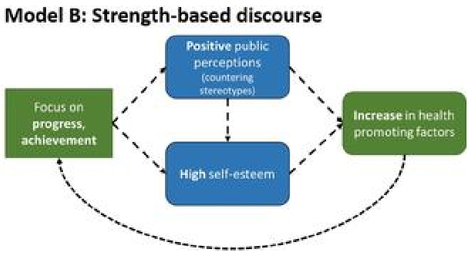
In addition to the issues described above, the Closing the Gap rhetoric is problematic because it focuses on Aboriginal and Torres Strait Islander health relative to non-Indigenous health. According to the current metrics, we can only 'close the gap' if Aboriginal and Torres Strait Islander health improves *more quickly* than non-Indigenous health improves. This is a fundamental flaw. While the 'gap' between Aboriginal and Torres Strait Islander and non-Indigenous health certainly has value as a benchmark, it should not be the only way we measure progress in improving Aboriginal and Torres Strait Islander health. We also need to track what is happening *within* the Aboriginal and Torres Strait Islander population.

> According to the current metrics, we can only 'close the gap' if Aboriginal and Torres Strait Islander health improves *more quickly* than non-Indigenous health improves. This is a fundamental flaw.

How we talk about Closing the Gap matters because focus on the persisting gap can have detrimental impacts on the wellbeing of Aboriginal and Torres Strait Islander peoples (Figure 4).[4] For example, negative reporting perpetuates negative stereotypes about Aboriginal and Torres Strait Islander peoples, and can fuel and galvanise discrimination and racism. It can also impact negatively on the self-esteem and the emotional health of Aboriginal and Torres Strait peoples, as they continue to hear negative stories about themselves, their families and communities. This can then influence health behaviours. For example, because of discrimination, Aboriginal people may avoid using health services, or they might not receive best-practice medical care when they do. It can also affect the public appetite for programs, particularly if the impression is given that no progress is being made. This can create a cycle, where the constant focus on gaps can actually make the gaps bigger – and perpetuate inequality.

This is why we also need to focus on improvements that are occurring *within* the Aboriginal and Torres Strait Islander population, as well as keeping an eye on the 'gap'. Examples of progress include large declines in smoking prevalence, cardiovascular mortality, and infant mortality. Such achievements should be accessible as a source of pride to communities, and communicating these improvements may feed additional improvement (Figure 4).





Are current Closing the Gap targets achievable?

There are no biological impediments to achieving equality in health outcomes for Aboriginal and Torres Strait Islander peoples.

To improve Aboriginal and Torres Strait Islander health and close the gap:

- We must stay the course, with enhanced and sustained investment over the long-term.
- We must set targets that are evidence-based. We need to maintain current measures but also include more sensitive measures that tell us about improvement *within* the Aboriginal and Torres Strait Islander population.
- We should track progress against intermediate indicators that can change over a shorter time frame, in addition to our primary indicators (such as mortality rates) which take a longer time to change.
- We need to use rigorous and transparent methods to measure change over time.

***Note:** The mortality rate difference is the absolute difference of the two mortality rates (Aboriginal and Torres Strait Islander child mortality rate minus non-Indigenous mortality rate). The mortality rate ratio is the ratio of Aboriginal and Torres Strait Islander mortality relative to non-Indigenous mortality rate (Aboriginal and Torres Strait Islander child mortality rate divided by non-Indigenous mortality rate).*

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1. Data from NSW, Qld, NT, WA, SA, NT Registries of Births, Deaths and Marriages (accessed via ABS.Stat 9 Feb 2018).
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Ray Lovett, Katherine Thurber [https://twitter.com/k_thurber] , Roxanne Jones and Emily Banks are part of the Aboriginal and Torres Strait Islander Health Program [https://rsph.anu.edu.au/research/projects/mayi-kuwayu-national-study-aboriginal-and-torres-strait-islander-wellbeing] at the National Centre for Epidemiology and Population Health, Australian National University, and conduct research on the social and cultural determinants of Aboriginal and Torres Strait Islander health and wellbeing. Their approach is to conduct research in partnership with Aboriginal and Torres Strait Islander individuals, communities, and organisations, and to frame our work using a strengths-based approach, where possible. Follow the program @Mayi_Kuwayu [https://twitter.com/Mayi_Kuwayu]

Appendix 6.14

ACSPRI course
Data analysis using Stata

ACSPRI
Australian Consortium for
Social & Political Research Inc.

CERTIFICATE OF COMPLETION

This certificate is awarded to

Roxanne Jones

For attendance of the short course on:

Data Analysis using Stata

which was run at the

ACSPRI Winter Program
26th – 30th June 2017
University of Queensland

Betsy Blunsdon

Signed by Betsy Blunsdon
for the Australian Consortium for Social and Political Research Inc. (ACSPRI)

Appendix 6.15

Professional Certificate in Indigenous Research

Student Number: 1026213 01 Feb 2019

Ms Roxanne Jones
31 port arthur st
lyons ACT 2606

THE UNIVERSITY OF
MELBOURNE

ACADEMIC TRANSCRIPT

Completion and Conferral Summary:

Professional Certificate in Indigenous Research
Completed 28 Nov 2018. Conferred 13 Dec 2018.

Professional Certificate in Indigenous Research

Year	Code	Title	Points	Mark	Grade
2018	MULT90022	Indigenous Research	25.00	077	H2A

Weighted Average Mark for this course 77.000

End Of Transcript

Neil Robinson
Academic Registrar

The University of Melbourne www.unimelb.edu.au

An Australian University established by an Act of the Victorian Parliament in 1853, the University of Melbourne is a public-spirited institution with excellence in research, learning, teaching and external engagement.

The University is registered with the Commonwealth Register of Institutions and Courses for Overseas Students (CRICOS number 00116K).

Course information, including subject descriptions and assessment requirements, are detailed in the handbooks available at http://handbook.unimelb.edu.au .

The University of Melbourne's current Grading Scheme

The information provided in the table below was correct as of 21 November 2016. Any changes will be published on the University's Grading Scheme website at http://grading-schemes.unimelb.edu.au/ .

Grade	Mark	Explanation
H1	80 – 100%	First Class Honours
H2A	75 – 79%	Second Class Honours Division A
H2B	70 – 74%	Second Class Honours Division B
H3	65 – 69%	Third Class Honours
P	50 – 64%	Pass
N	0 – 49%	Fail
NH	49%	Not completed/fail. Used when a student fails because they have not satisfactorily completed all prescribed (hurdle) requirements and would otherwise have passed the subject.
FL	-	Fail. Used for subjects marked on a pass/fail basis.
CMP	-	Completed. Only used for subjects marked on a pass/fail basis. CMP denotes that the subject was passed.
CNT	-	Continuing. Used for subjects that run over more than one teaching period where the subject has not been completed.
CTC	Refer to the explanation	Continuing – Completed, for subjects undertaken over multiple teaching periods. CTC denotes that a student has completed and passed the subject and is used for all teaching periods except the final one. On completion of the final teaching period an overall grade is recorded. A % mark is also recorded against each teaching period except for subjects marked on a pass/fail only basis.
CNF	Refer to the explanation	Continuing – Failed, for subjects undertaken over multiple teaching periods. CNF denotes that a student has been enrolled in and failed the subject and is used for all teaching periods except the final one. On completion of the final teaching period a fail grade is recorded. A % mark is also recorded against each teaching period except for subjects marked on a pass/fail only basis.
WD	-	Withdrawn from the subject after the date for making subject changes without penalty has passed.
NA	-	Not Assessed. Used for subjects that are non-assessable, such as Community Access Program audit studies.
GNS	-	Grade Not Submitted. Denotes that the assessment has not yet been finalised.
***	***	Denotes that a result is not applicable to the subject or that a result is unavailable.

Notes:

A. Successful completion of Honours courses usually requires a minimum grade of H3.

B. Previous University grading schemes can be accessed at http://grading-schemes.unimelb.edu.au/ .

C. Grading schemes for institutions that have now become part of the University (amalgamated institutions) for example: Melbourne Education (including Melbourne Teachers' College and Hawthorn Institute of Education), the Victorian College of the Arts, the Victorian College of Agriculture and Horticulture and The University of Melbourne TAFE can be accessed at http://grading-schemes.unimelb.edu.au/ .