Disproportionate Epidemiology:
Differential Impact of Disease and Flood on the Socio-Economically Marginalised

A thesis submitted for the degree of Master of Philosophy (Applied Epidemiology) of The Australian National University

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Statement of originality

This is to certify that the content of this thesis is my own work. I acknowledge that all projects were undertaken in collaboration with community, relevant organisations and colleagues and due recognition of their contributions have been made in each chapter.

Veronica Matthews

25 June 2021

Acronyms

ABS…………………….Australian Bureau of Statistics
ACON………………….. AIDS Council of New South Wales
APSGN…………………Acute post-streptococcal glomerulonephritis
ARF……………………. Acute rheumatic fever
CAG……………………. Community Advisory Group
CDNA………………….. Communicable Diseases Network Australia
CFA ……………………. Confirmatory factor analysis
CXR……………………..Chest radiography
FACS……………………Family and Community Service
GAS……………………. Group A streptococci
LGA…………………….Local Government Area
LGBTQ+……………….Lesbian, Gay, Bisexual, Trans Gender, Queer +
LHD……………………..Local Health District
LTBEx………………….London TB Extended Contact Tracing Team
LTBI……………………. Latent tuberculosis infection
MAE……………………Master of Philosophy in Applied Epidemiology
MDR-TB……………. Multi-drug resistant tuberculosis
MoU……………………Memorandum of University
NCEPH……………..…National Centre for Epidemiology and Public Health
NCIMS………………..Notifiable Conditions Information Management System
NHMRC……………….National Health and Medical Research Council
NPA……………………. Northern Peninsula Area, Queensland
NSW…………………… New South Wales
NT………………………Northern Territory
NTAC…………………. National Tuberculosis Advisory Committee
PCCM…………………..Primary Clinical Care Manual
PHC………………..……Primary Health Care
PHESS…………………..Public Health Event Surveillance System
PTSD……………..……Post-Traumatic Stress Disorder
QH……………………. Queensland Health
RHD……………………..Rheumatic heart disease
TB…………………….. Tuberculosis
TCHHS…………………Torres and Cape Hospital and Health Service
UCRH…………………..University Centre for Rural Health, The University of Sydney
WHO……………………World Health Organisation
XDR-TB………………..Extensively drug resistant tuberculosis

Acknowledgements

Thesis abstract

This thesis presents four projects completed to fulfil the core competencies of the Master of Philosophy in Applied Epidemiology (MAE). My 'field' placement was my place of employment – the University Centre for Rural Health (UCRH) in Lismore (Bundjalung Country). The UCRH builds rural health workforce capacity by providing education to medical, nursing and allied health students during rural practice placements in the Northern Rivers region of NSW. The UCRH also conducts research relevant to the health needs of rural communities. Strategic research priorities of the UCRH focus on rural population health, health equity and health systems and service research.

Data Analysis (*Belonging and inclusivity make a resilient future for all: a cross-sectional analysis of post-flood social capital in a diverse Australian rural community*): In partnership with Community Advisory Groups in the Northern Rivers region of New South Wales, I conducted a cross-sectional analysis to examine the association between the components of social capital (community participation and personal social cohesion) and psychological distress six months after the 2017 major flood event and how this association may have varied for marginalised groups relative to other participants. While marginalised groups reported lower levels of social capital compared to other groups, the analysis showed that informal social connectedness and feelings of belonging were important factors for all, associated with reduced risk of psychological distress post-flood.

Research Project (*Longitudinal cohort study of long term mental health outcomes after flooding in a rural community – less about the event, more about what has or hasn't happened since*): Following on from the data analysis project, I led the design and implementation of a two-year survey for participants who consented to follow-up with the primary aim of assessing long-term psychological outcomes following the 2017 major flood including the impact of secondary stressors (e.g., persistent damage, insurance disputes etc) and levels of social capital. We found that secondary stressors were more proximally associated with psychological morbidity after two years compared to the flood event itself. Informal social connectedness, belonging and optimism were again important predictors of reduced mental health harm over the 18-month study period. These findings are useful for mental health service planning needs for communities affected by flood over the longer-term.

Outbreak investigation (*Recurrent outbreaks of acute post-streptococcal glomerulonephritis (APSGN) in the Northern Peninsula Area (NPA), Queensland in 2019*): In partnership with Queensland Health and local NPA health staff, I assisted with an outbreak investigation of APSGN in the NPA, Queensland. APSGN results from the body's response to repeated

Streptococcus pyogenes (a group A streptococci - GAS bacteria) infection usually via skin or upper respiratory tract. My role involved designing and maintaining spreadsheet information to monitor population screening and treatment of skin and throat sores for all children (aged 1 to <17 years) in the NPA. As this was the second outbreak to occur within six months, the investigation highlighted the need for sustained health promotion programs to minimise the occurrence of skin conditions and in the long term, improved socio-economic, community infrastructure and housing conditions to reduce inequities in GAS infections (and APSGN) between Aboriginal and Torres Strait Islander and non-Indigenous populations.

Surveillance system evaluation (*Tuberculosis surveillance in New South Wales - developing data systems for effective contact investigations*): In partnership with NSW Health Protection, I facilitated the development of a generic contact investigation module for tuberculosis (TB) disease for the NSW Notifiable Conditions Information Management System (NCIMS). TB Coordinators across NSW were consulted to: evaluate the current contact investigation data system; assess gaps; and develop data specifications for a new NCIMS module that would meet their needs for effective contact tracing and reporting. While implementation of the new module did not occur within the MAE project timeframe, discussion initiated by this work contributed to development of a NCIMS contact tracing data system for COVID-19 in 2020.

Other MAE course requirements completed included: a teaching session on Aboriginal and Torres Strait Islander research ethics to my cohort colleagues; a group teaching session on strengthening mental health and wellbeing during the MAE for the 2019 cohort; a lay report on the flood research for LGBTQ+ community organisation, ACON; "Lesson From the Field" on strategies to manage sensitive topics in survey research; a report and presentations to health promotion and public health conferences on preliminary findings of my data analysis project investigating associations between social capital and mental health in community after a major flood event.

Contents

Chapter 1: Thesis Overview

Introduction and overview of field placement

I began my Masters of Applied Epidemiology (MAE) journey after many years in Aboriginal and Torres Strait Islander health systems research, where I developed a passion for story-telling through data. I was keen to advance my data/epidemiological skills through the MAE program and was lucky enough to be accepted with the support of my employer, the University Centre for Rural Health (University of Sydney) in Lismore, New South Wales, where I was based for the duration of the MAE. While location in a rural health academic institute presented some challenges with respect to fulfilling MAE competencies, it also presented great opportunities to highlight rural and remote health and associated equity issues. Hence the title of my thesis describes a common theme across my MAE projects: disproportionate impacts of disease and weather-related disasters on sectors of our community already doing it tough. A participatory approach is woven throughout my MAE studies reflecting principles of respectful and appropriate ways of accessing and using data in partnership with stakeholders and communities from which the data is sourced.

Summary of core course requirements and thesis guide

To fulfil MAE competencies, I was required to complete the following:

a) analyse a public health dataset such as surveillance data;

b) design and conduct an epidemiological study;

c) investigate an acute public health problem or threat (typically a disease outbreak); and

d) evaluate or establish a surveillance or other health information system.

While undertaking the above projects, I was also required to:

e) a literature review that demonstrates skills in conducting a targeted literature search and synthesis of the relevant information;

f) preparation of an advanced draft of a paper for publication in a national or international peer-reviewed journal;

g) a report on the project to a non-scientific audience such as the community or other stakeholder, as a press release, or in the form of a ministerial brief;

h) an abstract and oral presentation of the project at a national or international scientific conference; and

i) provide teaching sessions and learning epidemiology lessons from the field.

Table 1 provides a thesis guide to my projects and core course competencies.

Table 1: Summary and location of MAE projects and core competencies within this thesis.

Thesis Chapter	a) Data analysis	b) Research study	c) Investigate outbreak	d) Evaluate surveillance system	e) Review literature	f) Publish peer-review article	g) Report to lay audience	h) Present at conference	i) Teach
1. Introduction and overview									👍
2: A Cross-Sectional Analysis of Post-Flood Social Capital in a Diverse Australian Rural Community	👍				👍	👍	👍	👍	👍
3. Longitudinal cohort study of long term mental health after flooding in a rural community.		👍			👍				
4. Recurrent outbreaks of acute post-streptococcal glomerulonephritis (APSGN) in the NPA, Qld in 2019			👍		👍				
5. Tuberculosis surveillance in NSW: developing data systems for effective contact investigations				👍	👍				

Teaching and lessons from the field

During the MAE, I prepared and delivered a session to the 2018 cohort on ethics and values in Aboriginal and Torres Strait Islander health research, drawing on experiences of various projects to highlight best practices according to the national NHMRC guidelines (Appendix 1). It was a privilege to share this experience with my MAE colleagues and increase awareness of ethics and protocols when working with Aboriginal and Torres Strait Islander communities.

My "Lesson From the Field" arose through the Community Recovery after Flood project and I describe the issue in the preface to Chapter 2 under Lessons Learnt. It related to sensitive topics in survey research which, if not considered or planned for sufficiently, has the potential to impact engagement and response rates. The lesson itself is in Appendix 2 to this Chapter.

I participated in a combined teaching session with colleagues Brady McPherson and Dharshi Thangarajah to discuss with the 2019 cohort common psychological wellbeing issues during

MAE studies. It covered topics such as imposter syndrome, difficult working relationships and work-life balance etc. We offered some tools and resources to support students navigating heavy workloads and poor self-esteem (Appendix 3).

Summary of public health impact

Each of these MAE projects have described a need for system improvement within public health and its interactions with other sectors that impact on determinants of health and wellbeing. Targeted efforts also require close community engagement.

The Community Recovery after Flood findings (Chapter 2 and Chapter 3) have contributed to a sparse body of research on mental health impacts from river flooding and have improved understanding of the Northern NSW local context, an area prone to weather-related disasters. This project as highlighted the relationship between flood exposure and short- and long-term mental health outcomes for a broad cross-section of community, including socio-economically marginalised respondent groups. Outcomes indicate that to strengthen community mental health and wellbeing, a multi-sectoral and participatory approach is required in disaster planning and response. Improving community resiliency will require their direct involvement in the design of strategies that boost social connectedness and sense of belonging. While recommended strategies may not fall directly within mental health service delivery or the public health sector (e.g., financial support for damage repairs), if targeted appropriately to alleviate mental health stressors, the outcomes will benefit both community and the health system in the long run. Continual dialogue (lessons learnt, how can we improve next time) and regular community-wide needs assessments will ensure appropriate targeting of strategies in pre- and post-disaster contexts.

Aboriginal communities experience disproportionately high rates of acute post-streptococcal glomerulonephritis (APSGN) and tuberculosis (TB) compared to Australian born non-Indigenous people. Primordial prevention of these diseases requires attention to social and economic determinants of health such as improved housing and sanitation facilities and increased access to quality education, employment and health services. Repeated outbreaks of APSGN in Northern Peninsula Area Aboriginal and Torres Strait Islander communities in 2019 highlighted these inequitable issues faced by Australian First Nations communities. The response by local community facilitated by local health staff was inspirational to achieve over 90% of all children in the region screened and almost 100% skin and throat sores treated. The repeated outbreaks highlighted the need for regular skin health programs and attention to improvements in environmental health and housing infrastructure.

Evaluating the NSW surveillance system for TB highlighted inefficient data management processes for TB contact tracing across the state, making difficult communication and reporting processes across Local Health District boundaries. Specifications for a new contact tracing module were developed in partnership with NSW TB coordinators for implementation into the Notifiable Conditions Information Management System. These discussions also fed into development of a contact tracing module for COVID-19, highlighting the value of efficient data systems for effective contact investigations. While the TB module was unable to be tested in the timeframe of my MAE, from a desktop analysis, the new surveillance infrastructure will improve the simplicity, timeliness, usefulness and acceptability of the system for users and improve data quality and completeness.

Appendices

Appendix 1: Teaching session on values and ethics in Aboriginal and Torres Strait Islander health research

Six core values

https://nhmrc.gov.au/about-us/publications/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities
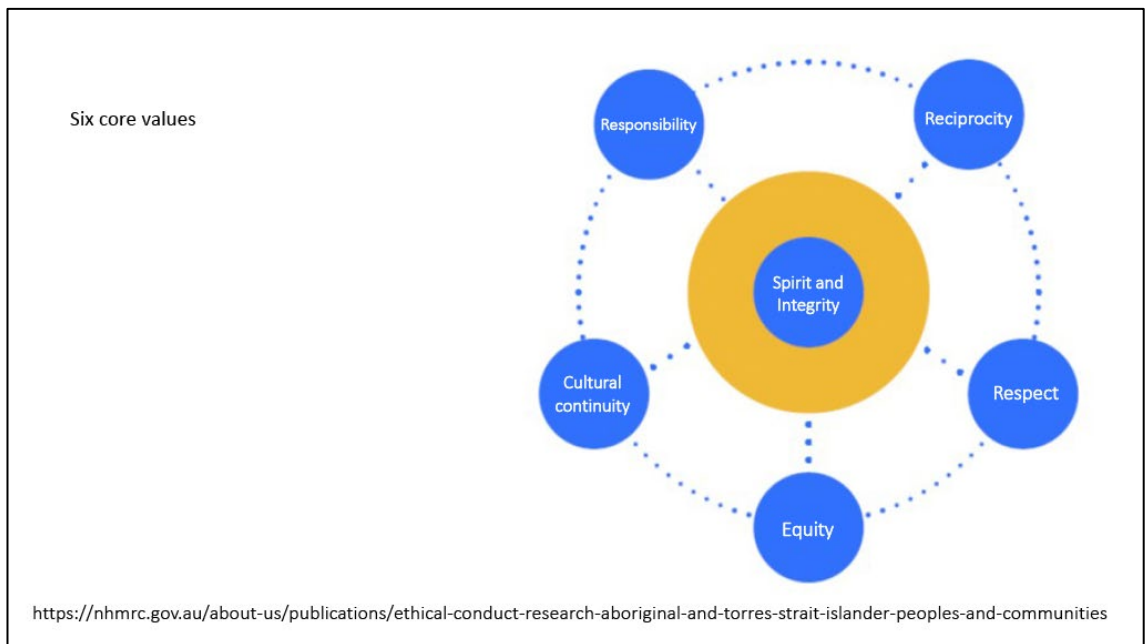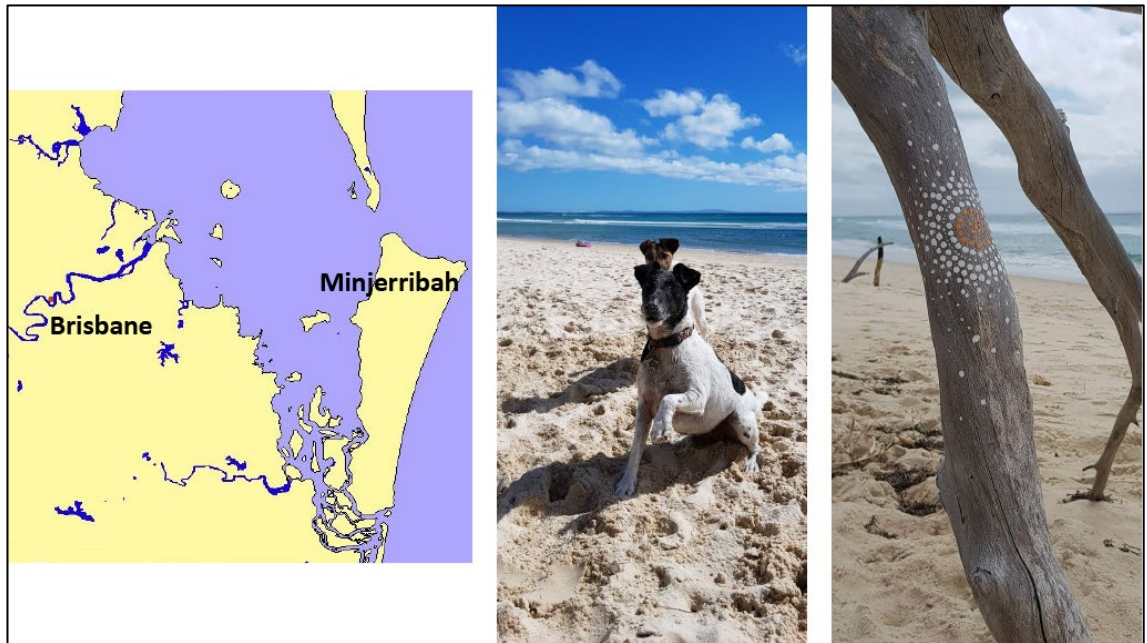
Aremella Arratyenye-lleme

DOING IT RIGHT

'both ways' knowledge exchange, generation & translation

Improve community's understanding of research and researchers understanding of community

the Lowitja Institute | Australia's National Institute for Aboriginal and Torres Strait Islander Health Research

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Aremella Arratyenye-lleme

DOING IT RIGHT

Knowledge translation concept mapping

"*making big words into little words, so community and researchers can talk to each other*" – Glen Sharpe, Researcher, Interpreter

Aremella Arratyenye-lleme

DOING IT RIGHT

Knowledge translation concept mapping

- Sharing knowledge
- Two-way
- Working together

Aremella Arratyenye-lleme

DOING IT RIGHT

Knowledge translation concept mapping

- Culture, law, environment
- Trust
- Honesty
- Understanding

Aremella Arratyenye-lleme
DOING IT RIGHT

Knowledge translation concept mapping

Equity
- Everyone gets what they need to access opportunities
- Fairness, justice, rights
- Equal distribution of benefits
- Equal value Aboriginal/Western systems

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Aremella Arratyenye-lleme
DOING IT RIGHT

Knowledge translation concept mapping

Cultural continuity
- Strengthen & grow culture
- No cultural damage
- Unique culture, language & identity across communities
- Be aware of sensitive issues
- Be aware of history & its consequences

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Aremella Arratyenye-Ileme

DOING IT RIGHT

Knowledge translation concept mapping

- Acting in good way
- Letting people know what's happening
- Share knowledge
- Caring for people & country
- Social & family protocols

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Aremella Arratyenye-Ileme

DOING IT RIGHT

Knowledge translation concept mapping

- Relationship building
- Adequate time/planning
- Learning & listening
- Be prepared to be flexible
- Local community part of research team

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Slide 1

Aremella Arratyenye-Ileme

DOING IT RIGHT

"If research is about Aboriginal people, then Aboriginal people must be included, from the beginning through the whole process, and acknowledged and recognised." Roxanne Highfold, Central Arrernte

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Slide 2

COMMUNITY INFORMATION SESSION

PERSISTENT ORGANIC POLLUTANTS IN SEAFOOD

- research project conducted by the National Research Centre for Environmental Toxicology
- investigating contaminant levels in seafood and what this means for community in terms of its consumption
- inform community on initial results and seek input and assistance with project

When: 10am – 12pm Sunday 28 May 2006
Where: Moreton Bay Research Centre
Cnr Flinders Ave & Fraser Street
Dunwich

morning tea & lunch provided all welcome

- health risk assessment
- minimal input
- survey tool trialled with local land council
- local Aboriginal people employed for doorknock
- concerns from Elders impact on traditional seafood
- poor attendance info sessions

Report card – keeping research on track

Build relationships	
Develop ideas	
Develop project & approval	✓
Data collection	✓
Data analysis	✓
Translating results	

- insufficient community engagement in project development
- limited opportunity for 2-way learning
- need multiple methods of communication
- no funding for research translation products
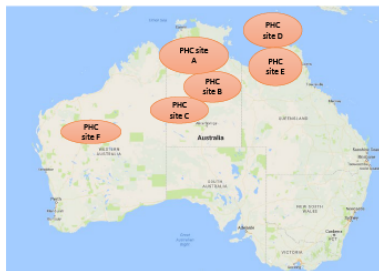
AIM:

Identify "high-improving" services

Understand the "secrets" to their success to share with others

- development of data collection tools; project governance; "learning community" formation
- early on site visits to discuss participation – combination of senior academic leadership and Indigenous representation

3 year funded NHMRC project

Report card – keeping research on track

Build relationships	✓	
Develop ideas		
Develop project & approval	✓	
Data collection	✓	
Data analysis	✓	
Translating results	✓	

- building relationships based on two-way learning
- formal Aboriginal leadership

An "All Teach, All Learn" Approach to Research Capacity Strengthening in Indigenous Primary Health Care Continuous Quality Improvement

Karen McPhail-Bell[1,2*], Veronica Matthews[2], Roxanne Bainbridge[3], Michelle Louise Redman-MacLaren[3,4], Deborah Askew[5,6], Shanthi Ramanathan[7], Jodie Bailie[2] and Ross Bailie[2] On Behalf of the Centre RCS Lead Group

- health services presenting own results, data sovereignty
- utilising learnings in project to help 'striving' services

Leveraging
Effective
Ambulatory
Practice

AIM:

Identify "striving" services through self-nomination

Understand context, assist with 'toolbox' of interventions
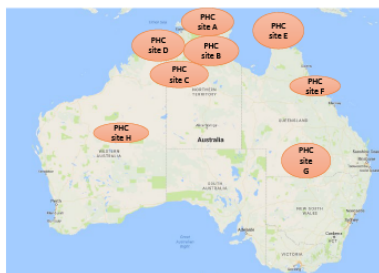
- prior reputation
- development of data collection tools; project governance; "learning community" formation
- two-way learning
- Indigenous and non-Indigenous co-leadership

3 year funded NHMRC project

Central Land Council

PERMIT TO ENTER AND REMAIN ON ABORIGINAL LAND

COMMONWEALTH OF AUSTRALIA   *Aboriginal Land Rights (Northern Territory) Act 1976*
NORTHERN TERRITORY OF AUSTRALIA   *Aboriginal Land Act (1980)*

The person(s) whose name(s) are set out below are authorised to enter onto Aboriginal Land according to the details set out below and subject to the general and special conditions set out below or attached to this Permit.
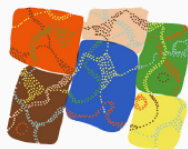
Health from the Grass Roots:
Aboriginal health priorities project
Northern Rivers, NSW

*From the community,
with the community*

AIM: work together with local Aboriginal community to identify health priorities, then work with community & health organisations to develop research projects to address priorities

APPROACH:
- Indigenous led, community driven, employment of local community peer workers
- based on community priorities, not researcher priorities
- two-way learning and capacity building

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Road Map 3: A strategic framework for improving Aboriginal and Torres Strait Islander health through research
Report of Community Consultations

What does success look like?

- improved health outcomes
- increased collaboration & partnership models
- larger number of Indigenous researchers
- great integration of Indigenous knowledge & ways of working through all stages of research

Appendix 2: Sensitive topics in survey research

Lessons from the Field - Sensitive topics in survey research

Research is considered sensitive *'if it requires disclosure of behaviours or attitudes which would normally be kept private and personal, which might result in offence or lead to social censure or disapproval, and/or which might cause the respondent discomfort to express'* (Wellings et al. 2000).

Sensitive research addresses some of society's most pressing social issues and policy questions. Although ignoring the ethical issues in sensitive research is not a responsible approach to science, shying away from controversial topics, simply because they are controversial, is also an avoidance of responsibility. (Seiber et al. 1988)

The LFF teleconference will be conducted on Friday 6th December 2019 between 14:00 – 15:00 AEDST. The zoom link for the teleconference is: https://uni-sydney.zoom.us/j/224309566
Alternative dial: +61 2 8015 6011 or +61 8 7150 1149 (Meeting ID: 224 309 566). If you have any trouble please call me on 0423 826 160.

Learning objectives
By the end of this LFF participants should be able to:
- Understand the need for ethically and culturally sensitive research in public health
- Understand implications of researching sensitive topic areas in survey methodology and other aspects of research design
- Apply strategies to minimise the risk of harm and bias when researching sensitive topics

Resources
1. Liamputtong, P. (2007). The Sensitive Researcher: Introduction to Researching Vulnerable People. In: Researching the Vulnerable. London, SAGE Publications Inc.
2. Tourangeau R. Sensitive topics. In: Lavrakas P, editor. Encyclopedia of Survey Research. Thousand Oaks: SAGE Publications, Inc. (2008).
3. Lensvelt-Mulders G. Surveying sensitive topics. In: de Leeuw E, Hox J, Dillman D, editors. International Handbook of Survey Methodology. 1st ed. New York: Routledge (2008).
4. Northern Rivers Community Recovery after Flood – six months survey

Background – researching the marginalised in the context of climate change

Sub-population groups in our society that are 'impoverished, disenfranchised, and/or subject to discrimination, intolerance, subordination and stigma' have an increased 'relative risk or susceptibility to adverse health outcomes' (Liamputtong 2007). Addressing these disparities requires research that is ethically and culturally sensitive. Marginalised population groups, such as Aboriginal and Torres Strait Islander communities, have been exposed to research that has negated their own culture and identity, resulting in further disenfranchisement. Principles of safe and ethical research include notions of reciprocity, partnership, participation, protection, and equity that benefits both researchers and community groups (NHMRC 2018).

Northern Rivers Community Recovery after Flood

Risk of climate change impacts are known to exacerbate existing inequalities in all countries (regardless of their level of development) (Lowe et al. 2013, IPCC 2014). The north coast region of New South Wales (NSW) is a 'hotspot' for natural disaster declarations with recent extensive flooding, extended drought and extreme bushfire conditions (Sewell T et al. 2016). Following a severe flood in early 2017, a community-academic partnership was established in the north coast region to describe (via community survey six months after the flood) the: relationship between flood exposure and mental health outcomes; influence of mediating factors (e.g., socio-demographic factors, pre-flood mitigation systems, and disaster relief responses); and how it varies across population groups including socio-economic marginalised populations (the poor, Aboriginal and Torres Strait Islander community, LGBTQ+ community). Community Advisory Groups (CAGs - comprised of local government and state agencies, business representatives and community organisations, including advocacy organisations representing marginalised groups) were formed to help design and implement the survey, which was available online and in paper format (attached). Advice from the CAGs was instrumental as the survey included a number of sensitive topic areas.

TASKS

For the following tasks, you are the epidemiologist on the team, overseeing data collection and analysis. You read up on sensitive research with vulnerable populations … see attached book chapter 'The Sensitive Researcher' pages 1-7, by Liamputtong (2007); encyclopedia entry on 'Sensitive Topics' by Tourangeau (2008) and book chapter on 'Surveying Sensitive Topics' (pages 461-470) by Lensvelt-Mulders (2008).

Question 1

During your MAE (or prior experience) have you worked on projects involving marginalised population groups? If so, describe what the project was, why the groups were considered vulnerable and what steps may have been taken to ensure ethically and culturally safe research.

Question 2

According to Tourangeau, what are three categories of sensitive issues that may be found in surveys? Provide examples of topics that may fall within each.

The three categories are
1. Intrusive questions - inappropriate in everyday conversations, e.g., sexual behaviours; religious affiliations; views on political topics; income level; medical history etc.
2. Threat of disclosure - concerned about the possible consequences of giving a truthful answer should the information become known to a third party, e.g., illegal activities such as illicit drug use; teenagers asking questions about smoking etc
3. Social undesirability (a specific form of threat of disclosure)– admitting violation of a social norm, e.g., health behaviours, frequency of drinking alcohol, doing exercise, number of sexual partners; abortion etc.

Question 3

a) Describe three methodological difficulties that may arise when conducting sensitive research? b) What are possible strategies to overcome each?

1. Sampling – marginalised populations groups are often 'hidden' and 'difficult-to-reach' via conventional sampling methods as they do not constitute a large proportion of the overall population, or are widely dispersed in that population. As a result, identifying a sampling frame becomes difficult and probability sampling is unlikely to obtain sufficient numbers of the population group of interest.
   Strategies: Pre-screening step to identify potential respondents belonging to key interest groups. Conduct random sample from pre-screen list. Snowball (non-probabilistic) samples potentially more effective to locate hidden or hard-to-reach population groups, however this will limit generalisability of findings and the ability to make inferences from analysis.
2. Increased non-response rates – due to sensitive nature of questions, respondents may avoid answering by not completing the item (item non-response) or by refusing to participate all together (unit non-response). This type of non-response will rarely be random and will cause biases, leading to underestimation of the sensitive variable.
   Strategies: Response rates can be increased by making topic salient to participants - why is your study important and useful. Other important information to include in introductory material includes: what will be done with results; who is conducting the survey (provides survey authority); privacy statement; amount of time it will take to complete; and contact numbers for more information. Use of incentives such as small gifts as a token of appreciation for their participation before completion of the survey. Consider ordering of questions within a survey – start and end with easier, less threatening questions.
3. Misreporting – participants may deliberately provide inaccurate, more socially acceptable responses in order to present a positive image. This type of bias may lead to both underreporting or over-reporting of an issue (e.g., many respondents may underestimate alcohol consumption due to social norms, but for younger age groups, excessive drinking questions may encourage boasting).
   Strategies: Use 'forgiving wording' as per example in reading about providing a more permissive frame of reference when leading into a question about voting/not voting (Tourangeau 2008).

Question 4

a) In the 'Community Recovery after Flood' survey, what may be some of the sensitive topics or triggering points that could cause harm/distress? b) Highlight some of the strategies utilised within the survey that may minimise non-response bias and risk of harm to participants. c) Do you have any other advice on ways to improve the design of the survey to minimise non-response and bias?

1. a) Whole survey is centred on a traumatic event and associated mental health impact which is deeply personal and mental health is often a topic which many do not like to discuss openly.
   b) Strategies: We did not use the term 'mental health' within the survey due to the stigma associated with it. Instead, we used 'health and wellbeing' in the introductory text as the main focus of the survey. The very first question is a free-text opportunity to allow respondents to discuss upfront what was on their mind. Any distress caused by completing the questionnaire was acknowledged and apologised for in the introductory material, and contact information for counselling and support services featured prominently throughout.
   c) Shorter survey would likely improve response rates.
2. a) There are difficult questions about being aware of suicide in community and personal suicidal ideation (Qus 22 & 23).
   b) Strategies: Contact information for counselling and support services was provided directly after.

c) We could have broken up the section on health a bit so more difficult items (like suicidal ideation) are placed before or after less difficult items.
3. a) There are many demographic questions (19 questions in total). Having so many can be viewed as a violation of privacy.
b) Strategies: We placed the demographic questions at the end of Part 1 to the survey. When particularly sensitive demographic questions are placed at the beginning of a survey, participants may choose not to answer them or any of the other survey questions. If these questions are placed at the end of the survey, participants may be more likely to answer them because they have already invested their time in completing the survey. However, even if they choose not to answer the demographic questions, they will still likely submit their incomplete survey. Further, in long surveys, asking demographic questions at the end of the survey is better because fatigued participants who are anxious to finish the survey may find it easier to answer simple demographic questions about themselves.
c) Include introductory section to demographics to explain reasons for collection. Revise number of demographic questions asked (Dobosh 2017).

General strategies to increase response rates: Working with CAG that included advocacy groups who know their constituents and how best to work with them. The survey was pitched as a call to action – emphasising respondent's cooperation will support ongoing community recovery and responses to future disasters. Confidentiality of the survey increased through self-administration and we also emphasised confidentiality in the introductory section. We ordered questions in Part 1 of the survey to start out with straight-forward factual questions about flood damage, leading into the questions about impact on mental health and then finished with easier questions about demographics. We made Part 2 optional to lessen burden on respondents. Use of prize draw as an incentive to participate, with more chances to win if both parts were completed.

Here are the non-response rates for particular items in the survey, which can provide an indication of the sensitivity of research questions:

Survey Qu Number	Item	% Non-response (N = 2,530 responses)
Q31	LGBTQ+	18.0
Q42	Household income level	9.2 + 13.2 'prefer not to say'
Q21	Any PTSD items	9.2
Q20 c) & d)	Any anxiety items	8.9
Q20 a) & b)	Any depression items	8.5
Q35	Employment status	7.2
Q34	Education level	7.1
Q40	Receipt of income support	8.3
Q29	Indigenous status	7.0
Q30	Gender	7.0
Q26	Age	7.1
Q22	Suicide in community	5.6
Q23	Suicidal ideation	6.1
Q19	General health status	4.3
Q3	Flooding in suburb	0.2

Consistent with other research, household income had a high non-response rate in comparison with other items, particularly after taking into account respondents who selected 'prefer not to say'. Several items contributed to assessments of probable post-traumatic stress (PTSD), probable anxiety and depression. Non-response for these items ranged between 8.5 to 9.2%. Most socio-demographic questions had similar non-response rates, apart from the sexual identity question. There was higher non-response to socio-demographic items compared to suicide and general health questions. The relatively high rate of non-response to sexual identity surfaced as an issue during the survey period.

Scenario issue

The Community Recovery After Flood Survey was open for a period of six to seven weeks in Sept-Oct 2019 (coinciding with the marriage equality plebiscite). Approximately half-way through the data collection period, you start receiving reports from your fieldworkers that community members are refusing to complete the survey and ripping up surveys when they reach the demographic section. It appears the question on sexuality is causing heightened emotion and anxiety within community and has also resulted in abuse towards your field workers. The project team are concerned that this may substantially impact response numbers. They turn to you for advice.

Question 5

Based on what you have learnt about sensitive research, would you advise in this circumstance? What would be the implications of these regarding non-response rates?

Option 1 – modify introduction to the demographics section of online survey to explain why we are collecting the information. (Note: the paper survey has been disseminated and can't be changed.)

Including more explanation as to why the project is collecting the demographic information could improve unit and item response rates.

Option 2 – create another online survey that has the sexual identity question removed for promotion through general networks and retain the original version for promotion through LGBTQ+ networks.

While creation of an alternative survey may increase unit response rates, it would reduce overall sample number for LGBTQ+ community due to missing information where respondents are not provided an opportunity to identify. Not all LGBTQ+ community members maybe connected in to local networks, hence may not receive the survey with the sexual identity question. This will impact on the use of these records in analysis.

Option 3 - train fieldworkers about why sexual identity question was included and provide appropriate responses if questions raised about its inclusion.

Similar to Option 1, provision of more explanation to potential respondents about reason for inclusion may improve unit and item response rates.

Option 4 – retain online survey as is.

Likely to continue to have same level of non-response bias across survey period.

Other points:

Selective non-response may be associated with general characteristics of the study population (i.e., previous research showing women, higher educated people more likely to respond to a survey) or directly linked to actual outcome variables of interest – more likely the case for sensitive topics (e.g., patients with poorer health may be less likely to complete quality-of-life questionnaires). This indicates that people who are less likely to respond would be more likely to report health risks, leading to under-estimation of risk behaviours(Cheung et al. 2017).

One would also expect bias when investigating associations between variables, particularly when there are moderating effects of demographic characteristics. While underestimation of prevalence estimates has been consistent across studies comparing the effect of non-response bias in health survey results, the same studies have shown no essential difference in strengths of associations between variables for total population samples compared to samples subject to non-response (Van Loon et al. 2003, Maclennan et al. 2012, Cheung et al. 2017). This implies that within-subject analyses are insensitive to non-response bias, perhaps suggesting that the underlying mechanism between exposure and health outcome does not differ in a systematic way for non-respondents versus respondents.

What we did: It is very difficult to quantify non-response bias without information on non-respondents. We ran a sensitivity analysis comparing impact of flood exposure on mental health for all data (including records with missing socio-demographic data) and the dataset with complete records only. This showed that there was minimal difference in parameter estimates and no differences in patterns of results between the full dataset and the dataset with missing socio-demographic records removed. Therefore, we proceeded with complete case analysis, removing records with missing socio-demographic data. Where data was missing from outcome variables (PTSD, anxiety, depression), these were removed from those analyses only.

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Milli Vanilli video
(true imposters)

Wellbeing during the MAE

Veronica
Brady
Dharshi

Objectives

1. Be aware of and recognise common challenges faced during the MAE that can negatively affect psychological wellbeing.

2. Be provided with a list of resources and evidence-based strategies to help overcome negative feelings and maintain good psychological wellbeing.

Session outline

- Common MAE challenges
- Small group discussion
- Brainstorm
- Summary of challenges and strategies
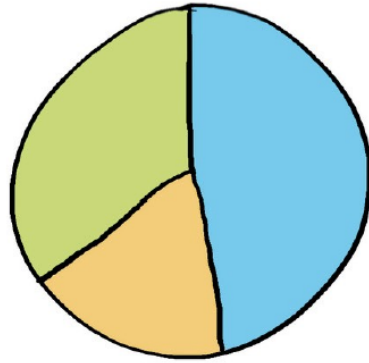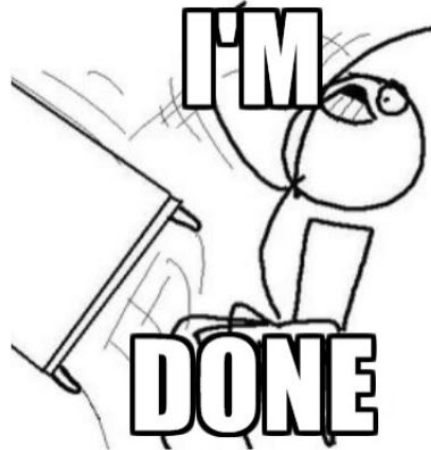
Small group discussion

Spend 10 minutes discussing:

1. Any challenges you've experienced relating to work, study, or other similar situations, and
2. Any strategies you found helpful.

Common challenges

- Imposter syndrome
- Navigating difficult supervisor and/or workplace relationships
- Feeling overwhelmed or stressed
- Work-life balance
- MAE projects vs. workplace activities
- Feeling isolated
- Moving - separation/family
- Losing motivation
- Procrastinating writing
- Managing supervisors

Some strategies and resources

- Each other! E.g. Whatsapp or Facebook groups
- Talk to supervisors or other MAE staff
- ANU Counselling Centre
- Workplace advisors
- MAE Alumni
- Take time off
- Design your day (and sticking to it) (https://www.amanthaimber.com/blog/dr-amantha-imber-on-deliberately-designing-your-work-day)
- Recognise when you need to say 'no'
- Recognise negative thoughts as just thoughts!
- Self-care
- Don't suffer in silence!

Mindfulness

https://www.youtube.com/watch?v=SEfs5TJZ6Nk

Chapter 2: Belonging and Inclusivity Make a Resilient Future for All: A Cross-Sectional Analysis of Post-Flood Social Capital in a Diverse Australian Rural Community

Preface

I joined the University Centre for Rural Health (UCRH) a couple of days after the major 2017 flood in Lismore. It was a devastating event for the Northern Rivers community, with loss of life and hundreds of residential and commercial premises flooded. Concerned about mental health impacts within community after the flooding event, the UCRH research team initiated a partnership with local community and government agencies to co-design a study documenting flood experience and mental health and wellbeing impacts of diverse sectors (spanning different age groups, the Aboriginal and Torres Strait Islander community, business owners, people on low income, farmers, LGBTQ+ community etc) and across severity of exposure (unaffected, indirectly impacted, directly flooded). With minimal resourcing, we were constrained in our ability to define and utilise a sampling frame to undertake a random sample of the Northern Rivers population through conventional survey techniques such as random digit dialling and household mailouts. Instead, utilising the networks generated through the study's community partnership, we employed a purposive snowball sampling approach to reach the groups we had set out to recruit, some of which are difficult to reach through traditional random sampling methods. Our pragmatic approach however, limits our capacity to generalise findings to other settings. The 'Community Recovery after Flood' study had a local focus, aiming to quantify relationships between flood impact and psychological morbidity and to provide valuable insights to inform local disaster preparedness and response planning, increasing the resilience of community for future flooding events that are more likely to occur due to a warming climate.

I led the coordination of the Community Recovery after Flood study working with the 'flood team' through planning, implementation, analysis and dissemination. We received expert

input from Prof Virginia Murray, a consultant in Global Disaster Risk Reduction for Public Health England, Prof Tony Capon and Prof Helen Berry, from the Institute of Planetary Health at the University of Sydney. We held monthly Community Advisory Group meetings immediately after the flood and co-designed a conceptual model (*Flood Impact Framework*, Figure 1) based on prior empirical evidence and community experience. The Framework guided the development of a 58-item questionnaire, comprising validated instruments where available and bespoke measures to capture concepts within the Framework. We piloted and refined the survey with 30 volunteer community members representing our diverse target groups. Ethical clearance was obtained from the University of Sydney Human Research Ethics Committee (reference-2017/589), the Aboriginal Health and Medical Research Council Human Research Ethics Committee (reference-1294/17) and (subsequently) the Australian National University Human Research Ethics Committee (reference-2019/186).

We were able to complete the planning, design and ethics approvals within four to five months and disseminated the questionnaire via online and paper formats at six-months after the flood (around September/October 2017). We recruited staff with media experience and public engagement experience that were well-known within community to assist with survey distribution. We conducted an extensive local media (print, broadcast, and social media) and advertising campaign that included posters and paper surveys (with reply-paid postage) left in central community locations such as post offices, libraries, coffee shops and store fronts of charitable organizations such as Lifeline, St Vincent de Paul and the Salvation Army. Project staff promoted the survey at various community events including farmers' markets, and through the local postal service, we deposited postcards in residential mailboxes with information on accessing the survey. At the end of the recruitment period, we conducted a door-to-door survey in randomly selected neighbourhood blocks of Lismore and Murwillumbah to assess response bias, participation rates, and effectiveness of recruitment strategies. Choice of neighbourhood block was based on ABS 2016 census mesh blocks (around 100 dwellings per block), stratified by land use pattern (residential, primary production or commercial) and exposure classification (from local council maps indicating that the land was

flooded or not flooded). An estimated 1,494 individuals resided in the door-knock area, 70% of which were in flooded mesh-block areas (weighted such that they had twice the probability of selection). Data were collected from 713 individuals in 399 residences, 48% of the estimated residential population. From this sub-study we ascertained that our recruitment advertising strategy raised awareness in approximately 50% of residents within the door-knock areas (equally across both flooded and non-flooded blocks) and approximately 5% had already completed the survey (again, equally across both flooded and non-flooded blocks). The majority of those who had completed the survey were women (69%). Individuals who had not completed the questionnaire were asked if they were willing to do it. A total of 110 declined (17%), the majority of whom (62%) did not live in the flooded areas, and 537 agreed. More information on the sampling methodology and outcome is provided below and in our published study protocol (Longman et al 2019).
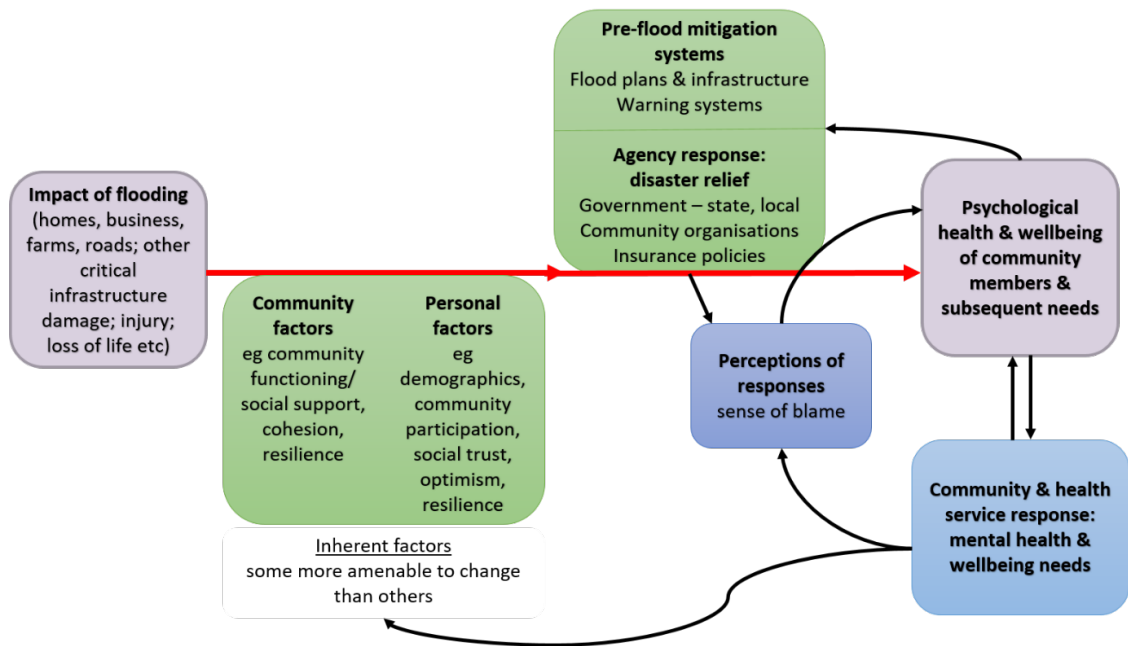
Figure 1: Flood Impact Framework

In this data analysis chapter, I present my confirmatory factor analysis (CFA) and hierarchical logistical regression analysis that investigates the associations between components of social capital (community participation and personal social cohesion) and psychological distress six-

months after the flood and how these associations may vary for marginalised groups relative to other participants.

Lessons Learnt

This rapidly evolving, logistically complex project presented many challenges – the primary one being the design of the sampling strategy within the context of minimal resourcing. Our choice of method was not intended to obtain representation of the broader Northern NSW population, but rather to obtain respondents in each category of interest to enable comparison of experience among the key interest groups. The more conventional probabilistic sampling techniques can present their own challenges, with studies reporting low response rates, selection bias, difficulty identifying appropriate sampling frames and delays in capturing post-event data. They also recognize their inability to adequately capture the experiences of marginalised or displaced populations. Our pragmatic, purposive sampling approach was able to overcome some of these limitations, enabling us to measure disaster experiences within diverse and hard-to-reach sub-population groups.

We canvassed a broad range of sensitive topics within the Community Recovery after Flood survey, which meant undertaking some forward planning to mitigate the potential for participant harm. The whole survey is centred on a traumatic event and associated mental health impact which is deeply personal and mental health is often a topic which many do not like to discuss openly. We did not use the term 'mental health' within the survey due to the stigma associated with it. Instead, we used 'health and wellbeing' in the introductory text as the main focus of the survey. The very first question is a free-text opportunity to allow respondents to discuss upfront what was on their mind. Any distress caused by completing the questionnaire was acknowledged and apologised for in the introductory material and contact information for counselling and support services featured prominently throughout. We recruited field-workers with a background in counselling and social work to ensure they were equipped with the skills to support participants as required.

While we thought the mental health questions (including suicidal ideation) may be the most triggering, it was in fact a tick box demographic question in the survey that had the highest

individual item non-response rate. "Do you consider yourself to be: lesbian, gay or homosexual; straight or heterosexual; bisexual; queer; transgender?" (question wording recommended by the national LGBTQ+ advocacy organisation, ACON). The six-month survey coincided with the marriage equality plebiscite and we started to receive reports from fieldworkers that community members were sometimes verbally abusing them and refusing to complete the survey when they reached this question. Concerned about the impact on response numbers and bias, we took the question out from the online version of the survey but retained it in a version that was circulated through ACON networks. In retrospect, I regret this decision as we effectively silenced the LGBTQ+ community, perpetuating their marginalisation for the sake of a few intolerant, ignorant people and an unknown level of response bias. Due to the amount of missing data from removing the question, we were subsequently unable to conduct sub-analysis on this group as part of this paper. We will analyse the data from LGBTQ+ respondents separately in a forthcoming paper.

Lastly, in terms of the data analysis, the CFA took some stamina and persistence (it took me over a year). As highlighted in this chapter, we used previously validated measures of community participation and personal social cohesion. CFA examines how well these fitted with our survey data. It took some time for a novice to understand how CFA works and then being able to conduct it with accessible software. I used two software packages for different aspects, Stata with its ability to estimate polychoric correlation matrices (handles both binary and continuous indicators) and AMOS to generate factor score weights unavailable in Stata.

Public Health Implications

Our Community Recovery after Flood findings have improved understanding of the local context by highlighting the relationship between severity of flood exposure and mental health outcomes, including for respondents most in need, such as Aboriginal and financially disadvantaged respondents. These respondent groups reported lower levels of social capital compared to general community participants. Despite this, informal social connectedness and belonging were important factors for all participant groups and were associated with reduced risk of ongoing distress and probable PTSD six months post-flood. Through participatory

processes with specific groups, these findings can inform tailoring of safe and effective strategies to build social capital and resilience.

Abstract

In 2017, marginalised groups were disproportionately impacted by extensive flooding in a rural community in Northern New South Wales, Australia, with greater risk of home inundation, displacement and poor mental health. While social capital has been linked with good health and wellbeing, there has been limited investigation into its potential benefits in post-disaster contexts, particularly for marginalised groups. Six months post-flood, a cross-sectional survey was conducted to quantify associations between flood impact, individual social capital and psychological distress (including probable post-traumatic stress disorder). We adopted a community-academic partnership approach and purposive recruitment to increase participation from socio-economically marginalised groups (Aboriginal people and people in financial hardship). These groups reported lower levels of social capital (informal social connectedness, feelings of belonging, trust and optimism) compared to general community participants. Despite this, informal social connectedness and belonging were important factors for all participant groups, associated with reduced risk of psychological distress. In this flood-prone, rural community, there is a pressing need to build social capital collectively through co-designed strategies that simultaneously address the social, cultural and economic needs of marginalised groups. Multiple benefits will ensue for the whole community: reduced inequities; strengthened resilience; improved preparedness and lessened risk of long-term distress from disaster events.

Structure of this chapter

This chapter was published in the *International Journal of Environmental Research and Public Health* presented in Appendix 1. Two oral presentations on this project (International Union for Health Promotion and Education IUHPE – 23rd World Conference on Health Promotion, Rotorua, Aotearoa NZ, 2019; and a keynote presentation at the Australian Public Health Conference, Adelaide, 2019) are in Appendix 2. Finally, as a side project, I prepared a plain-

language summary of the flood research findings related to the LGBTQ+ respondents for ACON

in 2018 (Appendix 3).

Appendix 1: Journal article: 'Belonging and Inclusivity Make a Resilient Future for All: A Cross-Sectional Analysis of Post-Flood Social Capital in a Diverse Australian Rural Community'

Article

Belonging and Inclusivity Make a Resilient Future for All: A Cross-Sectional Analysis of Post-Flood Social Capital in a Diverse Australian Rural Community

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Abstract: In 2017, marginalised groups were disproportionately impacted by extensive flooding in a rural community in Northern New South Wales, Australia, with greater risk of home inundation, displacement and poor mental health. While social capital has been linked with good health and wellbeing, there has been limited investigation into its potential benefits in post-disaster contexts, particularly for marginalised groups. Six months post-flood, a cross-sectional survey was conducted to quantify associations between flood impact, individual social capital and psychological distress (including probable post-traumatic stress disorder). We adopted a community-academic partnership approach and purposive recruitment to increase participation from socio-economically marginalised groups (Aboriginal people and people in financial hardship). These groups reported lower levels of social capital (informal social connectedness, feelings of belonging, trust and optimism) compared to general community participants. Despite this, informal social connectedness and belonging were important factors for all participant groups, associated with reduced risk of psychological distress. In this flood-prone, rural community, there is a pressing need to build social capital collectively through co-designed strategies that simultaneously address the social, cultural and economic needs of marginalised groups. Multiple benefits will ensue for the whole community: reduced inequities; strengthened resilience; improved preparedness and lessened risk of long-term distress from disaster events.

Keywords: floods; mental health; social capital; inequality; Indigenous populations; low-income populations

1. Introduction

In disaster contexts, the value of close social networks is well documented for logistical, financial and emotional support, alleviating psychological stress following traumatic experiences [1]. Disaster management policies are increasingly drawing attention to investment in social resources as another form of 'capital' to help communities and individuals more effectively prepare, survive and recover from disaster events such as floods [2,3]. Social capital acts as 'informal insurance', facilitating a community's collective action to accelerate recovery [4]. However, previous post-disaster research has shown that social capital does not always benefit everyone due to existing prejudices that may slow down recovery for marginalised groups [4].

Social capital has been variously described and measured either as individual perspectives or as community-level structures and characteristics [5]. Widely adopted in public health research, Putnam's concept of social capital takes a macro-level approach, placing it as a collective resource strengthened by civic engagement, informal social connectedness, trust and social identity to facilitate group-level coordinated action with individual-level health consequences [5–7]. Putnam's conceptualisation contains an implied causal mechanism whereby forms of community participation (e.g., volunteering) influence levels of social cohesion (e.g., social trust) [8,9].

Bonding, bridging and linking social capital describe network characteristics and flows of resources within and across groups: bonding refers to resources accessed within tightly knit groups of similar socio-economic and demographic profiles; bridging refers to resource flow between groups with weaker ties and different profiles, and; linking refers to resource flow across gradients of authority and power [7,10]. Where bonding social capital provides resources and support for 'getting by', bridging and linking social capital are important for 'getting ahead' [11]. All forms of social capital may work to promote health but they can also have costs and negative consequences for marginalised individuals [12,13], particularly where bonding capital reinforces exclusive social identities to the detriment of others external to the group [7,10]. Similarly, a lack of bridging capital reinforces social hierarchies [13]. Marginalised groups experience gaps in all forms of social capital [12,14,15] which may lead to increased health inequalities [10,16]. Therefore, having a better understanding of how social capital operates within a community may offer insights into how positive aspects (such as bridging ties) can be intentionally strengthened to more effectively address inequalities and improve the health and wellbeing of marginalised groups [5,13].

Social capital in health and resilience research is generally measured by its structural and cognitive components [6,8]. The structural component describes the nature and extent of community participation through which individuals develop social networks and the cognitive component describes the social cohesion resulting from community participation [8,9] or what people 'do' and 'feel' [17]. Personal social cohesion is assessed through individual subjective perceptions of levels of belonging, social trust (trust in strangers), generalised reciprocity (kindness of strangers) and optimism (hope for the future) [6]. Mental health may both be a product of or facilitator for social capital [9]. Longitudinal studies have demonstrated a positive, bi-directional relationship between mental health and structural components of social capital: better mental health leads to greater community participation/social connectedness and greater participation/connectedness leads to better mental health [9,18], including following a flooding event [19]. In this reciprocal relationship, social connectedness is a stronger, more consistent predictor of mental health than mental health is of social connectedness [18].

In 2017, record-breaking rainfall in Northern New South Wales (NSW) from ex-Tropical Cyclone Debbie (the second most destructive cyclone in Australia) caused widespread flooding, inundating local business districts and residential areas on a scale not seen in over forty years [20]. Shortly after, a community-academic partnership was formed to design and implement a study examining potential relationships between flood exposure and mental health and wellbeing outcomes [21]. Two Community Advisory Groups (CAGs) were established in Lismore

and Murwillumbah, the main population centres of the region. They consisted of local health and community organisations, business groups and state and local authorities who have responsibility for flood planning, emergency response, mental health service provision and/or advocacy and support for particular subgroups within the community such as farmers, business owners, Aboriginal and Torres Strait Islander people and the socio-economically marginalised. Together with the CAGs, a conceptual framework was developed (the flood impact framework) which theorises pathways between flood exposure and psychological outcomes influenced by mediating factors at personal, community and organisational levels (e.g., socio-demographics, community cohesion, organisational disaster relief efforts) [21]. Based on published evidence, social capital was included as one of many potential mediators. It was predicted that greater levels of community participation and social cohesion would be protective against psychological distress and that this relationship would vary for different groups including marginalised people in the region. We define 'marginalised' as people with "… compromised or severely limited access to the resources and opportunities needed to fully participate in society and to live a decent life. Marginalised people experience a complex, mutually reinforcing mix of economic, social, health and early-life disadvantage, as well as stigma" [15, page 4]. A better understanding of how social processes work for these groups in a post-disaster context could improve the participatory co-design of resilience-building strategies, a process that in itself may promote social capital [22,23].

Northern NSW is a flood-prone region with over 30 flood disaster declarations in the decade from 2004 to 2014 [24]. Compared to state-level population characteristics, the Northern NSW rural region has higher proportions of people living with an underlying vulnerability, lower median household incomes and greater government income support reliance (e.g., single parent, disability, unemployment, and youth payments) [25]. The region also has a higher proportion of Australia's First Nations people (4.1%) compared to the state average (2.9%) [26]. It is important to note that Aboriginal and Torres Strait Islander status does not in itself indicate marginalisation [15]; rather, it is the common intergenerational disadvantage and ongoing systemic racism that leads to a significant proportion experiencing marginalisation.

During the 2017 flood, marginalised groups (Aboriginal and Torres Strait Islander participants and participants in receipt of income support) were disproportionately impacted by the flood with a greater risk of home inundation, displacement and adverse mental health outcomes [27]. Despite substantial evidence that social capital can promote health and wellbeing, there has been limited empirical investigation into its potential mitigating effect against adverse psychological outcomes following weather-related disasters and how this may vary for marginalised groups. This study investigates at an individual level, associations between the components of social capital (community participation and personal social cohesion) and psychological distress following a major flood event in rural Australia. It examines how social capital has different effects on mental health for marginalised groups relative to other participants. Our aim is to use these findings to highlight what might or might not work in intervention design to assist community groups to strengthen social capital and adaptive capacity within this flood-prone region.

2. Materials and Methods

Data were taken from a cross-sectional survey of adults (16 years and older) in Northern NSW, six months after the region experienced extensive flooding. The questionnaire was formulated on the basis of the flood impact framework described above and outlined in our study protocol [21]. To minimise survey fatigue, the questionnaire contained instructions advising participants of the choice to complete a short version of the questionnaire (that included items on participants' socio-demographic characteristics, flood exposure and their psychological health) or a longer version (all of the above as well as measures of community participation and personal social cohesion). A small prize draw (gift voucher for a local business) was offered as an incentive,

with an increased number of entries given for completion of the full questionnaire. The prize draw was not advertised as part of the survey recruitment process.

To comprehensively understand the psychological impact within the community, we aimed to recruit participants from different socio-economic backgrounds experiencing different degrees of flood exposure. We utilised a local community-partnered purposive snowball sampling technique, where the CAGs reached out to their networked constituents offering support and encouraging completion of the questionnaire. This approach was particularly important for certain sectors of the community, as a degree of trust is required to engage socio-economically marginalised groups, including Aboriginal and Torres Strait Islander people and people living with disadvantage. For the purpose of this analysis, we defined the latter as recipients of the following types of income support as markers for chronic financial hardship and living with social marginalisation [15]: single parent support; unemployment support; youth allowance; disability support; and carer support. Our snowball sampling approach was supplemented by an extensive local media (print, broadcast and social media) and advertising campaign, including posters and paper surveys (with reply-paid postage) left in central community locations such as post offices, libraries, coffee shops and store-fronts of charitable organisations such as Lifeline, St Vincent de Paul and the Salvation Army. Project staff promoted the survey at various community events including farmers' markets, and postcards were deposited in residential mailboxes with information on accessing the survey [21].

Our sampling approach resulted in a total of 2046 respondents completing the full version of the survey [21]. Given that most Aboriginal and Torres Strait Islander people in the Northern NSW area identify as Aboriginal, we respectfully use this term while recognising the diversity of First Nations culture that exists within the region. All participants gave their informed consent for inclusion before completing the questionnaire. The study was approved by the University of Sydney Human Research Ethics Committee (reference−2017/589) and the Aboriginal Health and Medical Research Council Human Research Ethics Committee (reference−1294/17).

2.1. Measures

Participants' sociodemographic data included age, sex, Aboriginal and Torres Strait Islander status, relationship status, employment status, type of income support payments and educational qualifications. For flood exposure, a cumulative exposure index (CEI: range 0–5) was derived by summing the number of damage sites experienced out of five possibilities: suburb; non-liveable areas of their home (e.g., garden shed, garage); liveable areas of their home (e.g., bedrooms); income-producing property (business/farm); and the home of a significant other [21].

Self-report measures for post-flood distress included a single ongoing distress item from the Brief Weather Disaster Trauma Exposure and Impact Screen ('Are you still currently distressed about what happened during the flood?') [28] and the Post Traumatic Stress Disorder Checklist (PCL−6) [29], a brief clinical screening tool (cut-point for probable diagnosis ≥14) that was introduced as a list of 'complaints' that 'people sometimes have' after severe rain and flooding. Details of how the Brief Weather Disaster Trauma Exposure and Impact Screen was developed are presented in Appendix A; the measure was field-tested and deployed as part of the Queensland Government's annual Self-Reported Health Status survey following severe flooding in the summer of 2010−11 [28]. It consists of four items adapted from previous research investigating post-traumatic stress disorder (PTSD) and depression following trauma in adults, adolescents and children within the Australian population. The yes/no 'still currently distressed' item from this measure was used for this analysis to allow for assessment of ongoing stress and anxiety related specifically to the flooding event (as distinct from anxiety arising from other causes) and for comparability to other similar studies in which it has been used [28]. For the PCL−6, respondents were asked to rate items on a 5-point Likert-type scale that evaluated experiences of intrusive memories, numbing/avoidance and hyper-arousal symptoms. The PCL−6 has shown adequate diagnostic performance in primary care settings including for

minority populations (sensitivity 80–92%; specificity of 72–76%) [30,31]. Outcome variables were coded as binary for ongoing distress (yes/no) and probable PTSD (yes ≥ 14; no < 14).

The questionnaire included measures representing structural and cognitive constructs of social capital: community participation and personal social cohesion, respectively (Table 1). Previous research has proposed an association between these constructs with enhanced community participation building personal social cohesion which, in turn, positively influences mental health and wellbeing [6,8,9], including among Aboriginal respondents [32]. The extent of respondents' agreement with statements that related to community participation and personal social cohesion was reported on a seven-point Likert-scale (the higher the score, the higher the level of agreement). We reversed the scoring for negatively worded statements. We utilised items from the Australian Community Participation Questionnaire that describe different domains of community participation: informal social connectedness (spontaneous, informal in-person connections); civic engagement (participation in organised activities) and political participation [33]. The use of social media was added as another form of community participation. The breadth of participation was measured by summing the number of participation activities (eleven in total, possible range 0–11). Individuals' subjective perceptions of the quality and quantity of their community participation [6] were also measured. Personal social cohesion comprised an individual's subjective perception of their sense of belonging (self-categorisation as belonging to a group and cognitive evaluation of the perceived social supports available for connecting, confiding and seeking help) [12,34], feelings of belonging (affective or emotional response to group membership) [6], social trust [12,35–37], generalised reciprocity [12,35]) and trait optimism [38]. Dispositional optimism (a tendency to expect good outcomes over bad) has been strongly linked to social trust and a sense of belonging and has been shown to be related to mental health within the Australian population [6,32]. For this reason, it is included as part of the concept of 'personal social cohesion', or the sense of social cohesion present in individuals.

Table 1. Social capital measures used within the Northern NSW Community Recovery after Flood survey.

Construct	Items	Source
	Community Participation	
Informal Social Connectedness	I make time to keep in touch with my friends; I chat with my neighbours when I see them; I spend time with extended family members (relatives who don't live with me)	Australian Community Participation Questionnaire (ACPQ) [33]
Social Media Engagement	I am active on social media (e.g., Facebook, Snapchat, Instagram)	New
Civic Engagement	I take part in community-based clubs or associations (e.g., Rotary, CWA, book club, Lions); I go to arts or cultural events; I attend community events such as farmers' markets, festivals and shows; I take part in sports activities or groups; I volunteer locally (e.g., Meals on Wheels, school fete, Rural Fire Service); I attend worship services or go to prayer meetings	ACPQ [33]
Political Participation	I get involved with political activities (e.g., through interest groups, public meetings, rallies)	Adapted from ACPQ [33]
Perceptions of Participation	I enjoy the time I spend with others socially; I would like to spend more time with others socially	Adapted from Berry, 2008 [39]
Construct	**Personal Social Cohesion**	**Source**
Sense of Belonging	When I feel lonely, there are several people I could call and talk to; I have family or friends I can confide in; I feel that I'm on the fringe in my circle of friends; I don't often get invited to do things with others; There are people outside my household who can offer help in a crisis.	Adapted from Interpersonal Support Evaluation List (ISEL) [34]
Feelings of Belonging	I feel like an outsider; I feel that I belong; I feel included.	Adapted from Berry (unpublished)
Social Trust	Most people keep their word; Most people do what they say they'll do; Most people around here succeed by stepping on others; Most people tell the truth when they're sorting out a problem; You can't be too careful with some people; Most people can be trusted.	Adapted by Berry & Rodgers [36] from Organisational Trust Inventory (OTI) [37] & World Values Survey (WVS) [35]
Generalised Reciprocity	Most people try to be helpful; Most people look out for themselves	Adapted from WVS [35]
Trait Optimism	Overall, I expect more good things to happen to me than bad; In uncertain times, I always expect the best; If something can go wrong for me, it will; I'm always optimistic about my future	Selected from Life Orientation Test – Revised [38]

Following data cleaning and coding, we examined the distribution of individual social capital items to determine appropriate analysis techniques. Where Likert-scale scores for the social capital measures were bimodal in distribution, we converted these to binary variables (scores 1–4 allocated 0: unsure or disagree; scores 4–7 allocated 1: agree). Since there was a mixture of ordinal and binary variables, polychoric correlations were used for subsequent confirmatory factor analysis (CFA) as outlined below.

2.2. Data Analysis

CFA was used to examine how well the previously defined measures of community participation and personal social cohesion fitted with our survey data [40]. For each of the social capital constructs described above, one-factor congeneric models were estimated on polychoric correlation matrices using maximum likelihood estimation with Stata software (StataCorp. 2017. *Stata Statistical Software: Release 15*. College Station, TX: StataCorp LLC.) and the user-written command -polychoric- (author Stas Kolenikov, 2016). To derive factor score weights for subsequent regression analysis, CFA was replicated in Amos (Arbuckle, J. L. (2006) Amos Version 25.0, Chicago: SPSS.) using asymptotically distribution-free estimation on raw data (polychoric correlation functionality unavailable), an appropriate technique for ordinal, non-normal data, small models and large sample sizes (>1000) [41]. Item loadings and fit statistics were comparable across the two estimation methods (Appendix B). Model goodness of fit was assessed using the comparative fit index (CFI—value of >0.95 indicates excellent model fit) and root mean square error of approximation (RMSEA—<0.05 indicates an excellent model fit, 0.05–0.08 indicates acceptable fit) [40]. Once optimal models were identified, we assessed internal consistency by calculating composite reliability scores using Jöreskog's rho (acceptable score > 0.70).

Following identification of the one-factor congeneric models, two sets of composite measures were developed: unweighted (by taking the mean score of items within the composite); and weighted (taking mean score of items within the composite after applying factor score weights from the CFA). Descriptive statistics were produced for sociodemographic information and the unweighted social capital measures. Differences in sociodemographic variables and social capital scores across respondent groups (Aboriginal; financial hardship; and 'other' (or general respondent group)) were tested using independent sample t-tests/two proportions z-tests and Mann-Whitney U tests respectively. Kendall's rank correlation coefficients (tau-b, T_b) were calculated to examine the strength and direction of bivariate associations within respondent groups. Multiple hierarchical logistic regression models were tested to examine the independent contribution in prespecified order of items theorised to influence mental health outcomes following a flood (socio-demographic characteristics, flood exposure, community participation and social cohesion). While causality cannot be inferred from cross-sectional designs, hierarchical regression analysis allowed examination of the *plausibility* of the concept that community participation is associated with greater personal social cohesion which, together, supports positive mental health outcomes. Both weighted and unweighted social capital composite variables were tested in the models, however, there was no substantive difference between the analyses with respect to independent variables that significantly influenced mental health outcomes. Hence, unweighted results are reported as they are easier to interpret and replicate if needed in future analyses.

Prior to multivariate analysis, we tested for interactions between sociodemographic characteristics and (i) flood exposure and (ii) social capital variables to examine how the combination of personal factors with flood experience, social participation and social cohesion were associated with reporting each psychological issue. Given the number of interactions tested, we utilised a conservative *p*-value (<0.01), to guide the addition of statistically significant interactions to the relevant multivariate model step as described below.

Four blocks of variables (sociodemographic factors, flood exposure, community participation and personal social cohesion) were added sequentially to assess the unique proportion of variance each contributed to mental health problems. Tjur's 'coefficient of

discrimination' (*D* – the difference in mean of predicted probabilities of having symptoms of psychological distress versus no symptoms), analogous to the coefficient of determination (R^2) in linear models, was used to evaluate the explanatory power of each block [42]. Non-significant contributors to explaining variance in psychological outcomes were removed from each step starting with the variable with the lowest standardised beta coefficient. Changes in beta values from one step to the next were examined to assess mediation effects in the relationship between community participation, social cohesion and mental health. The model was re-evaluated after each deletion until only significant predictors (*p*-value < 0.05) remained in each model. Odds ratios (ORs) and 95% confidence intervals (CIs) were reported for a total of six separate hierarchical logistic regression models calculated for two flood-related outcome measures ('ongoing distress' and 'probable PTSD') for each key interest group (Aboriginal respondents; respondents in receipt of financial hardship support; and 'other' respondents). Respondents who did not complete a health outcome measure were excluded from analysis for that indicator only.

3. Results

The CFAs were carried out on the full respondent dataset (*n* = 2046); results are detailed in Appendix B and summarised in Table 2. 'Attending worship services' (standardised loading = 0.22) was not strongly associated with the Civic Engagement construct. We included this item separately in subsequent regression analyses rather than attempt to fit it in a CFA. The WVS items measuring Generalised Reciprocity ('most people try to be helpful', 'most people look out for themselves') were weakly correlated in our dataset (polychoric ϱ = 0.23). These, too, were added separately in regression analyses. The remaining items demonstrated acceptable scale reliability (ϱ) and goodness of fit (CFI and RMSEA values) within their CFAs and were retained in one-factor model solutions (Table 2).

Table 2. Confirmatory Factor Analysis for composite social capital constructs using polychoric correlation matrices (n = 2046).

Construct	Factor Loadings (range)	CFI	RMSEA	95%CI	ϱ Reliability
Informal Social Connectedness	0.60–0.83	1.000	0.000	(0.000–0.040)	0.72
Civic Engagement	0.45–0.81	0.991	0.058	(0.041–0.078)	0.73
Sense of Belonging	0.43–0.86	0.997	0.048	(0.028–0.071)	0.75
Feelings of belonging	0.67–0.88	1.000	0.000	(0.000–0.050)	0.85
Social Trust	0.36–0.82	0.997	0.032	(0.016–0.049)	0.77
Trait Optimism	0.55–0.88	1.000	0.029	(0.000–0.073)	0.82

CFI: Comparative Fit Index; RMSEA: root mean square error of approximation; 95% CI: Confidence Interval.

Of the total 2046 respondents who completed the full version of the survey, 1888 who provided complete sociodemographic data constituted the dataset for analysis. Of the respondent group, 3.5% (*n* = 67) were Aboriginal and 15% (*n* = 287) were respondents in financial hardship. Over one-third of Aboriginal respondents (*n* = 24) were also in receipt of types of income support related to chronic hardship. To obtain mutually exclusive groups and to minimise confounding, these were retained in the Aboriginal respondent group and excluded from the financial hardship category. Overall, the majority of respondents were women (69%, *n* = 1304) and aged between 45 to 64 years (53%, *n* = 995) (Table 3). Aboriginal and financially disadvantaged respondents were more likely to be younger, single, unemployed and have lower educational attainment. In the six months immediately following the flood, approximately one in five respondents was still distressed and one out of seven reported probable PTSD. There were higher proportions of Aboriginal and financial hardship respondents indicating ongoing distress and probable PTSD compared to 'other' respondents.

Table 3. Demographic profile and mental health outcomes by respondent group.

Characteristic	Category	Aboriginal Respondents (n = 67; 3.5%)		Respondents in Financial Hardship (n = 287; 15.2%)		Other Respondents (n = 1534; 81.3%)		Total (n = 1888)	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
Age		46.5 ##	14.0	48.8 ###	13.0	52.4	14.4	51.7	14.3
		n	%	n	%	n	%	n	%
Sex	Female	49	73.1	197	68.6	1058	69.0	1304	69.1
Employment	Not in employment^	15	22.4 ***	132	46.0 ***	144	9.4	291	15.4
Education	University level	20	29.9 ##	88	30.7 ###	735	47.9	843	44.7
Relationship status	Single	31	46.3 ***	178	62.0 ***	401	26.1	610	32.3
Mental health outcomes	Ongoing distress	28	41.8 ***	92	32.1 ***	305	19.9	425	22.5
	Probable PTSD	24	35.8 ***	94	32.8 ***	173	11.3	291	15.4

^In addition to respondents looking for paid work or unable to work due to long-term illness, 'not in employment' also includes respondents of working age in full-time education, looking after family and home and/or doing regular unpaid volunteer work. Mean/proportion of respondents within the marginalised group is significantly greater (*) or smaller (#) than the mean/proportion in 'other' respondents *,# $p < 0.05$; **,## $p < 0.01$; ***,### $p < 0.01$.

There were no significant differences in social capital scores between Aboriginal and hardship respondent groups (Table 4). However, informal social connectedness scores were significantly lower in both marginalised groups compared to 'other' respondents. Civic engagement and breadth of community participation (the number of different types of community activities participated in) was also significantly lower for respondents in financial hardship compared to 'other' respondents. For personal social cohesion, both marginalised groups had significantly lower levels of belonging, social trust and optimism compared to 'other' respondents.

Table 4. Medians and interquartile ranges (IQR) for social capital variables in three respondent groups (higher scores indicate greater agreement with perception statements; n = 1888).

Social Capital Construct	Aboriginal respondents (*n* = 67)			Financial Hardship Respondents (*n* = 287)			Other Respondents (*n* = 1534)	
	Med.	IQR		Med.	IQR		Med.	IQR
Community participation (score range 1–7)								
Informal Social Connectedness	5.3	(4.0–6.0)	**	5.0	(4.0–6.0)	***	5.7	(4.7–6.0)
Social Media Engagement	5.0	(4.0–6.0)		5.0	(4.0–6.0)		5.0	(3.0–6.0)
Civic Engagement	4.0	(2.8–5.0)		4.0	(3.0–4.8)	***	4.2	(3.2–5.2)
Religious Engagement	2.0	(1.0–4.0)		1.0	(1.0–3.0)	*	2.0	(1.0–4.0)
Political Participation	4.0	(1.0–5.0)		4.0	(2.0–5.0)		3.0	(2.0–5.0)
Breadth of participation (0–11)	6.0	(4.0–7.0)		5.0	(3.0–7.0)	***	6.0	(4.0–8.0)
Perceptions of participation (1–7)								
Enjoyment (enjoy the time spent socially)	6.0	(5.0–6.0)	**	6.0	(5.0–6.0)	***	6.0	(5.0–7.0)
Sufficiency (desire to spend more time socially)	5.0	(4.0–6.0)		5.0	(4.0–6.0)		5.0	(4.0–6.0)
Personal Social Cohesion (1–7)								
Sense of Belonging	4.8	(4.0–6.0)	**	4.8	(4.0–5.6)	***	5.4	(4.6–6.0)
Feelings of Belonging	5.0	(3.3–6.0)	*	4.3	(3.3–5.7)	***	5.3	(4.3–6.0)
Social Trust	4.2	(3.3–4.8)	***	4.0	(3.5–4.7)	***	4.7	(4.0–5.2)
Reciprocity - People try to help	5.0	(4.0–6.0)		5.0	(5.0–6.0)		5.0	(5.0–6.0)
Reciprocity - People look after themselves	5.0	(4.0–6.0)		5.0	(4.0–6.0)		5.0	(4.0–6.0)
Optimism	4.5	(3.5–5.8)	***	4.5	(3.8–5.3)	***	5.3	(4.3–5.8)

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$: Mann-Whitney U tests compare mean rank of scores between Aboriginal and 'other' respondents and financial hardship respondents and 'other' respondents. (Note: Two distributions may have equivalent medians but different rank sums. For example, enjoyment of community participation scores, marginalised respondent groups had lower rank sums (other than those at the median) compared to 'other' respondents.).

In unadjusted analyses, Kendall rank correlation coefficients showed that higher severity of flood exposure was associated with higher levels of ongoing distress and probable PTSD at six months for all respondent groups (Table 5). As expected, most social capital variables were negatively correlated with psychological distress outcomes. Also, as predicted, community participation variables were less likely to be significantly associated with psychological distress compared to personal social cohesion variables (i.e., participation has a more distal influence on psychological outcomes compared to social cohesion). Informal social connectedness was significantly associated with ongoing distress only among 'other' respondents. Both informal social connectedness and civic engagement were associated with lower probable PTSD scores for respondents in receipt of financial hardship support and 'other' respondents. Among Aboriginal respondents only, higher social media engagement was associated with lower levels of ongoing distress and probable PTSD. Participating in a larger range of activities (greater breadth of participation) was significantly associated with lower probable PTSD scores for both financial hardship and 'other' respondents.

Table 5. Kendall Rank Correlation Coefficients between social capital variables and mental health outcomes for each respondent group.

Social Capital Construct	Aboriginal Respondents (n = 67)				Financial hardship Respondents (n = 287)				Other Respondents (n = 1534)			
	Ongoing Distress		PTSD		Ongoing Distress		PTSD		Ongoing Distress		PTSD	
Flood Exposure #	0.39	***	0.22	*	0.29	***	0.24	***	0.31	***	0.26	***
Community Participation												
Informal Social Connectedness	−0.04		−0.13		−0.01		−0.15	**	−0.06	*	−0.09	***
Civic Engagement	−0.04		−0.10		−0.001		−0.11	*	−0.03		−0.07	**
Social Media Engagement	−0.25	*	−0.25	*	−0.03		−0.06		0.01		−0.01	
Religious Engagement	0.04		−0.10		−0.03		−0.08		0.001		−0.04	
Political Participation	0.06		−0.01		0.04		−0.02		0.03		−0.01	
Breadth of Participation	−0.03		−0.18		−0.04		−0.11	*	−0.03		−0.09	***
Perceptions of Participation												
Enjoyment of time socialising	−0.24	*	−0.23	*	−0.08		−0.17	**	−0.14	***	−0.20	***
Sufficiency of time socialising	0.02		0.04		0.09		0.07		−0.01		0.01	
Personal Social Cohesion												
Sense of Belonging	−0.23	*	−0.38	***	−0.12	*	−0.29	***	−0.14	***	−0.17	***
Feeling of Belonging	−0.29	**	−0.42	***	−0.15	**	−0.35	***	−0.13	***	−0.21	***
Social Trust	−0.23	*	−0.34	**	−0.08		−0.18	**	−0.11	***	−0.14	***
Reciprocity - people try to help	−0.22		−0.39	***	−0.03		−0.17	**	−0.09	***	−0.11	***
Reciprocity - people look after themselves	0.18		0.27	*	0.03		0.004		0.05	*	0.08	***
Optimism	−0.21	*	−0.24	*	−0.19	***	−0.24	***	−0.16	***	−0.20	***

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; $^{\#}$ Cumulative Exposure Index (CEI).

Higher levels of personal social cohesion were significantly associated with lower levels of probable PTSD in all respondent groups. Belonging and optimism were significantly associated with less ongoing distress for respondents in financial hardship. Similarly, these constructs, in addition to social trust, were associated with less ongoing distress for Aboriginal respondents (Table 5).

Tables 6 and 7 summarise the unweighted hierarchical logistic regression results across all three respondent groups for ongoing distress and probable PTSD at six months respectively (weighted analyses produced trivial and non-significant differences in estimates with identical patterns of associations, so are not presented here). There were no significant interactions detected at $p < 0.01$ between sociodemographic characteristics and flood exposure or social capital variables.

Table 6. Parameter estimates and associated statistics of multiple hierarchical logistic models predicting flood-related ongoing distress for each respondent group, controlling for sociodemographic factors[‡].

Model Block	Aboriginal Respondents (n = 66)				Financial Hardship Respondents [†] (n = 280)				Other Respondents (n = 1477)			
	aOR	(95%CI)	ΔD	D	aOR	(95%CI)	ΔD	D	aOR	(95%CI)	ΔD	D
1. Flood Exposure (CEI)			0.22	0.29			0.10	0.11			0.13	0.14
	2.73	(1.52–4.91)	**^		1.86	(1.46–2.38)	***^		2.15	(1.90–2.42)	***^	
2. Community Participation												
2 A. Type & extent of participation											0.01	0.15
Informal Social Connectedness	-				-				0.86	(0.77–0.97)	*	
2 B. Perceptions of participation			0.05	0.34							0.01	0.16
Enjoy time spent socially	0.59	(0.37–0.95)	*^		-				0.76	(0.67–0.87)	***	
3. Personal Social Cohesion							0.05	0.16			0.02	0.18
Sense of Belonging	-				-				0.81	(0.68–0.96)	*^	
Optimism	-				0.62	(0.48–0.79)	***^		0.74	(0.64–0.86)	***^	

[‡] Age, sex, education level, employment and relationship status; [†] In receipt of following income support: single parent payment, unemployment allowance, youth allowance, disability support, carer payment; D = Tjur's coefficient of discrimination; $^*p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$; ^Predictor made an independent significant contribution in the third and final model; adjusted odds ratios (aORs) reported are for the model in which the predictors were added.

Table 7. Parameter estimates and associated statistics of multiple hierarchical logistic models predicting flood-related probable PTSD for each respondent group, controlling for sociodemographic factors‡.

Model block	Aboriginal Respondents (n = 67)				Financial Hardship Respondents † (n = 283)				Other Respondents (n = 1463)			
	aOR	(95%CI)	ΔD	D	aOR	(95%CI)	ΔD	D	aOR	(95%CI)	ΔD	D
Socio-demographic Factors				0.12								0.02
Education (non-university level)	4.56	(1.12–18.60) *			-				1.68	(1.20–2.35) **		
Employment (not in employment)	-				-				2.08	(1.31–3.29) **		
Relationship status (single)	-				-				1.44	(1.02–2.05) *		
1. Flood Exposure (CEI)			0.07	0.19			0.07	0.09			0.10	0.12
	1.69	(1.06–2.72) *			1.63	(1.30–2.05) ***^			2.22	(1.91–2.58) ***^		
2. Community Participation												
2 A. Type and extent of participation			0.08	0.27			0.03	0.12			0.02	0.14
Informal Social Connectedness	0.53	(0.31–0.92) *			0.71	(0.56–0.89) **			0.72	(0.63–0.83) ***		
2 B. Perceptions of participation							0.04	0.16			0.04	0.18
Enjoy time spent socially	-				0.76	(0.61–0.95) *			0.60	(0.51–0.70) ***^		
Sufficient time socialising	-				1.30	(1.08–1.56) **			1.16	(1.02–1.32) *		
3. Personal Social Cohesion			0.18	0.45			0.09	0.25			0.06	0.24
Feeling of Belonging	0.41	(0.23–0.71) ** ^			0.48	(0.37–0.62) *** ^			0.65	(0.55–0.76) ***^		
Optimism	-				-				0.67	(0.55–0.81) ***^		

‡ Age, sex, education level, employment and relationship status; † In receipt of following income support: single parent payment, unemployment allowance, youth allowance, disability support, carer payment; D = Tjur's coefficient of discrimination; * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; ^ Predictor made an independent significant contribution in the third and final model; adjusted odds ratios (aORs) reported are for the model in which the predictors were added.

3.1. Aboriginal Respondents

None of the socio-demographic factors for Aboriginal respondents made an independent contribution to explaining their 'still distressed' status six months after the flood. Higher levels of flood exposure were strongly associated with ongoing distress (aOR 2.73; 95% CIs: 1.52–4.91) and remained that way in the final model, explaining most model variance (change in Tjur's D = 22%) (Table 6). After adjusting for socio-demographic characteristics and flood exposure, social media engagement was not significantly associated with ongoing distress. While types of community participation were not significant in the model, enjoyment of participation was strongly associated with less distress (aOR 0.59; 95% CIs: 0.37–0.95). None of the personal social cohesion variables was independently significantly associated with ongoing distress for this respondent group.

Compared to ongoing distress, there were different patterns of association between flood exposure, social capital and probable PTSD for Aboriginal respondents (Table 7). Higher levels of educational attainment made a significant independent contribution to explaining lower probable PTSD scores. This variable became non-significant when flood exposure was added to the model. Flood exposure was associated with a higher risk of probable PTSD explaining a further 7% of the model. Greater informal social connectedness was significantly independently associated with lower PTSD risk, while perceptions about the quality and quantity of time spent with others did not further explain PTSD outcomes. The contribution of flood exposure and informal connectedness became non-significant with the addition of the social cohesion variables. Feelings of belonging (aOR 0.41; 95% CIs: 0.23–0.71) were strongly associated with lower levels of probable PTSD and explained most of the model variance (18%) for Aboriginal respondents.

In summary, in the final models, consistent with predictions in our flood impact framework, post-flood ongoing distress was explained in order of magnitude by greater levels of flood damage and lower scores of enjoying social participation. A greater risk of post-flood probable PTSD was mainly explained by lower feeling of belonging scores.

3.2. Respondents in Financial Hardship

Socio-demographic variables were not significantly associated with ongoing distress for respondents in financial hardship six months after the flood. Similar to Aboriginal respondents, higher levels of flood exposure were strongly associated with ongoing distress (aOR 1.86; 95% CIs: 1.46–2.38) explaining most of the model variance (10%) (Table 6). Neither type nor perceptions of community participation made any contribution to explaining ongoing distress. Greater optimism (aOR 0.62; 95% CIs: 0.48–0.79) was the only component of social cohesion that was significantly associated with lower levels of ongoing distress, explaining a further 5% of the variance in the model.

Similar to ongoing distress patterns of association, socio-demographic factors were not significantly associated with probable PTSD and greater flood exposure was strongly associated with a higher risk of probable PTSD (1.63; 95%CIs: 1.30–2.05) explaining 7% of the model variance (Table 7). In contrast to ongoing distress, informal social connectedness (aOR 0.71; 95% CIs: 0.56–0.89), enjoying participation (aOR 0.76; 95%CIs: 0.61–0.95) and having sufficient quantity of social time (aOR 1.30; 95% CIs: 1.08–1.56) were significantly associated with probable PTSD. Increased feelings of belonging (aOR 0.48; 95% CIs: 0.37–0.62) was the only social cohesion variable that was significantly associated with lower probable PTSD scores. The addition of feelings of belonging explained a further 9% of the variance and rendered the community participation indicators non-significant in the probable PTSD model.

As predicted, in the final models for respondents in financial hardship, post-flood distress was explained in order of magnitude by greater levels of flood exposure and lower optimism scores. Post-flood probable PTSD was explained in order of magnitude by greater flood exposure and lower feeling of belonging scores.

3.3. General Community Respondents

Socio-demographic variables for 'other' respondents were not significantly associated with ongoing distress six months after the flood (Table 6). As with both marginalised respondent groups, higher levels of flood exposure were strongly associated with reports of ongoing distress (aOR 2.15; 95% CIs: 1.90–2.42) explaining most variance in the model (13%). Unlike marginalised respondent groups, there was a significant association between higher levels of informal social connectedness and less distress (aOR 0.86; 95%CIs: 0.77–0.97). Similar to Aboriginal respondents, enjoying community participation was significantly associated with less ongoing distress for the general respondent group (aOR 0.76; 95% CIs: 0.67–0.87). Having a greater sense of belonging (perceived social supports) (aOR 0.81; 95% CIS: 0.68–0.96) and optimism (aOR 0.74; 95% CIs: 0.64–0.86) were also significantly associated with less distress. The contribution made by informal connectedness and enjoying community participation became non-significant when these social cohesion variables were added to the model.

Lower educational attainment, not being in paid employment and single relationship status made independent contributions to increasing the risk of probable PTSD for the general respondent group (Table 7). These demographic factors, however, became non-significant in subsequent model steps. Again, like both marginalised respondent groups, higher levels of flood exposure were strongly associated with probable PTSD (aOR 2.22; 95% CIs: 1.91–2.58). Unlike marginalised groups, however, flood exposure explained most variance in probable PTSD outcomes for general community respondents (10%). There were similar patterns of association between social capital variables and probable PTSD between the general respondent group and those in financial hardship. Higher informal social connectedness (aOR 0.72; 95% CIs: 0.63–0.83) and enjoying social participation (aOR 0.60; 95% CIs: 0.51–0.70) were significantly associated with lower probable PTSD scores. Wanting to spend more time with others (indicating a degree of social isolation; aOR 1.16; 95%CIs: 1.02–1.32) was significantly associated with an increased risk of probable PTSD. Of all community participation variables, only enjoyment of participation remained significant in the final model for 'other' respondents. Like marginalised groups, lower scores for feelings of belonging (aOR 0.65; 95% CI: 0.55–0.76) were associated with higher probable PTSD scores. In addition, however, greater optimism (aOR 0.67; 95% CI: 0.55–0.81) was also strongly associated with less PTSD symptomology for the general respondent group.

In summary, significant associations in the final models align with predictions in our flood impact framework. Post-flood distress was explained in order of magnitude by greater flood exposure and lower optimism and a sense of belonging scores (perceived availability of social supports). Post-flood probable PTSD was explained by greater flood exposure and lower quality of social participation, feelings of belonging and optimism scores.

4. Discussion

Broadly, our findings support the propositions that (i) the components of social capital may be causally related in that community participation may be an important contributor to the formation of social cohesion; and (ii) while exposure to a flood event harms mental health across the whole community, the mental health of those with more social capital is not as severely harmed as those with less social capital. We examined the relationship between social capital and mental health among Aboriginal, financially disadvantaged and other members of the general community six months following a severe flood event. As expected, the greater participants' exposure to the flood, the greater the likely harm to their mental health, particularly so for marginalised community members. Social capital played an important role in the degree of flood-related harm people reported in that those with higher levels of social capital reported less harm to their mental health than did those with less. However, the strength and nature of this effect varied by the group.

4.1. Aboriginal respondents

With lower levels of informal social connectedness, belonging, social trust and optimism, Aboriginal respondents had less social capital than the general respondent group. These findings are in line with other social capital analyses in Aboriginal population-representative surveys [32,43,44]. As in previous studies, we found subtle differences in what mattered most for mental health and wellbeing compared to other respondent groups. Aboriginal respondents were like other groups in that individuals with greater feelings of belonging were less likely to experience post-flood PTSD. In contrast to other groups, optimism did not feature amongst the social cohesion factors that mattered most for Aboriginal respondents in terms of reducing the likelihood of ongoing distress.

Social capital and resilience can mean different things for different populations, suggesting that the way it is measured in the general Australian population may not adequately capture concepts of social participation and cohesion important to Aboriginal communities [32,45]. The community participation variables used in this study have been validated previously in an Australian Aboriginal community [6,30] and our study confirms the relevance of the participation variables (including social media engagement as a new type of participation) to Aboriginal participants. Yet, from an Aboriginal perspective, there are other characteristics of social relationships and resilience that are important in overcoming adversity. Relational identity is key, that is, the knowledge of and connection to one's own community, culture and Country [46]. Colonisation severely disrupted these connections, the impact of which is still acutely felt today. Land dispossession, social and cultural dislocation (including the destruction of languages) and systematic genocide (including the forced removal of children from their Aboriginal families) have led to inter-generational trauma with devastating consequences for social and emotional wellbeing. Systemic and interpersonal racism reinforces socio-economic exclusion and mistrust in mainstream institutions [44,45] and has been linked to depression in Aboriginal people [47]. Consequently, there are significant chronic disparities across socio-economic and health indicators between Aboriginal and non-Indigenous Australians. The active resistance by and survival of Aboriginal communities throughout history and against ongoing adversity speaks to their strength, resilience and determination. The cultural context of this resilience (strong familial links, connection to country, language and ceremony) is protective in the face of repeated tragedies that Aboriginal communities often experience [48,49] and our study provides further evidence of how this may operate in the face of natural disasters.

While a strong sense of shared identity and belonging (bonding capital) within Aboriginal communities is important for their resilience and wellbeing, there is complexity in the link between Aboriginal social capital and social mobility. In the general community, connecting to other groups with different social identities has the potential to help one 'get ahead' by making accessible new opportunities and resources [11]. To receive some form of mutual benefit in this way intrinsically involves trust and reciprocity with an expectation of some form of 'repayment' (the amount and timing of which is not fixed) [50]. Considering the historical and cultural contexts described above, the pursuit of broader linkages (bridging capital) for Aboriginal people may be limited where their trust in members of the general community is compromised and their within-community social capital may not be valued or have currency outside of their community due to racial prejudices [45].

Despite the importance of historical and cultural contexts, consideration of these contexts is not currently evident in the development of local-level disaster risk reduction strategies. Active and equal participation of and leadership by Aboriginal people has resulted in successful public health responses to entrenched domestic violence within a community [48] and in prioritising the safety of Aboriginal communities during the current COVID−19 pandemic [51], demonstrating the importance and effectiveness of culturally-led solutions to complex threats to health and wellbeing. In a similar way, there is a great opportunity for Aboriginal-led approaches to address disaster risk that would benefit the whole community. For instance, Caring for Country initiatives, where Aboriginal and Torres Strait Islander knowledge is used appropriately to care

for traditional lands and seas, have continually demonstrated multiple social, cultural, ecological, economic and health benefits [52–54]. These Aboriginal-led partnerships strengthen culture as well as enhance respect and appreciation of Aboriginal knowledge within mainstream populations [54]. By focusing on cultural context, strengthening connection to Country and increasing social networks, such initiatives will likely enhance feelings of belonging for Aboriginal people, a key driving factor influencing post-disaster distress.

A novel finding from this study is that social media may be a promising avenue for strengthening informal social connectedness for Aboriginal communities. Compared to the general community and those in financial hardship, Aboriginal respondents with higher social media usage were less likely to indicate post-flood distress and PTSD, perhaps because it increases social connectedness in this group. Previous research has shown social media use to be more common among Aboriginal compared to non-Indigenous people [55]. There is complexity in the relationship between the use of technology and social connectedness. Whether it enhances the quality of social relationships depends on the type of platform, motives for use and whether it is used actively or passively which, in turn, are influenced by socio-demographic characteristics [56,57]. In this study, the relationship between social media and distress for Aboriginal respondents was non-significant after controlling for socio-demographic characteristics, indicating that these characteristics may mediate the relationships. A more nuanced understanding is required to develop strategies to enhance its effectiveness in reducing isolation for this group. Social media can be an effective tool if used to strengthen existing relationships or initiate new meaningful ones (rather than as a substitute for real-life interaction) [57]. It may also be an effective vehicle for managing disaster risk and providing health messaging and education [55,58].

4.2. Respondents Living with Financial Disadvantage

Like Aboriginal community members, people living with financial disadvantage (as indicated in this study by being in receipt of certain types of government income support), had less social capital than general community members (including lower levels of informal social connectedness, civic engagement, belonging, social trust and optimism) supporting other research showing income inequality to be a consistent predictor of community participation [59], social isolation and sense of belonging [60].

Compared to general community members, those in financial hardship were more likely to be single, unemployed and have lower educational attainment levels. Quality of time spent socially and feelings of belonging were what mattered most for those in financial hardship with respect to probable PTSD outcomes. As a corollary, those wanting to increase the quantity of time spent socially (social isolation) were more likely to experience post-flood PTSD. Reasons for social isolation can be structural (i.e., lack of resources to enable access to social activities; lack of opportunity to access social networks otherwise available through education or employment); interpersonal (i.e., being avoided by others due to prejudice and discrimination); and personal (e.g., embarrassment, concern about stigmatisation or poor health) [60]. Because of these issues, people in financial hardship generally avoid social situations perceived as challenging, tending instead to socialise with others experiencing the same marginalisation. As a result, they generally have commensurately smaller and less reciprocal networks [60,61]. Places of belonging for the financially marginalised tend to be community support agencies or drop-in centres due to the economic and social support they provide. While relationships generated with service providers (e.g., providing food, housing, employment support, etc) are beneficial, they are not spontaneous relationships but are 'deliberately constructed' and do not necessarily meet the social needs of marginalised people [61]. Similar to Aboriginal people, bonding social capital is an important buffer against poor mental health while lack of bridging social capital can be detrimental. For example, low-income individuals living in affluent areas can have worse mental health (exacerbated by social exclusion) compared to those living in deprived neighbourhoods [14,59].

People in financial hardship with greater optimism (a tendency to expect positive outcomes in the future), were less likely to experience ongoing distress. Optimists refuse to give up [62]. Instead, they tend to look for benefits in adversity and employ more effective coping strategies than pessimists, making them more resilient to stressful events [63]. This is relevant to coping with a flood: optimism moderates the relationship between the level of household damage in a disaster and personal recovery [64]. Optimists' persistence in overcoming personal obstacles has also been attributed to their ability to forge bridging relationships across demographic and socio-economic divides [63]. In this study, greater informal social connectedness was related to greater optimism for people in financial hardship and associated with lower levels of ongoing distress. Resilience-building strategies for financially marginalised groups may benefit from interventions that build meaningful bridging relationships in environments that are safe and enjoyable from their perspective [6]. Such co-designed initiatives, preferably simultaneously addressing economic needs, will enhance agency and hope for the future [65].

4.3. Other Members of the General Community

Less optimistic members of the general community were more likely to show signs of post-flood distress and PTSD. This concurs with previous post-disaster research showing optimism reduces the likelihood of developing PTSD, suggesting a possible pathway to improve recovery and prevent adverse mental health impact [64]. General community members with a sense of belonging were also less likely to indicate long-term distress. It makes intuitive sense that post-disaster distress can be mitigated for individuals by turning to emotional, financial and social supports available through personal networks for recovery assistance. As for marginalised groups, greater feelings of belonging (the emotional evaluation of connectedness) decreased the likelihood of post-flood PTSD. Belonging is a fundamental human need [66]. There is a critical link between belonging and shared social identity and a belief that one's life is meaningful which is important for wellbeing across different social groups, particularly for those that experience systematic social exclusion [60,66].

4.4. Belonging and Inclusivity Make for a Resilient Future

Feelings of belonging that are enhanced, possibly created, by participation and social inclusion are key to alleviating post-flood distress for this diverse rural community. Belonging and shared identity are multifaceted, comprising our material possessions, immediate and extended social networks as well as the place we call home [67]. Receiving increasing attention in post-disaster recovery research is the psychology of place (incorporating social and geographical contexts) and the concept of 'solastalgia' [67–69]. In NSW rural communities, feelings of belonging and perceptions of one's environment are important for resilience [70]. Perhaps reflecting Aboriginal notions of connection to Country and its importance for wellbeing, solastalgia describes the sense of loss experienced by individuals when the surrounding environment changes to the extent that it no longer resembles home or becomes a place of danger in a disaster-prone area [68]. Extreme events that destroy homes and livelihoods or which force evacuation and long periods of displacement are known to exacerbate mental health issues, particularly for marginalised groups [27,67].

Given the complexity of social capital and the subtle variation in how it operates across different socio-economic groups, approaches to developing resilience strategies must involve the very groups for which they are designed. This analysis has pointed out key issues that may work to boost social connectedness for marginalised groups. In-depth qualitative research is required to fully understand the contextual and cultural factors that shape the specific needs of these different groups to jointly enhance participation and social cohesion for improved community adaptive capacity and disaster resilience. Compared to urban areas, rural communities tend to be known for high levels of some social capital (such as community participation and trust) but they can also have lower levels of tolerance for diversity, undermining their 'collective efficacy' [71].

So, while participatory approaches are critical, it is important that intervention strategies not be compartmentalised within social groups. Rather, we need to design strategies that consider broader contexts and are structured to be inclusive (e.g., interactions between social groups) to maximise the effectiveness of social capital interventions to strengthen overall community resilience.

4.5. Strengths and Limitations

Our sampling approach, while necessary to meet the goals of this study, constrains our ability to generalise our results to the broader population. Further, this is a self-report, cross-sectional design that limits our ability to untangle complex pathways to determine cause and effect and the presence of bi-directional relationships between social capital and mental health. Hence, our study design does not permit conclusions about whether social capital was directly protective against flood-related harm to mental health. Pre-existing mental health status may have biased responses and without pre-disaster community participation and social cohesion measures, we cannot be sure how the flood influenced social capital across the respondent groups.

While the proportion of Aboriginal respondents was close to the proportion living within Northern NSW, the small number of Aboriginal respondents reduced statistical power and may have led to the exclusion of meaningful predictors of flood-related distress. Where sample numbers were small, our analysis focused largely on the direction of associations and whether they were consistent with our expectations of the relationships between social capital, flood exposure and psychological distress. Our results were consistent with other studies investigating Aboriginal and Torres Strait Islander social capital [32,43,44] and can usefully inform future research with this population in the co-design of disaster risk reduction strategies. While validation studies of the Australian Community Participation Questionnaire and feelings of belonging included an Aboriginal community [6,32], our other social capital measures have been wholly designed and validated within so-called Western populations and may not adequately represent the experiences of other cultural groups. We also recognise that social capital for groups cannot be understood in isolation, but as part of an interacting set of capitals within the community that encapsulates human (knowledge, skills, the health of individuals), natural (land, water and biological resources), physical (infrastructure, equipment and technological resources) and financial (income, savings, credit, etc) dimensions that also influence the adaptive capacity of rural communities [72].

Despite these limitations, our findings are consistent with our expectations and with other studies that have used population-representative samples and other study designs. We aimed to use a theoretically-driven approach to describe and quantify the relationships between flood impact, social capital and mental health with a particular focus on comparing the experiences of different types of community members. Using directly flood-related measures of mental health and adjusting for a very wide range of relevant socio-demographic controls, we found support for our proposition that social interactions, supports and cohesion are important in mitigating distress related to the flood.

A particular strength of our study was the close engagement with the community which led to our pragmatic, purposeful sampling approach that enabled measurement of these theoretical relationships for diverse, vulnerable sub-population groups. The CAGs continued to meet regularly over a period of 18 months during which findings were shared and interpretative discussions held to inform report writing and the dissemination of findings [21]. The aim of the community-academic partnership was to undertake useful research and disseminate findings addressing community-driven information needs. Our theories were supported by the findings which provide new insights on the development of local public health and disaster management policies aimed at strengthening dimensions of social capital to reduce post-disaster mental health. With Northern NSW being a flood-prone area [24], it is inevitable that this region will experience similar disasters in the future. There is a pressing need therefore to strengthen community social

capital collectively through co-designed strategies that simultaneously address social and economic exclusion, cultural needs and environmental restoration. Multiple benefits for the community will ensue: reduced inequities; strengthened psychological well-being and resilience; lessened risk of long-term personal distress from disaster events; and reduced need for expensive individual psychological interventions [73] which are inequitably available and accessed [74,75].

5. Conclusions

Following the 2017 Northern NSW flood, Aboriginal and financially disadvantaged respondents reported lower levels of social capital (informal social connectedness, feelings of belonging, trust and optimism) compared to general community participants. Despite this, informal social connectedness and belonging were important factors for all participant groups and were associated with reduced risk of ongoing distress and PTSD.

Although it is well established that social capital is vital to promoting and maintaining positive mental health and wellbeing, there is relatively little research on how social capital influences psychological outcomes from weather-related disasters and, specifically, for marginalised population groups. Our study has deconstructed social capital to highlight what matters most for socio-economically marginalised groups to inform tailoring of safe and effective resilience-building strategies. Access to social capital is not homogeneous, with various groups subject to differential barriers in building and benefitting from social capital and its benefits to mental wellbeing. Community-level interventions are required tailored to specific groups through participatory processes. Future studies will be able to further disentangle these concepts, especially with regard to cause and effect, and to study how social capital operates in broader community contexts: which social resources benefit health for individual groups; and which characteristics of the wider social environment may promote such benefits.

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Conflicts of Interest: The authors declare no conflict of interest.

Appendix A

Brief Weather-related Disaster Trauma Exposure and Impact Screen

Development and Source

Construction of the Brief Weather-related Disaster Trauma Exposure & Impact Screen occurred in 2009 and was based on Australian research with adults [76] and a body of Australian research on post-natural disaster PTSD in children and adolescents [19,77]. The measure was field-tested and deployed as part of the Queensland Government's annual Self-Reported Health Status survey following severe flooding in the summer of 2010–11.

A more detailed summary of the derivation of items follows:

Item	Derivation
A weather disaster (e.g., flood, bushfire, storm, cyclone) damage or destroy your home.	Adapted from 'trauma exposure' items in McDermott et al. [19,77]: 'experienced damage to [your] home, including broken windows, damage to part or all of [your] roof or other home damage'. Exposure to the traumatic event (i.e., witnessing actual flames) and proxy measures of exposure such as home damage, are significant predictors of adverse emotional outcomes in all published predictive models.
Did any of the following happen as a result of this weather-related disaster? a) You thought you might die	Adapted from O'Donnell [76], item #6 from the final ten-item measure, p.929, 'During the event, I thought I was about to die'; and adapted from McDermott et al. [19,77]. In the latter research, of all measured variables, threat perception had the strongest relationship with post-disaster post-traumatic stress disorder.
b) You personally knew people who were killed or badly injured.	Adapted from O'Donnell [76], item #6 from the original list of peri-trauma items, *p*.926, 'I witnessed other people being killed or injured'; and adapted from McDermott et al. [19,77], perceived threat of death to self and perceived threat of death to parents (for children and adolescents).
c) You felt terrified, helpless or hopeless.	Consistent with diagnostic criteria (A2) for PTSD (DSMIV) and ICD entry criteria. Adapted from O'Donnell [76], item #5 from the final ten-item measure, p.929, 'At the time of the event, I felt terrified, helpless or hopeless'.
d) You are still currently distressed about it.	Allows calculation of point prevalence of post-disaster distress and differentiation from other possible causes of anxiety; can be validated against related constructs measured in the same survey. This item provides insight into whether ongoing stress and anxiety are directly related to the traumatic event (in addition to any relationships we may find with other measures of health and wellbeing).

Appendix B

Confirmatory Factor Analysis of Social Capital Constructs within the Northern Rivers Community Recovery after Flood survey (n = 2046)

Informal Social Connectedness (ISC: chat with neighbours, make time to keep in touch with friends, spend time with extended family members)

All items loaded significantly ($p < 0.001$) and strongly on a single ISC dimension (Table B1). The fit statistics indicated model saturation (or best possible fit). There was no significant difference in the path coefficients for a chat with neighbours and spend time with extended family, so these loadings were constrained to be equal. The resulting scale reliability was $\rho = 0.72$.

The factor score weights (Figure B1) calculated for use in regression analyses refers to the predicted value the latent variable ISC increases by with a one-unit increase in the agreement scores from respondents relating to ISC activities. For example, a one-unit increase in scores measuring agreement with 'I make time to keep in touch with my friends' is predicted to increase their informal social connection score by 0.457 units.

$X^2(1) = 0.09$
$p = 0.76$
RMSEA = 0.00 (95%CI 0.00-0.04)
CFI = 1.00
ρ reliability = 0.72

Factor score weights	DSFtimefr	DSFexfam	DSFchatnei
ISC	0.457	0.11	0.22
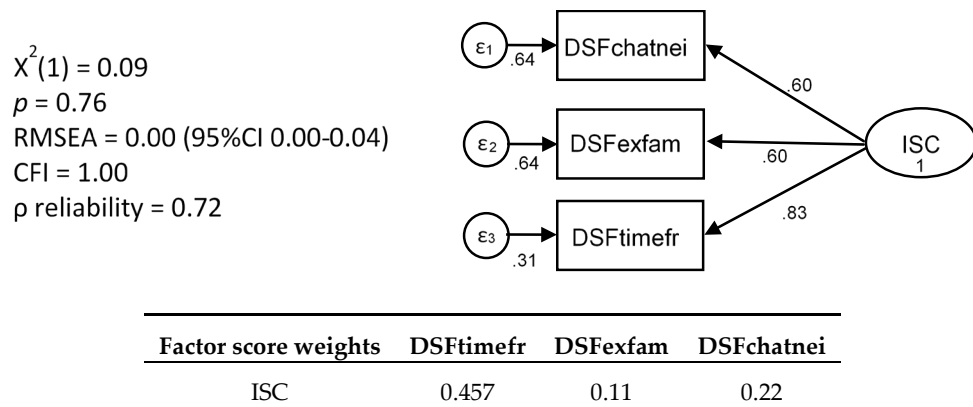
Figure B1. Final model for Informal Social Connectedness constructs of community participation.

Civic Engagement (CE: I go to arts and culture events, I attend community events, I volunteer locally, I take part in sports activities or groups, I take part in community-based clubs or association, I attend worship services or go to prayer meetings)

Attendance at worship services item was removed from the CE construct as it loaded weakly (standardised loading 0.22; $p < 0.001$) and correlated poorly with other items (polychoric $\rho < 0.2$). The remaining five items all loaded significantly and strongly, but the fit of the initial model was not satisfactory: $\chi^2(5) = 770.57$, $p < 0.001$, RMSEA = 0.274 (95%CIs:0.257–0.290), CFI = 0.76. After analysis of modification indices (which provides estimates of how much the chi-squared will be reduced if we changed the model by estimating extra parameters), we correlated the error terms for attending arts & culture events (DSFartcul) & community events (DSFcomev) items. This made conceptual sense as they are similar in terms of the 'passive' nature of attending events compared to the more 'active' items within this construct, such as volunteering and taking part in different activities. It also made conceptual sense to correlate the errors between volunteering (DSFvol) and participating at local sporting clubs (DSFsport) since these may co-occur, e.g., coaching or officiating matches. There was no significant difference in the path coefficients for attending arts & culture and community events, so these loadings were constrained to be equal. Following these changes, we obtained a satisfactory fit (Figure B2). All five items have a substantial loading (range: 0.45 to 0.81) that are significant at the $p < 0.001$ level. The resulting scale reliability was $\rho = 0.73$.
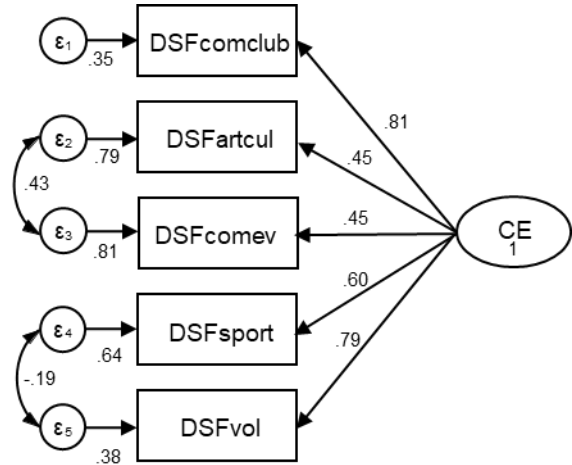
Factor score weights	DSFcomclub	DSFartcul	DSFcomev	DSFsport	DSFvol
CE	0.193	0.041	0.018	0.182	0.262

Figure B2. Final model for Civic Engagement constructs of community participation.

Sense of belonging (When I feel lonely there are several people I could call and talk to, I don't often get invited to do things with others, I feel that I'm on the fringe in my circle of friends, I have family or friends I can confide in, There are people outside my household who can offer help in a crisis).

This construct represents the cognitive aspect of belonging, i.e., self-categorisation as belonging to a group through which social supports are available for connecting, confiding and seeking help. The five items all loaded significantly and strongly, but the fit of the initial model was not satisfactory: $\chi^2(5) = 595.00$, $p < 0.001$, RMSEA = 0.240 (95%CIs:0.224–0.257), CFI = 0.857. Substantial modification indices indicated a correlation of errors between often not getting invited to do things with others (SFnotinv) and feeling on the fringe of friendship groups (SFfringe) and also between having several people to call if feeling lonely (SFlontalk) and often not getting invited to do things with others (SFnotinv). These items are part of the 'Belonging' subscale of the Interpersonal Support Evaluation List (ISEL) designed to measure the perceived availability of people to interact with [34]. Correlating these error terms improved our fit (Figure B3), and all were significant at the $p < 0.001$ level. All five indicators of SOB had substantial loadings (range: 0.43 to 0.86). Scale reliability was $\rho = 0.75$.
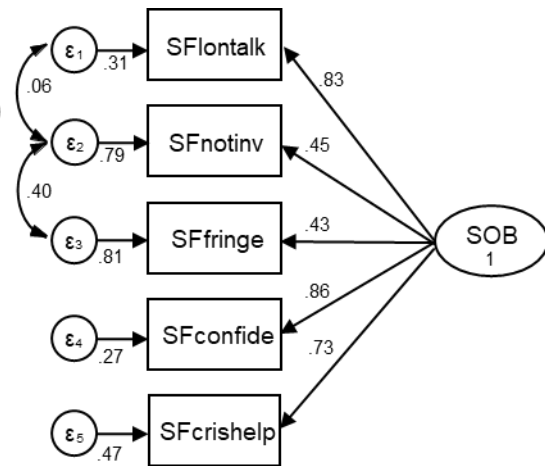
Factor score weights	SFlontalk	SFnotinv	SFfringe	SFconfide	SFcrishelp
SOB	0.297	0.094	0.168	0.369	0.200

Figure B3. Final model for Sense of Belonging construct of personal social cohesion.

Feelings of Belonging (FOB: I feel like an outsider, I feel included, I feel that I belong)

This construct represents the affective aspect of belonging, i.e., a person's emotional evaluation of social connectedness. All three items loaded significantly ($p < 0.001$) and strongly and the fit statistics indicated model saturation or best possible fit. As there was no significant difference in the path coefficients for feeling included and feeling of belonging, these loadings were constrained to be equal. The standardized loadings ranged from 0.67 to 0.88 and the resulting scale reliability was $\rho = 0.85$ (Figure B4).
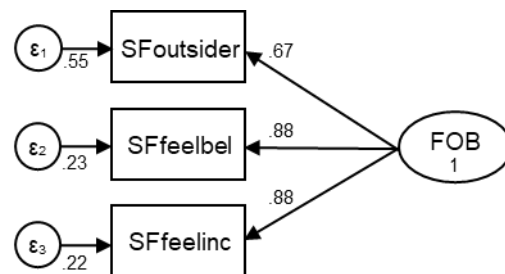
Factor score weights	SFoutsider	SFfeelbel	SFfeelinc
FOB	0.115	0.36	0.342

Figure B4. Final model for Feelings of Belonging construct of personal social cohesion.

Social Trust (ST: Most people around here succeed by stepping on others, Most people tell the truth when they're sorting out a problem, Most people keep their word, Most people do what they say they'll do, You can't be too careful with some people, Most people can be trusted).

All six items loaded significantly, but had poor model fit: $\chi^2(9) = 192.74$, $p < 0.001$, RMSEA = 0.100 (95%CIs:0.088–0.112), CFI = 0.958. Following analysis of modification indices, we correlated errors between: 'most people keep their word' (ATkeepword) and 'most people do what they say they'll do' (ATsaydo) items from the *Keeps Commitment* dimension of the Organizational Trust Inventory (OTI) [37]; the two World Values Survey items ('you can't be too careful with some people' - ATtoocare and 'most people can be trusted' - ATcantrust) [35]; and ATtoocare with the OTI item about people taking excessive advantage of others ('most people around here succeed

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by stepping on others' - ATsucstep). Correlating these error terms improved our fit (Figure B5) and the correlations were significant at the $p < 0.001$ level. Standardised loadings ranged from 0.36 to 0.82 and the resulting scale reliability was $\rho = 0.77$.
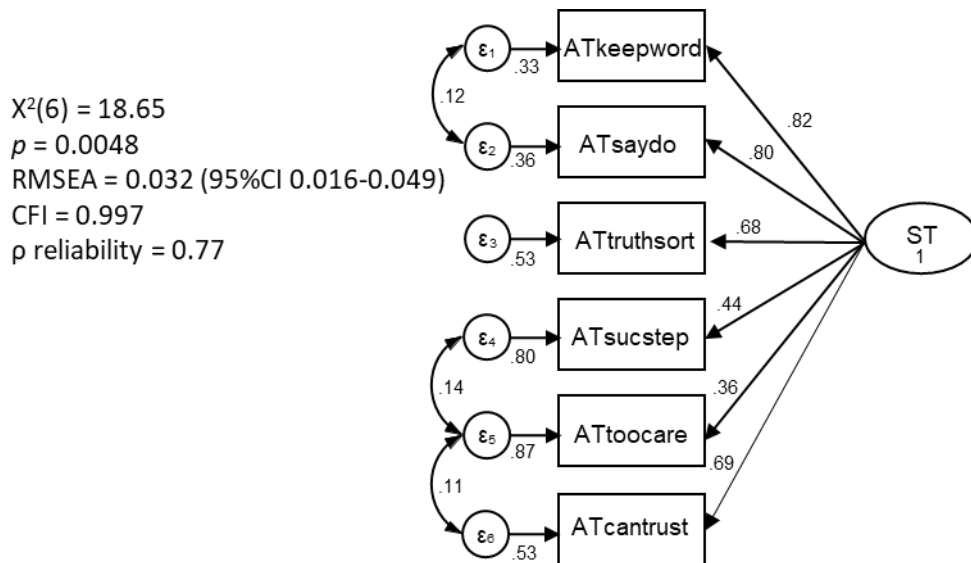
Factor score weights	ATkeepword	ATsaydo	ATsucstep	ATtruthsort	ATcantrust	ATtoocare
ST	0.249	0.222	0.198	0.168	0.167	0.028

Figure B5. Final model for Social Trust construct of personal social cohesion.

Trait Optimism (OPT: Overall, I expect more good things to happen to me than bad; In uncertain times, I always expect the best; If something can go wrong for me, it will; I'm always optimistic about my future)

All four items loaded significantly and strongly on the trait optimism (OPT) dimension, and the fit of the model was reaching adequacy: $\chi^2(2) = 30.76$, $p < 0.001$, RMSEA = 0.084 (95%CIs:0.059–0.111), CFI = 0.992. Following analysis of modification indices, we correlated errors between 'always expecting the best' (WEexbest) and 'always optimistic about my future' (WEopt); the positively framed items from the Life Orientation Test – Revised [38]. Correlating these error terms improved the adequacy of fit (Figure B6) and the correlation was significant at the $p < 0.001$ level. All four indicators of OPT had substantial standardised loadings (range: from 0.55 to 0.88). The resulting scale reliability was $\rho = 0.82$.
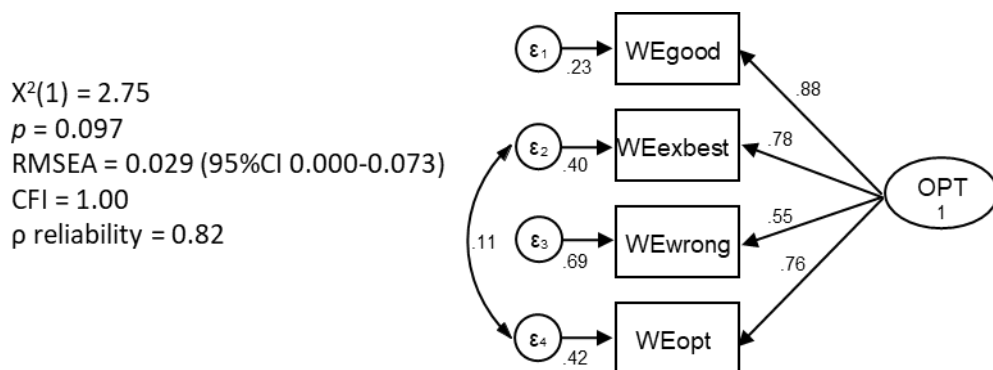
Factor score weights	WEgood	WEexbest	WEwrong	WEopt
OPT	0.452	0.200	0.275	0.185

Figure B6. Final model for Trait Optimism construct of personal social cohesion.

Construct		Stata		Amos [#]	
Informal Social Connection	x1: I make time to keep in touch with my friends	0.83	***	0.79	
	x2: I chat with my neighbours when I see them	0.60	***	0.62	***
	x3: I spend time with extended family members (relatives who don't live with me)	0.60	***	0.49	***
	RMSEA (95% CIs)	0.000(0.000–0.040)		0.071(0.030–0.119)	
	CFI	1.000		0.963	
Civic Engagement	x1: I take part in community-based clubs or associations (e.g., Rotary, CWA, book club, Lions)	0.81	***	0.63	
	x2: I go to arts or cultural events	0.45	***	0.34	***
	x3: I attend community events such as farmers' markets, festivals and shows	0.45	***	0.38	***
	x4: I take part in sports activities or groups	0.60	***	0.53	***
	x5: I volunteer locally (e.g., Meals on Wheels, school fete, Rural Fire Service)	0.79	***	0.66	***
	RMSEA (95% CIs)	0.058(0.041–0.078)		0.044(0.018–0.073)	
	CFI	0.991		0.989	
Sense of Belonging	x1: When I feel lonely there are several people I could call and talk to	0.83	***	0.78	
	x2: I have family or friends I can confide in	0.86	***	0.79	***
	x3: I feel that I'm on the fringe in my circle of friends (reverse scored)	0.43	***	0.34	***
	x4: I don't often get invited to do things with others (reverse scored)	0.45	***	0.35	***
	x5: There are people outside my household who can offer help in a crisis	0.73	***	0.67	***
	RMSEA (95% CIs)	0.048(0.028–0.071)		0.025(0.000–0.055)	
	CFI	0.997		0.999	
Feelings of Belonging	x1: I feel like an outsider (reversed scored)	0.67	***	0.67	
	x2: I feel that I belong	0.88	***	0.85	***
	x3: I feel included	0.88	***	0.85	***
	RMSEA	0.000(0.000–0.050)		0.000(0.000–0.067)	
	CFI	1.000		1.000	
Social Trust	x1: Most people keep their word	0.82	***	0.79	
	x2: Most people do what they say they'll do	0.80	***	0.78	***
	x3: Most people around here succeed by stepping on others (reverse scored)	0.44	***	0.32	***
	x4: Most people tell the truth when they're sorting out a problem	0.68	***	0.66	***
	x5: You can't be too careful with some people	0.36	***	0.34	***
	x6: Most people can be trusted	0.69	***	0.66	***
	RMSEA (95% CIs)	0.032(0.016–0.049)		0.011(0.000–0.036)	

Table B1. Comparison of CFA standardised factor loadings and model fit indices in Stata15 and Amos 25.

	CFI	0.997		0.998	
Trait Optimism	x1: Overall, I expect more good things to happen to me than bad	0.88	***	0.85	
	x2: In uncertain times, I always expect the best	0.78	***	0.74	***
	x3: If something can go wrong for me, it will (reversed scored)	0.55	***	0.44	***
	x4: I'm always optimistic about my future	0.76	***	0.72	***
	RMSEA (95% CIs)	0.029(0.000–0.073)		0.000(0.000–0.067)	
	CFI	1.000		1.000	

[#]Gaskin, J. & Lim, J. (2018), "Merge SRW Tables", AMOS Plugin; [***] $p < 0.001$; RMSEA – Root Mean Square Error of Approximation; CFI – Comparative Fit Index.

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After the Flood … partnership with community — Community recovery in the northern rivers

Community Recovery after Flood Survey – impact on mental health

Building resilience as adaptive strategy

Northern Rivers region ~200,000 pop
everyone ≥16 years, online & paper-based

Key groups: **people living with disadvantage**, farmers, business owners, older (+75) & younger (<25) ages, **Aboriginal & Torres Strait Islander**, LGBTIQ community

Exposure: various sites damaged (none, suburb, yard, home, business/farm, home of a loved one), displacement

Outcome: **post-traumatic stress** (PCL-6); anxiety (PHQ-2); depression (GAD-2); suicidal ideation; still distressed by flood?

Mediators: warning systems, post-disaster relief, insurance, **existing resilience** etc
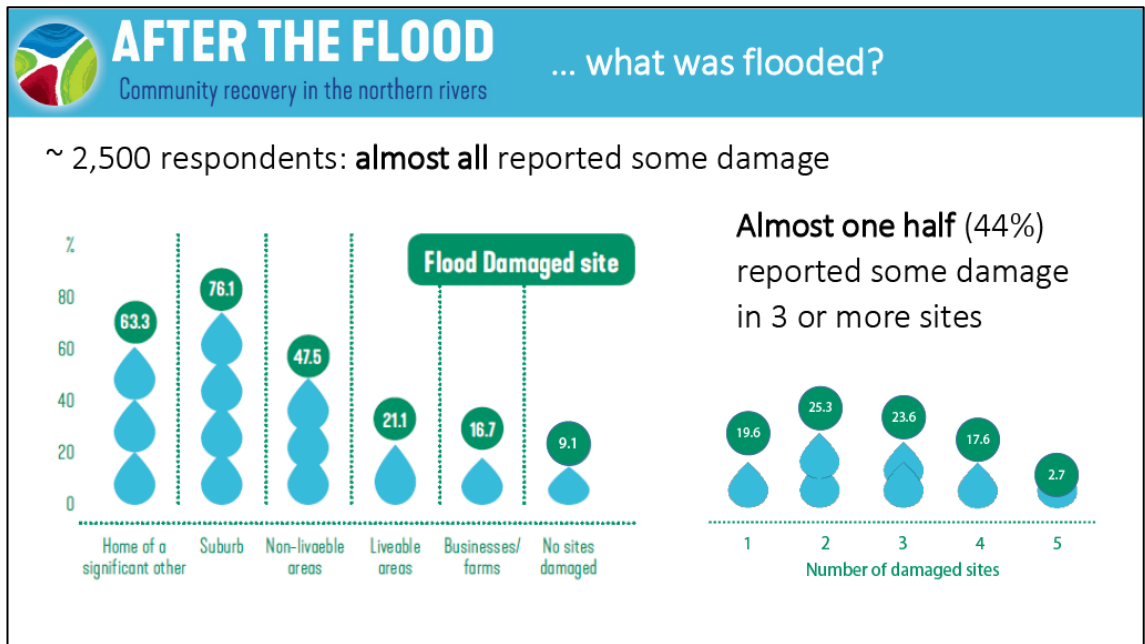
AFTER THE FLOOD ... what was flooded?
Community recovery in the northern rivers

~ 2,500 respondents: **almost all** reported some damage

Almost one half (44%) reported some damage in 3 or more sites

AFTER THE FLOOD
Community recovery in the northern rivers
... how respondents were affected

Of all respondents:

suicidal ideation 7%

probable PTSD 15%

22% reported being still distressed about the flood

About 20% reported two or more of these

probable anxiety 16%

15%

probable depression

Marginalised populations more impacted & affected
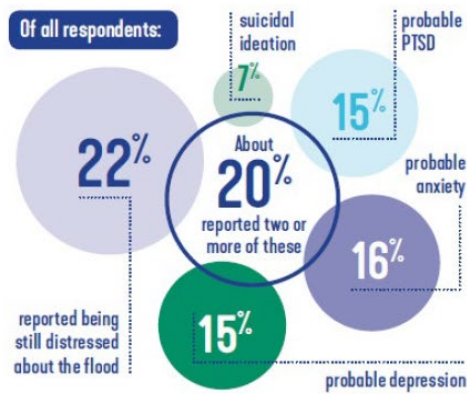
Flood damage (unadjusted)	In receipt of income support n=643 (vs no income support)	Aboriginal & Torres Strait Islander community n=77 (vs non-Indigenous)
Home flooded	●	●
Evacuated from home	●	●
Displaced ≥6mths	●	●
Mental health outcomes (after taking into account demographics & flood impact)		
Post-traumatic stress	●	
Anxiety	●	●
Depression	●	●
Suicidal ideation	●	

AFTER THE FLOOD
Community recovery in the northern rivers

Social environment & mental health

Social capital
- Community participation → Personal social cohesion → Health

↑ Mental health risk
↓ Social capital
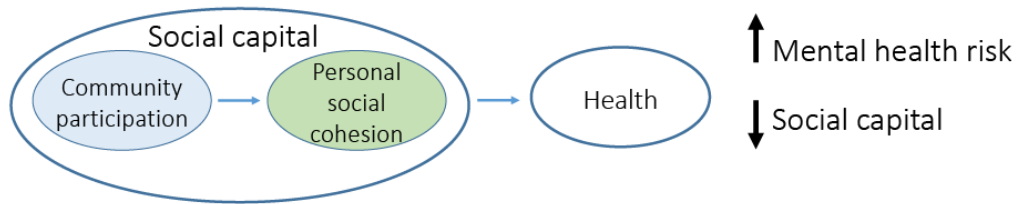
What people do... (more amenable to change)

Informal social connections: neighbours; friends; extended family etc

Civic engagement: volunteer, play sports, community-based clubs, arts and culture events etc

What people feel...

Sense of belonging

Social trust

Generalised reciprocity

Optimism

Berry & Welsh (2010), Berry & Shipley (2009)

Post-traumatic stress & resilience (adjusted for demographics & exposure)

Outcome: Probable post-traumatic stress Community Participation	Other respondents n=1,837	In receipt of income support n=543	Aboriginal or Torres Strait Islander n=65
Informal social connection	🟢		
Social Cohesion			
Sense / feelings of belonging	🟢	🟢	🟢
Enjoy time spent with others	🟢		
Like to spend more time socially with others		🔴	
Social trust	🟢		◯
Optimism	🟢	🟢	

🟢 = Protective factor   🔴 = Risk factor

AFTER THE FLOOD
Community recovery in the northern rivers

... where to from here

Key message: thorough understanding of community context for effective interventions to build resilience and adaptive capacity

What's next:
- Two-year follow-up survey (out now)
- Continued community collaboration:
  communicating, making sense of results
  priorities for future analysis/research/interventions
- Developing application for ongoing longitudinal study

AFTER THE FLOOD
Community recovery in the northern rivers

Acknowledgements/Contact

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- Community Advisory Groups
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http://ucrh.edu.au/after-the-flood

References:

Hirabayashi, et al. Global flood risk under climate change. Nature Climate Change. 2013;3:816; Berry & Welsh. Social capital and health in Australia. Social Science & Medicine. 2010;70(4):588; Berry & Shipley. Longing to belong: personal social capital and psychological distress in an Australian coastal region. Dept of Families, Housing, Community Services & Indigenous Affairs, 2009.

Flooding, mental health and equity: lessons for building resilience within Northern NSW

Veronica Matthews, Maddy Braddon, Jo Longman, James Bennett-Levy, Ross Bailie, Megan Passey, Geoff Morgan, Margaret Rolfe, Sabrina Pit, Jason Agostino, Helen Berry

Australian Public Health Conference, Adelaide, 2019

2017: ex-tropical cyclone Debbie

absence of typical conditions

extreme rainfall within 24hrs

climate change: more flooding predicted eastern Australia
(Hirabayashi et al 2013)

(The Conversation: http://theconversation.com/northern-nsw-is-no-stranger-to-floods-but-this-one-was-different-75701)

Northern NSW is no stranger to floods, but this one was different
April 7, 2017 5.31am AEST

Hirabayashi, et al. Global flood risk under climate change. Nature Climate Change. 2013;3:816

AFTER THE FLOOD
Community recovery in the northern rivers

Aims

Artist: Theresa Mason

Learning with community to inform the future:

- impact on psychological wellbeing? (short & long term)

- how to mitigate adverse impact, build on community strengths (social capital)?

- differences across groups (marginalised subpops)?

AFTER THE FLOOD ... timeline
Community recovery in the northern rivers

FLOOD
30 Mar-1 Apr
2017

Visit by
Public
Health
England

Survey 1
Sept-Oct
2017
(6 mths)

1 year on
2018

2 years on
2019

Survey 2
April-May

Public
meetings

Develop Flood Impact
Conceptual Framework

Community
Advisory Groups

AFTER THE FLOOD ... partnership with community
Community recovery in the northern rivers

Conceptual framework - flood impact on mental health & wellbeing

Longman et al. BMC Public Health. 2019;19(1):1255.

Building resilience as an adaptive strategy

At six months (Sept 2017)

Northern Rivers region ~200,000 pop
everyone ≥16 years, online & paper-based

Key groups: **people living with disadvantage**, farmers, business owners, older (+65) & younger (<25) ages, **Aboriginal & Torres Strait Islander, LGBTQ+ community**

Exposure: various sites damaged (none, suburb, yard, home, business/farm, home of a loved one), displacement

Outcome: **post-traumatic stress** (PCL-6); **anxiety** (PHQ-2); **depression** (GAD-2); suicidal ideation; still distressed by flood?

Mediators: warning systems, post-disaster relief, insurance, **existing social capital** etc

---

AFTER THE FLOOD
Community recovery in the northern rivers

... who took part in the survey?

More than **2,500** people responded to the survey

60% were women

8% were farmers

31% were business owners

48% were from Lismore
24% were from Tweed
20% were from other LGAs
(Byron, Ballina, Kyogle, Richmond Valley)

3.5% Aboriginal / Torres Strait Islander

6.8% LGBTQ+

31.8% Income support recipients*

*At time of the flood: age pension; veteran payment; single parent support; unemployment support; youth allowance; education support; disability support pension; carer payment

74

AFTER THE FLOOD
Community recovery in the northern rivers

... what was flooded?

~ 2,500 respondents: **almost all** reported some damage
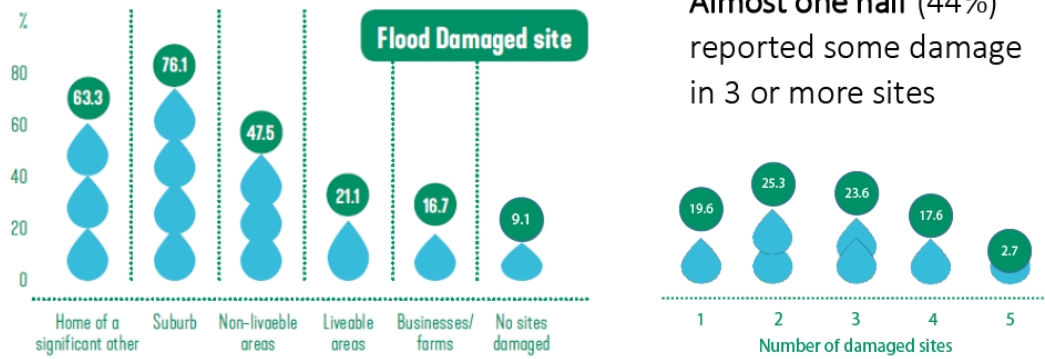
%
80
60
40
20
0

63.3

76.1

47.5

21.1

16.7

9.1

Flood Damaged site

Home of a significant other | Suburb | Non-livaeble areas | Liveable areas | Businesses/ farms | No sites damaged

Almost one half (44%) reported some damage in 3 or more sites

19.6

25.3

23.6

17.6

2.7

1 | 2 | 3 | 4 | 5

Number of damaged sites

AFTER THE FLOOD
Community recovery in the northern rivers

... how respondents were affected

Of all respondents:

22% reported being still distressed about the flood

suicidal ideation 7%

About **20%** reported two or more of these

probable PTSD 15%

probable anxiety 16%

15% probable depression
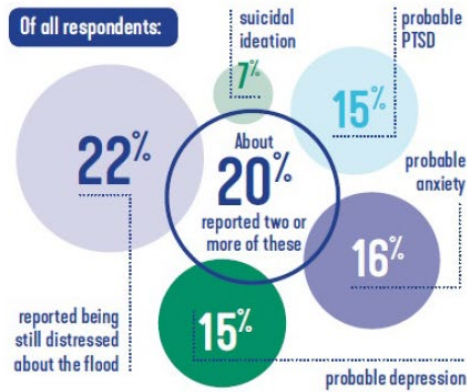
AFTER THE FLOOD
Community recovery in the northern rivers

... flood & mental health risk (logistic regression)

😑 Probable PTSD 😖 Probable anxiety 😫 Probable depression

INCREASED RISK

Business/farm flooded
- 10
- 4.9
- 4.6

Home flooded
- 12
- 4.6
- 4.3

Displaced ≥6 months
- 27
- 16
- 8.2

SEPT

NO EXPOSURE
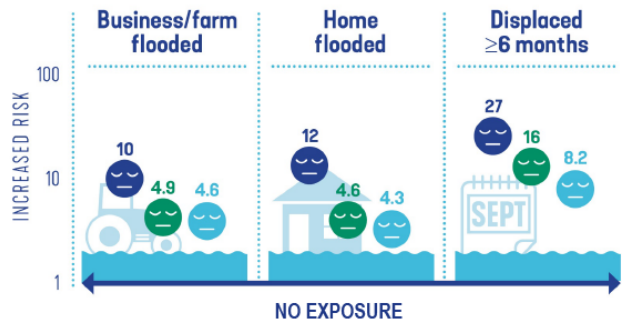
Compared to no damage, higher risk for respondents:

- whose properties were flooded

- who endured lengthy displacement

(after adjusting for age, sex, indicators of disadvantage)

Marginalised populations more impacted & affected (6 months, odds ratio 95%CI)

Flood damage (unadjusted)	In receipt of income support n=645 (vs no income support)	Aboriginal & Torres Strait Islander n=71 (vs non-Indigenous)	LGBTQ+ community n=139 (vs non-LGBTQ+)
Home flooded	2.08 (1.66-2.61)***	2.24 (1.34-3.73)**	1.85 (1.26-2.72)**
Evacuated from home	2.23 (1.73-2.88)***	3.00 (1.78-5.04)**	1.76 (1.16-2.66)**
Displaced ≥6mths	3.55 (2.24-5.64)***	2.81 (1.24-6.36)*	2.18 (1.09-4.37)*
Mental health outcomes (after taking into account demographics# & flood impact)			
Post-traumatic stress	1.60 (1.17-2.18)**	2.49 (1.41-4.39)**	2.15 (1.32-3.52)**
Anxiety	1.45 (1.08-1.96)*	2.95 (1.71-5.09)***	1.98 (1.24-3.16)**
Depression	1.50 (1.12-2.04)**	2.83 (1.63-4.91)***	1.45 (0.88-2.40)

#Demographics: age, sex, relationship status, education qualification, employment status
*p ≤ 0.05 **p≤0.01 ***p≤0.001

AFTER THE FLOOD
Community recovery in the northern rivers

... socio-economic groups

Based on flood map & ABS data – 2017 flood footprint

	Lismore township (N=5041)*		Tweed (N=5656)*		Northern Rivers** (N=239,604)	Greater Sydney Region (N=~5 mil)
	n	%	n	%	%	%
1st (lowest)	4587	91.0	2828	50.0	28.5	16.6
2nd	318	6.3	1761	31.1	31.2	15.8
3rd	128	2.5	873	15.4	24.7	18.0
4th	8	0.2	323	5.7	14.0	21.8
5th (highest)	0	0	0	0	1.7	27.8

Majority of people directly affected in flooded areas come from lowest two socio-economic groups - both in Lismore township (97%) & Tweed region (81%).

*Usual resident population, ABS 2016
**Richmond-Tweed SA3

AFTER THE FLOOD
Community recovery in the northern rivers

Social environment & mental health

Social capital

Community participation → Personal social cohesion → Health

↑ Mental health risk
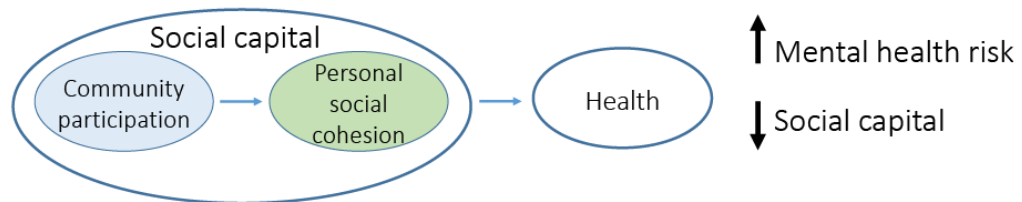
↓ Social capital

What people do... (more amenable to change)

What people feel...

Berry & Welsh. Social capital and health in Australia. Soc Sci Med 2010;70(4):588

AFTER THE FLOOD
Community recovery in the northern rivers

Social environment & mental health
(n = 1,900)

Social capital

Community participation → Personal social cohesion → Health
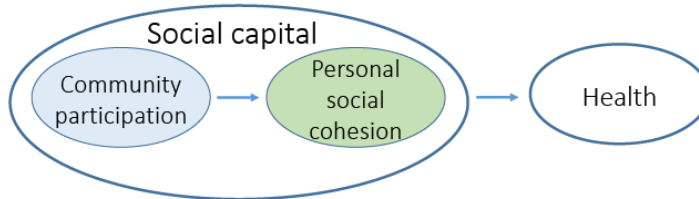
↑ Mental health risk
↓ Social capital

What people do... *(disagree/agree 7 point scale)*

Informal social connections: "active social life" "spontaneous & flexible"
eg chat with neighbours; spend time with friends, extended family; active on social media

Civic engagement: "organised aspects of community life"
eg volunteer; participate in sports; community-based clubs; arts/culture & community events

Berry et al. Preliminary development & validation of an Australian community participation questionnaire. Soc Sci Med. 2007;64(8).

AFTER THE FLOOD
Community recovery in the northern rivers

Social environment & mental health
(n = 1,900)

Social capital

Community participation → Personal social cohesion → Health
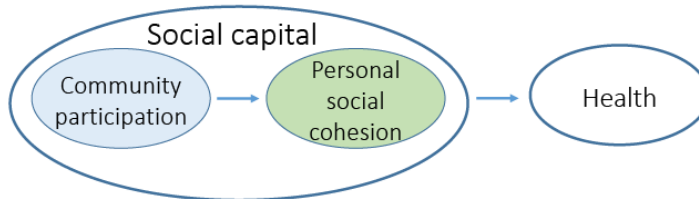
↑ Mental health risk
↓ Social capital

What people feel... *(disagree/agree 7 point scale)*

Sense of belonging (ISEL)   someone to talk to if lonely; don't often get invited to things; people outside of household that can offer support in crisis

Social trust (OTI/WVS)   most people tell the truth/keep their word, most people can be trusted

Reciprocity (WVS)   most people try to be helpful; most people look out for themselves

Optimism (Scheier etal 1994)   expect good things to happen; always optimistic

Berry & Shipley. Longing to belong: personal social capital and psychological distress in an Australian coastal region. FACSIA, 2009

AFTER THE FLOOD
Community recovery in the northern rivers

Methods: CFA, hierarchical logistic regression

Impact of flooding

Personal factors & social capital
demographics, community participation, social cohesion

Mental health & wellbeing
1. PTS
2. Anxiety
3. Depression
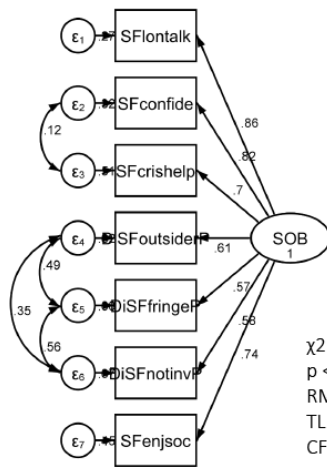
$\chi 2(10) = 31.63$
$p < 0.001$
RMSEA = 0.033 (0.02-0.046)
TLI = 0.994
CFI = 0.997
ρ reliability = 0.81

A. Socio-demographic factors
B. Flood impact (severity scale, how many locations damaged)
C. Community participation
D. Social cohesion

Social capital measures at 6 months (Mean(SD) scale 1 to 7)

Community participation	Other respondents n=1,281	In receipt of income support n=645	Aboriginal & Torres Strait Islander n=71	LGBTIQ+ community n=139
Informal social connection	5.33 (1.13)	5.26 (1.25)	4.98 (1.29)*	5.31 (1.00)
Civic engagement	4.14 (1.35)	4.15 (1.44)	3.90 (1.39)	4.25 (1.35)
Personal social cohesion				
Sense of belonging	5.36 (1.04)	5.07 (1.14)***	4.85 (1.36)***	5.11 (1.03)**
Optimism	5.04 (1.07)	4.80 (1.19)***	4.48 (1.42)***	4.81 (1.10)*
Social trust	4.76 (0.97)	4.60 (1.05)***	4.17 (1.20)***	4.74 (0.81)
Reciprocity	4.30 (0.96)	4.20 (0.99)*	4.01 (1.14)*	4.32 (0.79)

Independent t-test (subgroups vs 'other') *p<0.05 **p<0.01 ***p<0.001

Flood impact & resilience – probable PTS (6 months, odds ratio 95%CI)

Outcome: Probable PTS Adjusted for socio-demographics[#]		Other respondents (n=1,169)	In receipt of income support (n=645)	Aboriginal or Torres Strait Islander (n=71)	LGBTQ+ community (n=139)
Flood impact	🔵	2.38 (1.98-2.85)***	1.71 (1.42-2.05)***	1.61 (1.01-2.56)*	2.23 (1.41-3.54)**
Community Participation					
Informal social connection	🟢	0.64 (0.54-0.76)***	0.73 (0.61-0.87)**		
Social Cohesion					
Sense of belonging	🟢	0.56 (0.45-0.70)***	0.65 (0.46-0.92)*	0.30 (0.15-0.60)**	0.34 (0.18-0.65)**
Like to spend more time socially with others	🔵		1.72 (1.07-2.77)*		
Optimism	🟢	0.67 (0.53-0.84)**	0.78 (0.62-0.99)*		
Social trust	🟢	0.82 (0.68-0.98)*			

🟢 Protective factor
🔵 Risk factor

#Demographics: age, sex, relationship status, education qualification, employment status

*p≤0.05 **p≤0.01 ***p≤0.001

At 2 years (Apr 2019)

Target: 1st survey respondents who agreed to follow-up (n=1,265) online & paper-based

approx **40% responded** (n=488)

- 1.6% Aboriginal / Torres Strait Islander
- 11% LGBTQ+
- 25% Income support recipients

Mediators: health service supports, financial supports, existing social capital etc

Outcomes: same measures, post-traumatic stress (PCL-6); anxiety (PHQ-2); depression (GAD-2)

At 2 years (Apr 2019)

Target: 1st survey respondents who agreed to follow-up (n=1,265) online & paper-based

approx **40% responded** (n=488)

- 1.6% Aboriginal / Torres Strait Islander
- 11% LGBTQ+
- 25% Income support recipients

Exposure:

- 8.3% (vs 9.1%) No exposure
- 27% (vs 21%) Liveable areas flooded
- 52% (vs 44%) Damage in ≥ 3 sites

Outcomes:

- 18.0% probable post-traumatic stress
- 18.6% probable anxiety
- 15.7% probable depression
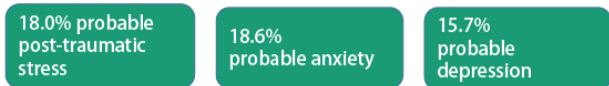
Change in social capital measures at 2 years (Mean (SD) scale 1 to 7)

	Other respondents n=328		In receipt of income support n=107		LGBTIQ+ community n=54	
Community participation	2017	2019	2017	2019	2017	2019
Informal social connection	5.41 (1.11)	5.40 (1.15)	5.18 (1.26)	5.07 (1.38)	5.20 (1.13)	5.16 (1.09)
Civic engagement	4.27 (1.33)	4.39 (1.32)	4.15 (1.46)	4.16 (1.39)	4.32 (1.41)	4.24 (1.53)
Personal social cohesion						
Sense of belonging	5.33 (1.11)	5.25 (1.11)	5.21 (1.08)	4.93 (1.24)**	5.12 (1.05)	5.04 (1.27)
Optimism	4.99 (1.06)	4.93 (1.10)	4.83 (1.16)	4.62 (1.19)**	4.75 (1.04)	4.65 (1.04)
Social trust	4.85 (0.96)	4.77 (1.01)	4.64 (0.97)	4.63 (1.12)	4.69 (0.81)	4.80 (0.97)
Reciprocity	4.34 (0.91)	4.36 (0.89)	4.26 (0.89)	4.17 (1.10)	4.28 (0.83)	4.24 (0.95)

Paired t-test *p<0.05 **p<0.01 ***p<0.001

AFTER THE FLOOD
Community recovery in the northern rivers

Other resilience stories

Qu: 'Thinking back, have the severe rain & flood resulted in you being able to make any positive changes in your life?'

5 categories of positive stories:

"Now doing a degree to further my education, to have back-up options if a flood occurs again & we no longer have work"

In own lives/family lives

"Looking after myself better.." "More massage" "Doing more activities, art, singing, dancing, writing, going out more"

Increased awareness / motivation for self care

In physical home

"Ended up cleaning, painting the house" "Decluttered" "Lifted items off the floor… built high shelving for possible future floods"

Community/place/environment

"Community as a whole is much stronger" "Seeing how everyone pulls together & helps each other out"

Belonging & participation

"Motivation to volunteer" "Friendships developed… community networks strengthened"

AFTER THE FLOOD
Community recovery in the northern rivers

Strengths & limitations

- cross-sectional design, limits ability to untangle cause and effect

- results relate to survey respondent group only – can't be extrapolated to broader pop

- lack of validated measures for particular subgroups, small numbers for some subgroups

✓ findings align with social capital theory

✓ new information related to social capital following flood amongst subpops

✓ provide focus for future intervention research

AFTER THE FLOOD
Community recovery in the northern rivers

Key messages

Understanding of community context for effective interventions to build resilience & adaptive capacity

1. Disproportionate effects across groups – requires **equity focus**
2. **Sense of belonging** key protective factor for all
3. **Prolonged psychological impact**
4. **Community partnerships** key to furthering understanding, develop strategies, build on strengths
5. **Resourcing** issues – advocacy

AFTER THE FLOOD
Community recovery in the northern rivers

Acknowledgements/Contact

Thank you

- OUR COMMUNITY
- Community Advisory Groups
- Survey piloters & doorknockers
- Funders:

veronica.matthews@sydney.edu.au

http://ucrh.edu.au/after-the-flood

AFTER THE FLOOD
Community recovery in the northern rivers

Mental health in the aftermath: initial findings from the community recovery after flood survey
The University Centre for Rural Health (The University of Sydney)

Dr Veronica Matthews
Dr Jo Longman
August 2018

Background

In late March/early April 2017 extreme rainfall from ex-Tropical Cyclone Debbie resulted in unprecedented water rises in rivers in the Northern Rivers. Almost all of the rain fell within 24 hours and flooded many regions of the Northern Rivers inundating the major population towns of Lismore and Murwillumbah, with extensive damage to housing and infrastructure. For many areas it was as severe as the worst flood on record (1974). The intensity of extreme rainfall experienced in eastern Australia, including northern NSW, is likely to increase due to global warming.

Floods are the most expensive weather-related event experienced in Australia. Whilst damage to the built and natural environment, and in some instances physical health, from flooding is immediately evident, floods also harm mental health and wellbeing. These harms are substantial.

What we know about floods and mental health and wellbeing is that there are short and longer-term impacts, and that vulnerable communities are affected the most. At the UCRH therefore, part of our analysis has focused on key populations including people identifying as LGBTIQ+, young people, older people, people identifying as Aboriginal and/or Torres Strait Islander and people living with the most socio-economic disadvantage. What we don't know is much around *river* flooding in *rural* areas or about the underlying risk within our own Northern Rivers community and the likely impacts of the floods. Therefore, in September-November 2017 (6 months after the flood) we undertook a cross-sectional survey of the community about their flood experience and mental health and wellbeing. Mental health and wellbeing was measured in five ways: still distressed about the flood, post-traumatic stress disorder (PTSD), anxiety, depression and suicidal ideation.

Results (all respondents)

More than **2,500** people responded to the survey

60% were women

8% were farmers

31% were business owners

48% were from Lismore

24% were from Tweed

20% were from other LGAs (Byron, Ballina, Kyogle, Richmond Valley)

3.3% Aboriginal

6% LGBTIQ+

1 | P a g e
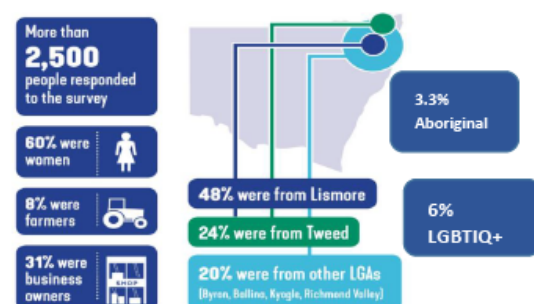
AFTER THE FLOOD

Community recovery in the northern rivers

Age groups of all survey respondents compared to the Northern Rivers population:

Age groups:
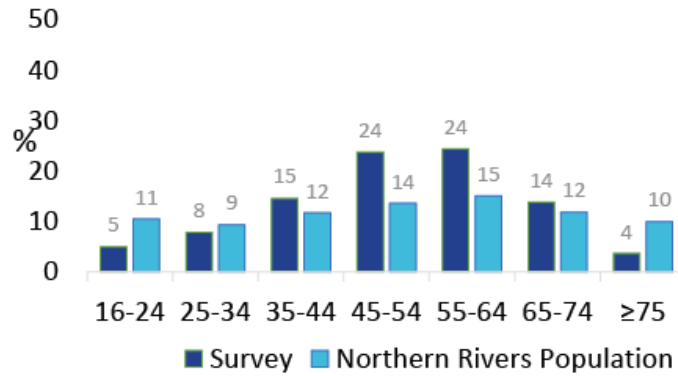
■ Survey ■ Northern Rivers Population

How all respondents were affected:

Of all respondents:

22% reported being still distressed about the flood

About 20% reported two or more of these

suicidal ideation 7%

probable PTSD 15%

probable anxiety 16%

probable depression 15%
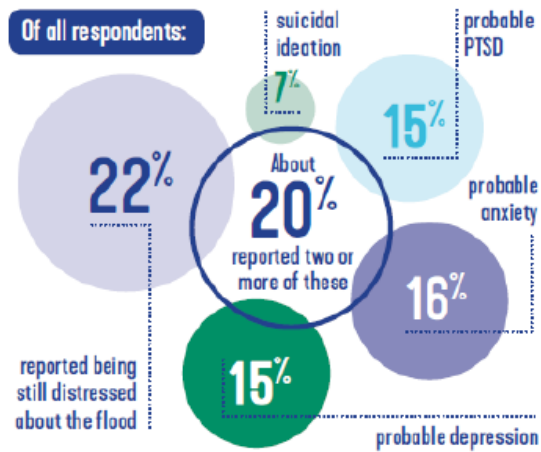
Results for LGBTIQ+ respondents

Quantitative data from LGBTIQ+ respondents

139 (6%) respondents identified as being LGBTIQ+. The following tables provide a comparison of descriptive and logistic regression analysis across LGBTIQ+ and non-LGBTIQ+ population groups regarding demographics, flood experience and mental health outcomes. *NB: Numbers across categories may not tally to total respondents due to missing information in the questionnaires.*

Table 1: Socio-demographic characteristics of survey respondents by LGBTIQ+ status.

			LGBTIQ+		Non-LGBTIQ+	
		Total respondents	**139**		**1,191**	
			n	(%)	n	(%)
Gender	Female		96	(69)	814	(68)
identity	Male		40	(29)	364	(31)
	Non-binary		3	(2)		
Age group	≥16-34years		23	(17)	167	(14)
	≥35-54years		73	(52.5)	457	(39)
	≥55-74years		42	(30)	490	(42)
	≥75years		1	(1)	63	(5)
Education	University degree or higher		81	(59)	488	(41)
level	Other		57	(41)	691	(59)
Employment	Unemployed/retired		42	(30)	395	(34)
status	Employed		96	(70)	779	(66)
Income	In receipt of income support		56	(41)	385	(33)
support#	Not in receipt of income support		81	(59)	782	(67)

#Income support payments at time of flood includes age pension, single parent support, unemployment support, youth allowance and disability support pension.

Table 1 shows that higher proportions of LGBTIQ+ respondents were younger (under 55 years), university educated and in receipt of income support compared to non-LGBTIQ+ respondents.

Table 2: Survey respondents' report of flood damage sites, evacuation and displacement (n&%). Results of univariate and logistic regression analyses shown with significant associations asterisked (*p<0.05; **p<0.001)

		Descriptive analysis				Statistical analysis (Ref group = Non-LGBTIQ+)	
		LGBTIQ+		Non-LGBTIQ+			
	Total respondents	**139**		**1,191**		**1,330**	
		n	(%)	n	(%)	Odds ratio	95% CI
Sites of flood damage, evacuation and displacement	No damage	11	(8)	135	(11)		
	Home of significant other	98	(71.5)	734	(63)	1.50	(1.02-2.22)*
	Suburb damaged	112	(81)	910	(76.5)	1.27	(0.82-1.98)
	Non-liveable area	79	(57)	565	(48)	1.43	(1.00-2.04)
	Liveable area	51	(37)	249	(22)	**2.15**	**(1.48-3.13)****
	Home evacuation	40	(29)	190	(16)	**2.10**	**(1.41-3.13)****
	Had to live elsewhere	32	(23)	186	(16)	1.58	(1.03-2.43)*
	Displaced >6mths	10	(7)	42	(4)	2.10	(1.03-4.28)*
	Business/farm damaged	18	(13)	206	(18)	0.84	(0.44-1.63)
Number of above sites damaged	1	25	(18)	239	(20)		
	2	25	(18)	301	(25)		
	3	37	(27)	282	(24)		
	4	33	(24)	193	(16)		
	5	8	(6)	41	(3)		

Table 2 shows that LGBTIQ+ respondents had twice the odds of reporting their homes flooded, having to evacuate and being displaced for more than 6 months in comparison to non-LGBTIQ+ respondents.

Table 3: Survey respondents' report of mental health outcomes (n&%). Results of multivariate logistic regression analyses also shown with significant associations asterisked (*p<0.05; **p<0.001).

		Descriptive analysis				Statistical analysis[#] (Ref group = Non-LGBTIQ+)	
		LGBTIQ+		Non-LGBTIQ			
	Total respondents	**139**		**1,191**		**1,330**	
		n	(%)	n	(%)	Odds ratio	95% CI
Mental health outcomes	Still currently distressed	42	(30)	247	(21)	1.35	(0.87-2.09)
	Probable post-traumatic stress	40	(29)	163	(14)	**2.47**	**(1.55-3.96)****
	Probable anxiety	41	(30)	167	(15)	**2.43**	**(1.56-3.78)****
	Probable depression	32	(23)	171	(15)	1.64	(1.03-2.63)*
	Any suicidal ideation	24	(17)*	77	(7)	**2.61**	**(1.54-4.45)****

[#]Adjusted for socio-demographic characteristics in Table 1 (income support, education level, employment status) and degree of flood exposure, ie, number of sites damaged presented in Table 2.

Table 3 shows that at six months post-flood, LGBTIQ+ respondents had over twice the odds of reporting symptoms of PTSD, anxiety and having suicidal thoughts compared to non-LGBTIQ+ respondents.

Qualitative data from LGBTIQ+ respondents

In the questionnaire, we offered respondents eight opportunities to write about their experiences and views. Here is what respondents identifying as LGBTIQ+ said. With the exception of the marriage equality comment, the content of these comments is similar to comments from non-LGBTIQ+ respondents.

SECONDARY STRESSORS (issues and situations that were a source of stress after the flood but related to it)

Marriage equality

"I should also say that the marriage equality debate and postal survey has also been - and continues to be - deeply impactful.... a second disaster that has caused immense harm. I'm thinking only now how those 2 things combined could have a particular and compounded impact on LGBTIQ+ people and communities in the Northern Rivers" No. 2024

Issues with flood insurance

26 of the 58 comments (45%) from people identifying as LGBTIQ+ coded to 'secondary stressors' were about insurance. 3 of them (5%) were positive and 95% were negative.

- Flood insurance too expensive/unaffordable
- Unable to get flood insurance
- Insurance company would not pay out
- Inconsistency – *"I know people in exactly the same circumstances as me and because their assessor ticked flood instead of cyclone they got nothing"* (No. 1751)
- Too slow
  - Paying out
  - Assessing
  - Resolving disputes
  - Repairing (insurance company builder taking a long time to do repairs – No. 196)
- Too hard to deal with/lack of support from insurance company
  - *"I am covered for flood at my home by my insurance company but I'm finding it almost impossible to deal with them as they are not understanding or supportive. I get extremely distressed having to contact them & push them to do what they should be doing. I feel like I need to be assertive & clear with them so I don't get underpaid but I keep crying & I don't have all the answers even about what I have lost & what everything is worth let alone the damage to the building. It's really overwhelming & traumatic & I'm crying heaps now just thinking about it."* (No. 94)
- Distress linked to insurance experiences
- Suggestions for improvements to insurance
  - Help/support/advocacy in dealing with insurance companies
  - Correct the situation where the Government declares the damage to be storm-related not a flood yet insurance companies will not pay out as they say it was a flood and the person has no flood insurance
  - Use of the Queensland model where the state underwrites the insurance (No. 440)

Issues with accommodation

- Some respondents were still displaced – *"To this day, and 6 months after the flood I am still living elsewhere and my property (in Lismore CBD) is still completely guttered… this has taken a huge toll emotionally, as well as physically as I had some help to clean up, but not much ongoing"*
- Highly disruptive having to find a new home

Issues with disaster relief payments

Respondents felt that:

- disaster relief payments were inadequate
- loans were inappropriate
- support payments should qualify on address

Issues with long term disruption – practical, physical and emotional

Respondents described various scenarios in which their lives were still considerably disrupted because of the flood including living arrangements, work, study, financial situation and still cleaning up to be done. Some respondents' described negative health effects, exhaustion, anxiety, stress and other emotional responses such as grief six months after the flood - *"there is a great grief in watching mould grow everywhere from your mattress to your family photos to your work clothes" (No. 493)*. Some of the distress was about being close to other people's trauma.

Issues with waste

There was a common concern about waste going into landfill, and suggestions about using creative resources in Lismore for restoring flood damaged items.

SUGGESTIONS FOR WARNING SYSTEMS AND EVACUATION

- Listen to locals (those with local knowledge of flooding) – this included the SES being controlled locally
- Personalise warnings, give earlier warnings, give consistent warnings
- More coordinated evacuation of the centre of town required, given it is known how Lismore floods
- Some respondents unable to evacuate as nowhere to go
- Need resiliency, flood and weather literacy training, and an updated flood action outline for big weather events including where to park cars, where to take pets, how to empty and move house/business contents
- Keep people engaged with community preparedness – embed a few significant activities in the community calendar that check in with preparedness
- Collate a register of spare rooms in people's houses to help those unable to return to theirs

SUGGESTIONS FOR COUNCILS

- Affordable housing that is not in the flood zone is required
- Educate people in e.g. understanding the BOM site, practising packing up etc.
- Install visual flood height reminders around the town
- Improve drains
- Consider better ways to handle the waste e.g. people willing to repair items
- Create a permanent 'wall' in the CBD of 'success' based stories
- Give the population instruction on how best to help others, and establish volunteer coordination earlier

SUGGESTIONS FOR SERVICES OR SUPPORTS NEEDED

- Accommodation (see secondary stressors above)
- Improved supports for homeless people
- More mental health services (telephone, support groups), people are still very distressed – suggestion of door knocking to overcome hesitancy
- Improved ongoing support (including mental health support) for flood victims who lost everything
- A helpline for the time of the disaster
- A volunteer task force who can help with pack up before the next flood
- Support people interacting with insurance companies (see secondary stressors above)
- Support for people cut off for days without utilities, food, water

Chapter 3: Longitudinal Cohort Study of Long Term Mental Health After Flooding in a Rural Community – Less About the Event, More About What Has or Hasn't Happened Since

Preface

A goal of the Community Recovery after Flood project was to form a basis for a longitudinal cohort study to assess the short- (1–2 years) and medium-term (3–5 years) mental health and wellbeing outcomes of Northern Rivers' communities affected by flood and associated needs, improving understanding of mental health and wellbeing effects over time. Within the six-month post-flood questionnaire, we asked respondents if they would be willing to be contacted in the future about possibly taking part in further research about the flood. Half of the respondents (n=1,265) to the six-month survey provided their contact information (phone, email and/or address) for follow-up. Together with the project's Community Advisory Groups, the UCRH 'flood team' developed and implemented a follow-up survey. We retained the same mental health outcomes and social capital measures and included questions on issues such as ongoing problems from the flooding for homes and businesses, outcomes of insurance claims and financial support applications, and health and wellbeing services accessed and whether they met respondent's needs.

My coordination of the first phase continued into this second phase of the project which specifically involved leading the design and development of the research protocol (Appendix 1) and year two survey, seeking ethics clearance and setting up the dissemination system based on respondent contact details. The questionnaire was set-up for online distribution (Qualtrics) and a paper version for mail distribution (Appendix 2). We had ethical approval to contact respondents a maximum of three times requesting their participation in the follow-up survey. The survey was open for a period of three weeks between 5th April and 10th May 2019. The mode of communication to invite participation varied depending on the type of contact information provided in the first survey. Where possible, online invitations were sent as this was our preferred method of collection data (paper versions required manual entering of data).

Due to level of incomplete socio-demographic data from respondents in the first survey (14%; n=350), two versions of the two-year survey were created: one that re-asked static socio-demographic questions again (five questions: age, born in Australia or overseas, primary language, Indigenous status, gender) and another version with these questions removed to reduce length and risk of survey fatigue.

Once data was collected, I performed the data analysis examining changes in self-reported mental health over time and the impact of secondary stressors related to the flood (including persistent home/business damage and insurance disputes) to improve understanding of long-term mental health following a major flood event. This chapter presents the findings of that analysis written for submission to a peer-reviewed journal. A plain language summary will be prepared for presentation and discussion with the Community Advisory Groups.

Lessons Learnt

Having two versions of the survey coupled with the complex survey dissemination system led to mistakes in relation to which survey version was sent to which respondent. As a result, our attempt at gathering missing socio-demographic questions failed and in retrospect, it would have been much simpler to have one survey version with all questions included.

The response rate meant we were unable to carry-out sub-group analysis for key interest groups such as Aboriginal respondents and respondents on income support. Limited resourcing prevented us from pre-advertising the follow-up opportunity among the study cohort which would have raised awareness and may have improved the participation rate.

Sending advance notice in combination with reminders as has been found to significantly improve the response rate in the 45 and up cohort study (1).

Public Health Implications

There is a shortage of research into the mental health effects on communities from river flooding, particularly in the longer term and in rural contexts. Our previous survey findings have improved understanding of the local context by highlighting the relationship between severity of flood exposure and mental health outcomes, including for respondents most in need (6). Findings from the two-year survey show minimal change in mental health outcomes of respondents between survey timepoints. Flood-related stressors experienced after the event contributed to ongoing distress and PTSD, highlighting a need to understand implications of various follow-on effects (persistent home or business damage/insurance disputes) and develop strategies to mitigate their impact. As per findings presented in Chapter 2, connectedness, belonging and trust were important factors lessening the risk of negative mental health outcomes. Results have improved our understanding of the extent to which mental health and wellbeing needs were being met after the flood (as per proposed pathways in the Flood Impact Framework (Chapter 2, Figure 1). Findings will be further interpreted with the project Community Advisory Groups and used to inform the strengthening of local policy and practice for flood preparedness and disaster response planning.

Abstract

There is increasing evidence that exposure to extreme weather-events such as floods adversely affects mental health for extended periods. In 2017, northern NSW experienced extensive flooding profoundly impacting community, particularly those who were flooded and displaced. To determine long-term mental health impact, we co-designed a two-year follow-up survey with community representatives for respondents who had consented to follow-up at an initial six-month survey. Thirty-six percent of the initial respondents (n=455) were included in the two-year analysis with 48 classified as non-disrupted, 108 disrupted and 299 flooded (homes and/or businesses). There was minimal improvement in mental health outcomes for respondents since the first survey six months after the 2017 flood. For flooded participants, rates of ongoing distress significantly increased from 40% to 55%. After adjustment for socio-economic confounders, the odds of adverse mental health outcomes were significantly higher in the flooded group compared to the non-disrupted/indirectly disrupted group for ongoing distress (OR 4.38, 99% CI 2.39–8.00) and probable PTSD (OR 6.15, 99% CI 2.00–18.84). Flooded participants were more likely to report persistent housing/business premises issues from the

flood (e.g., visible mould, structural complaints, reduced business income) and general stressors such as relationship issues and illness or injury. These more recent stressors were critical predictors of adverse mental health outcomes reported at two years even when severity of flood exposure was taken into consideration. Perceptions of informal social connectedness and belonging were important predictors of positive mental health outcomes over the study period. Resilient recovery after flood events needs to be supported by mental health service planning that considers the variety of secondary stressors experienced by affected communities over the longer term and invests in mechanisms that build social connectedness and belonging within community.

Background

The frequency of extreme weather events is rapidly increasing due to climate change resulting in a number of direct and indirect impacts on mental health and elevating rates of anxiety, depression and post-traumatic stress disorders (PTSD) (2, 3). One of the most destructive storms to make landfall in Australia, Tropical Cyclone Debbie crossed the northern coast of Queensland in 2017 and caused a trail of destruction hundreds of kilometres down the coast, primarily due to damaging winds, periods of torrential rainfall and widespread major flooding (4). Modelling has suggested that warmer sea surface temperatures from climate change will increase the intensity and penetration of tropical cyclones in Australia further inland and southward thereby subjecting a much larger geographic area to higher wind speeds and intense rainfall (4). It is predicted that under a warming climate, northern NSW will more regularly experience ex-tropical cyclone weather remnants, similar to that of Debbie in 2017 that resulted in a major flood event including the overtopping of the Lismore levee system built to protect the central business district and surrounding residential areas.

Due to the scale of the 2017 disaster and the likelihood of repeat events, a local community-academic partnership was developed within northern NSW to design and implement a study examining impact of flooding on mental health of various sectors of the community and to inform future public health action (5). Community Advisory Groups (CAGs) were formed consisting of local health and community organisations, business groups and state and local authorities who have responsibility for flood planning, emergency response, mental health service provision and/or advocacy and support for particular subgroups within the community such as farmers and business owners. The CAGs co-designed the "Community Recovery after Flood" survey and were critical in its distribution and the recruitment of respondents at six-months post-flood. Results from this initial survey showed elevated psychological morbidity

among flood-affected respondents (compared to respondents not affected) with greater impact on participants from socio-economically marginalised groups (6). Rates of still being distressed about the flood, probable PTSD, anxiety, and depression were particularly elevated for those whose homes or businesses were flooded and those who endured lengthy displacement. In addition, there was also a significant association between probable PTSD and respondents who were indirectly disrupted (i.e., not flooded but access to critical services were disrupted such as health and social care; food supplies; place of work or education; domestic electricity, gas supplies or telecommunications) (7). Social capital played an important role in the degree of psychological harm reported after the floods, with respondents with higher levels of social capital (community participation and personal social cohesion) reporting less harm to their mental health than did those with lower social capital (8). Informal social connectedness and feelings of belonging were especially important factors associated with reduced risk of ongoing distress and probable PTSD for all participant groups regardless of marginalisation status (8).

In the few studies that have examined longitudinal effects of flooding on mental health, adverse psychological impacts have been shown to persist. The English National Cohort Study of Flooding and Health identified significantly higher levels of probable PTSD and depression three years post-flooding in those whose homes were directly inundated compared to those unaffected (9). Persistent flood damage to homes was a strong predictor of adverse mental health outcomes (9). Other studies have indicated that secondary stressors resulting from the disaster (such as dealing with insurance disputes, slow pace of housing and utilities repairs, getting back into employment etc) can have more impact on mental health than the disasters themselves (10, 11). Social capital has also rarely been examined with longitudinal data with respect to its role in supporting long-term recovery after flooding (12).

In this two-year follow-up study, we assess mental health outcomes of participants and the impact of secondary stressors related to the flood (including persistent home/business damage and insurance disputes) to improve understanding of long-term mental health trajectories. We also aim to assess the change in mental health outcomes within respondents between survey timepoints (18-month duration) and identify possible predictors for psychological recovery such as social connectedness and feelings of belonging found to be important at 6 months. The findings will inform post-disaster interventions to strengthen psychological resilience for this study cohort, which in turn will support whole-of-community reconstruction and recovery.

Methods

This is a longitudinal study comprising a two-year follow-up of the Community Recovery after Flood respondent group that were living in northern New South Wales (NSW) during major flooding in 2017. Residents over the age of 16 years were eligible to participate in the study. Six Local Government Areas (LGAs) within the Northern Rivers region were included: Ballina Shire, Tweed Shire, Richmond Valley, Kyogle, Byron Shire and Lismore City (Figure 1). The total estimated residential population of these LGAs was 246,626 in 2016 (13). From the Australian Bureau of Statistics (ABS) 2016 census estimates (5 year age groups), 82% of this population was 15 and over (13). The region is a known hotspot for weather-related extreme events, particularly flooding (14).

Figure 1: Community Recovery after Flood study location, Northern NSW.

Initial six-month survey

The initial community co-designed questionnaire contained 58-items covering: socio-demographic characteristics (age, sex, relationship status, employment status, type of income support payments, and educational qualifications); flood exposure sites (suburb, non-liveable areas of their home, liveable areas of their home, business/farm and/or the home of a significant other flooded); flood experiences (evacuation, displacement and disruption to essential services); mental health outcome measures and items measuring individual social

capital (community participation and personal social cohesion) (5, 8). Mental health outcomes included a single ongoing distress item from the Brief Weather Disaster Trauma Exposure and Impact Screen 'Are you still currently distressed about what happened during the flood?') (8, 15) and brief clinical screening tools for depression (PHQ-2; cut-off score ≥ 3), anxiety (GAD-2; cut-off score ≥ 3) and post-traumatic distress (PCL-6; cut-off score ≥ 14) (16-18). The PCL-6 was introduced with reference to trauma related symptoms felt after severe rain and flood in the past four weeks. Scores higher than validated cut-offs indicate probable diagnosis. For social capital measures, we utilised items from the Australian Community Participation Questionnaire that describe different domains of community participation: informal social connectedness (spontaneous, informal in-person connections); civic engagement (participation in organised activities) and political participation (19). Sense of social cohesion comprised an individual's subjective perception of their sense of belonging (self-categorisation as belonging to a group and cognitive evaluation of the perceived social supports available for connecting, confiding and seeking help) (20, 21), feelings of belonging (affective or emotional response to group membership) (22), social trust (21, 23-25), generalised reciprocity (21, 24) and trait optimism (26).

The six-month survey was distributed using a purposive snowball sampling approach to recruit respondents via personal, social and local organisational networks of the CAGs and other business and community organisations. As explained in detail elsewhere, an extensive local media and advertising campaign supplemented the recruitment process to obtain respondents from a broad cross-section of the community (5). Our approach resulted in 2,530 participants responding to the initial survey.

Two-year follow-up survey

At two-years post-flood, a 46-item questionnaire was co-designed with the CAGs repeating the same socio-demographic, mental health and social capital measures in the initial baseline survey. The follow-up survey also included questions on persistent damage to homes or businesses from the flood such as ongoing structural damage, damage to farming/business property (e.g., stock, fences, machinery etc), reduced business income, visible mould in liveable rooms, sewage (drains) backing up and flooding, problems with septic tanks and problems with other utilities (e.g., drinking water, gas, electricity, etc). Respondents were also asked if they made an insurance claim for their home or business related to 2017 flood damage and the assessment outcome (claim approved/not approved). If not approved, the insurance claim status was labelled a dispute and included in the analysis as another form of

secondary stressor related to the flood. To determine the influence of other significant life stressors on mental health, the survey asked if respondents had experienced any of the following: relationship problems; arguments with neighbours; close family deaths; major personal illnesses or injuries; or whether they were impacted by another weather-related disaster (such as bushfire, drought or flood).

From the initial six-month survey, 1,265 (50%) participants consented to follow-up, providing a combination of email, telephone and address details. The study obtained ethical approval to contact people a total of three times to take part in this follow up survey. The survey was open for a three-week period around the two-year anniversary of the flood in 2019. A link to an electronic copy of the questionnaire was sent to participants who had provided an e-mail address (91%) with a paper copy of the same questionnaire sent by post to the rest (9%). All participants gave their informed consent for inclusion before completing the questionnaire. The study was approved by the University of Sydney Human Research Ethics Committee (reference 2019/121), the Aboriginal Health and Medical Research Council Human Research Ethics Committee (reference 1294/17) and the Australian National University Human Research Ethics Committee (reference 2019/186).

Statistical Analysis

Participants were categorised into three mutually exclusive exposure groups based on exposure information provided in the initial survey: flooded (directly disrupted due to flood water inundation into home/yard or business/farm), indirectly disrupted (home or business/farm not flooded but access to essential services was disrupted, i.e., access to their usual place of education or employment, health or social care services, food supplies, or household utilities (internet, electricity, gas, septic and wastewater)) and non-disrupted (neither directly or indirectly disrupted as described above) (7, 27). Given the importance of informal social connectedness, feelings and sense of belonging and trait optimism as predictors of positive mental health in respondents of the initial survey, we focused our attention on analysing the association of these four social capital constructs on mental health outcomes at year two.

Descriptive analyses were undertaken to compare sociodemographic characteristics, experience of flood-related secondary or other stressors and level of social capital and mental health outcomes at the two survey timepoints by exposure group. Chi-square tests were employed to determine if there were significant differences between exposure groups in relation to post-flood general life stressors experienced. To determine significance of mental

health and social capital changes over time by exposure group, McNemar's and paired t-tests were applied respectively. Prior to hierarchical regression analysis, potential interactions between flood exposure category and a) socio-demographic characteristics and b) other life stressors were checked to examine how the combination of personal factors with flood experience, were associated with reporting each mental health outcome. If statistically significant in unadjusted analysis, the interaction was added to the relevant multivariate model step as described below.

Four separate hierarchical logistic regression models were constructed to calculate the odds of experiencing symptoms (yes/no) related to four types of mental health outcome (continuing distress, probable PTSD, anxiety or depression) reported two years post-flood. Four blocks of variables (sociodemographic factors, flood exposure, post-flood stressors and social capital) were added sequentially to assess the unique proportion of variance each contributed to mental health outcomes. Due to low numbers of non-disrupted and indirectly disrupted participants reporting adverse mental health outcomes at year two, for this analysis, these two categories were collapsed and used as the reference. Tjur's coefficient of discrimination (D—the difference in mean of predicted probabilities of having symptoms of psychological distress versus no symptoms), analogous to the coefficient of determination (R^2) in linear models, was used to evaluate the explanatory power of each block.

As social capital is a putative predictor of psychological recovery in post-disaster contexts, we used conditional logistic regression modelling to assess changes in mental health outcomes according to level of connectedness, belonging and optimism. For this matched analysis, we used two observations (at six months and two years) for those respondents who reported direct flooding only (due to limited sample numbers in other exposure groups). Due to multiple tests conducted, the significance level for all analyses was set conservatively at $p<0.01$. Odds ratios (ORs) and 99% confidence intervals (CIs) are reported. Respondents who did not complete a mental health outcome measure were excluded from analysis for that indicator only. Stata software was used for statistical analysis (StataCorp. 2017. *Stata Statistical Software: Release 15*. StataCorp LLC, College Station, TX, USA).

Results

Of the 1,265 participants who had consented to follow up, 488 responded (39%). From a comparison of socio-demographics, flood exposure and mental health outcomes six months after the flood for the baseline cohort, those willing to be followed-up and those that completed both surveys, participants in the two-year survey tended to be older than 34 years

of age, university-educated and directly impacted by the flood (Table 1). There were similar proportions of female participants, unemployed participants and those on income support who agreed to follow-up and completed the two year post-flood survey.

Table 1: Comparison of demographics, flood exposure and mental health six months after the flood for the baseline cohort, those willing to be followed-up, those who completed the first survey only and those that completed both surveys.

| | | Total respondents (n=2,530) | | Consented to follow-up (n=1,265) | | Respondents that consented to follow-up | | | |
| | | | | | | First survey only (n=777; 61%) | | Both surveys (n=488; 39%) | |
	Six months post-flood	n	%	n	%	n	%	n	%
Age	16-34	323	12.8	163	12.9	122	15.7	41	8.4
	35-54	969	38.3	529	41.8	331	42.6	198	40.6
	55-74	965	38.1	521	41.2	292	37.6	229	46.9
	75+ years	93	3.7	44	3.5	26	3.3	18	3.7
Sex	Female	1628	64.3	892	70.5	553	71.2	339	69.5
Employment	Not in employment	373	14.7	175	13.8	108	13.9	67	13.7
Education	University level	1026	40.6	595	47.0	370	47.6	255	52.3
Relationship status	Single	756	29.9	401	31.7	238	30.6	163	33.4
Income support†	In receipt of income support	363	14.3	205	16.2	117	15.1	88	18.0
Flood exposure	No disruption	368	14.5	145	11.5	94	12.1	51	10.5
	Indirectly disrupted	664	26.2	372	29.4	256	32.9	116	23.8
	Flooded	1404	55.5	738	58.3	421	54.2	317	65.0
Mental health outcomes	Still distressed	543	21.5	318	25.1	173	22.3	145	29.7
	Probable PTSD	363	14.3	212	16.8	112	14.4	100	20.5
	Probable anxiety	384	15.2	219	17.3	124	16.0	95	19.5
	Probable depression	374	14.8	195	15.4	111	14.3	84	17.2

† In receipt of the following income support: single parent payment; unemployment allowance (Newstart); youth allowance; disability support; carer payment.

Of those that completed the two-year survey, 7% (n=33) were excluded due to insufficient demographic, flood exposure (level of disruption) or social capital information (Figure 2). Of the 455 included in the analysis, 48 participants (11%) were non-disrupted, 108 (24%) were indirectly disrupted and 299 (66%) were flooded (Table 2). Almost half of respondents (48%) who were directly flooded in 2017 reported persistent damage to their homes or businesses and approximately 14% experienced an insurance dispute. Among those who reported persistent damage, most concerns related to visible mould in liveable rooms such as bedrooms, bathrooms and living areas (25%), structural damage to homes (20%) and in relation to businesses (including farms), 22% reported reduced income at two years compared to before the 2017 flood.
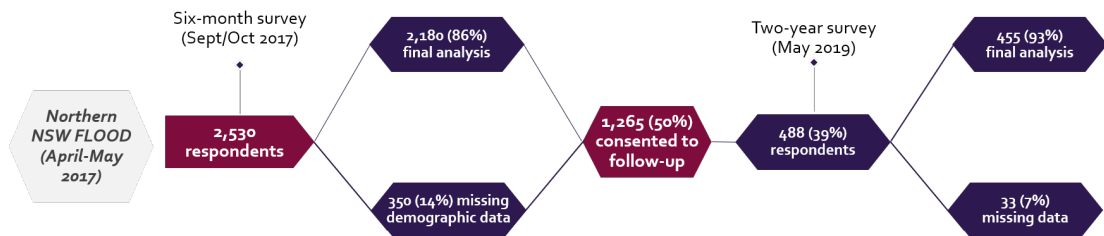
Figure 2: Participation and missing data exclusion rates across both Community Recover after flood surveys.

Respondents were predominantly women (70%) and people aged between 35 and 74 years (88%) (Table 2). At two-years post-flood, 15% of respondents were unemployed and 16% were in receipt of income support payments indicative of financial hardship: single parent support; unemployment support; youth allowance; disability support; and carer support (28).

Table 2: *Demographic profile, flood-related and other stressors two years after the flood by exposure group (N=455).*

		Total respondents (n=455)		Flooded (n=299;65.7%)		Indirectly disrupted (n=108;23.7%)		Non-disrupted (n=48;10.5%)	
Two years post-flood		n	%	n	%	n	%	n	%
Age	16-34	35	7.7	22	7.4	8	7.4	5	10.4
	35-54	173	38.0	112	37.5	44	40.7	17	35.4
	55-74	226	49.7	154	51.5	51	47.2	21	43.8
	75+ years	21	4.6	11	3.7	5	4.6	5	10.4
Sex	Female	317	69.7	209	69.9	76	70.4	32	66.7
Employment	Not in employment	70	15.4	52	17.4	12	11.1	6	12.5
Education	University level	222	48.8	130	43.5	63	58.3	29	60.4
Relationship status	Single	152	33.4	97	32.4	42	38.9	13	27.1
Income support†	In receipt of support	71	15.6	59	19.7	10	9.3	2	4.2
Flood-related stressors	Persistent damage	162	35.6	144	48.2	15	13.9	3	6.3
	Insurance dispute	43	9.5	41	13.7	2	1.9	0	0.0
Other stressors#		195	42.9	147	49.2	36	33.3	12	25.0

†In receipt of the following income support: single parent payment; unemployment allowance (Newstart); youth allowance; disability support; carer payment. # Other life stressors experienced by respondents since last survey (18 months ago): relationship problems; major illness or injury; close family member died; neighbour disputes; impacted by another weather-related disaster.

Across all participants, over 40% reported some form of significant life stressor in the last 18 months since the first survey timepoint. Flooded respondents were more likely to report a significant life stressor (49%) since the last survey compared to indirectly disrupted (33%) and non-disrupted groups (25%). The most frequently reported life stressors across all exposure groups in the last 18 months were relationship problems (17%), major injury or illness (15%) and death of a close family member (15%). Flooded respondents were also more likely than other exposure groups to report these stressors significantly so for a major illness or injury (19% vs 7/8%; $\chi2 = 9.8$ $p = 0.007$) (Table 3).

Table 3: Other general life stressors reported by respondents in the last 18 months by exposure group (N=455).

General life stressor	Total (N=455)		Flooded (n=299)		Indirect disruption (n=108)		Non-disrupted (n=48)		Chi^2 test of homogeneity
	N	%	N	%	N	%	N	%	
Separations/relationship problems	79	17.4	63	21.1	13	12.0	3	6.3	$\chi^2(2)=9.1$; $p=0.01$
Major injury/illness	68	14.9	56	18.7	8	7.4	4	8.3	$\chi^2(2)=9.8$; $p=0.007$
Spouse/close family member died	68	14.9	50	16.7	14	13.0	4	8.3	$\chi^2(2)=2.7$; $p=0.26$
Neighbour disagreements	41	9.0	35	11.7	6	5.6	0	0.0	$\chi^2(2)=9.0$; $p=0.011$
Impacted by another natural disaster	33	7.3	23	7.7	7	6.5	3	6.3	$\chi^2(2)=0.25$; $p=0.88$
Lost job	10	2.2	5	1.7	4	3.7	1	2.1	$\chi^2(2)=1.5$; $p=0.47$

Level of general distress post-flood increased between survey timepoints across all exposure groups, significantly so for flooded respondents (from 40% to almost 55%, $p < 0.001$) (Table 4). At two years post-flood, levels of probable PTSD, anxiety and depression remained elevated for flooded respondents in comparison to indirectly disrupted and non-disrupted groups. There were decreases in the proportion of flooded respondents reporting adverse mental health outcomes between survey timepoints, however these changes were not significant (at $p < 0.01$).

Social capital scores for informal social connectedness, belonging and optimism remained similar for the exposure groups over the survey timepoints apart from a significant decrease in sense of belonging for flooded respondents ($\bar{x}$ = 5.23 to 5.04; p = 0.0013) (Table 3).

Table 4: Changes in mental health outcome and social capital scores over two years by exposure group.

| | Flooded (n=299) | | | | Indirectly disrupted (n=108) | | | | Non- disrupted (n=48) | | | |
| | Six months | | Two years | | Six months | | Two years | | Six months | | Two years | |
	n	%	n	%	n	%	n	%	n	%	n	%
Still distressed	118	39.5	164	54.8 [**]	13	12.0	21	19.4	5	10.4	11	22.9
Probable PTSD	82	27.4	72	24.1	9	8.3	6	5.6	1	2.1	1	2.1
Probable anxiety	77	25.8	69	23.1	13	12.0	11	10.2	1	2.1	4	8.3
Probable depression	71	23.7	56	18.7	10	9.3	8	7.4	2	4.2	6	12.5
Social capital (score range 1 - 7)	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD
Informal social connectedness	5.36	1.15	5.28	1.21	5.31	1.15	5.39	1.22	5.41	0.96	5.51	1.12
Feelings of belonging	4.97	1.36	4.89	1.36	5.28	1.39	5.29	1.36	5.27	1.28	5.25	1.63
Sense of belonging	5.23	1.15	5.04	1.21 [#]	5.48	0.99	5.39	1.06	5.17	1.43	5.27	1.43
Trait optimism	4.81	1.11	4.74	1.16	5.23	0.95	5.12	0.95	5.23	1.11	5.11	1.08

$\bar{x}$ = mean; SD = standard deviation. Significant change between surveys - McNemar's test (for dichotomous mental health outcome variables): [**]$p<0.001$; [*]$p<0.01$. Two-tailed T-test for paired samples (for continuous social capital variables): [##]$p<0.001$; [#]$p<0.01$.

Table 5 summarises the hierarchical logistic regression results across all four mental health outcomes for all respondents. The full detail of each model is presented in Appendix 3. There were no significant interactions related to mental health outcomes detected between flood exposure and sociodemographic characteristics or between flood exposure and reporting life stressors in the last 18 months.

Still distressed about the flood

After adjusting for socio-demographic factors, being flooded was strongly associated with ongoing distress after two years (OR 4.38; 99% CIs: 2.39–8.00) explaining an additional 9% (change in Tjur's *D*) of the variance in still distressed outcomes (Table 5). Experiencing persistent home/business flood-related damage (aOR 3.89; 99% CIs: 2.10–7.19), an insurance dispute related to the flood (aOR 3.71; 99% CIs: 1.27–10.86) or other general life stressors in the last 18 months (aOR 1.95; 99% CIs: 1.08–3.52) were significantly associated with ongoing distress, explaining most model variance (12%). However, only the flood-related stressors remained significant in the final model. In the final block, trait optimism was independently significantly associated with lower levels of ongoing distress (aOR 0.72; 99% CIs: 0.52–0.99). In the matched pair analyses, the social capital concepts examined were not significantly associated with ongoing distress risk for flooded respondents (Table 6).

Probable Post-Traumatic Stress Disorder (PTSD)

Compared to ongoing distress, there were different patterns of association for probable PTSD between socio-demographics, stressors and social capital (Table 5). Socio-demographics explained most model variance (17%) with lower levels of educational attainment, being unemployed and receiving income support making significant independent contributions to explaining higher probable PTSD scores. After adjustment for socio-demographics, being flooded was strongly associated with probable PTSD two years after the event (OR 6.15; 99% CIs: 2.00–18.84). Having an insurance dispute was not independently associated with higher probable PTSD risk, however persistent home/business flood-related damage (OR 3.44; 99% CIs: 1.47–8.02) and other life stressors (OR 4.81; 99% CIs: 1.99–11.62) were strong predictors, remaining that way in the final model and explaining a further 12% of the model variance. The strength of the association between being flooded and probable PTSD diminished with the addition of the post-flood stressors (Appendix 3). Feelings of belonging (OR 0.52; 99% CIs: 0.32–0.85) and trait optimism (OR 0.51; 99% CIs: 0.33–0.78) were strongly associated with lower levels of probable PTSD two years post-flood, explaining an additional 12% of the model variance. In the matched pair analysis, informal social connectedness and feelings of belonging were associated with reduced risk of PTSD over time for flooded respondents (Table 6).

Probable Anxiety

After adjustment for socio-demographic factors, being flooded was independently significantly associated with probable anxiety (OR 2.52; 99% CIs: 1.11–5.69) (Table 5). However, once flood-related and other life stressors were added, the association became non-significant (Appendix 3). Experiencing persistent flood-related home/business damage (OR 2.34; 99% CIs: 1.11–4.95) or other life stressors (OR 4.20; 99% CIs: 1.96–9.04) confounded the relationship with flood inundation, remaining associated with probable anxiety in the final step and explaining a further 9% of the model variance (Table 5). Optimism (OR 0.48; 99% CIs: 0.33–0.72) was strongly associated with lower levels of probable anxiety, explaining most of the model variance (13%). The matched pair analysis confirmed the importance of optimism for flooded respondents significantly associated with reduced risk of probable anxiety over time (Table 6).

Probable Depression

In the first model block, being of younger age and unemployed were significant predictors, explaining 13% in variation in probable depression outcomes (Table 5). After adjusting for socio-demographics, neither flood exposure nor flood-related stressors were independently associated with probable depression. Experiencing other life stressors was a significant

predictor (OR 2.95; 99% CIs 1.31-6.63). Greater feelings of belonging (OR 0.60; 99% CIs: 0.38–0.96) and optimism (OR 0.51; 99% CIs: 0.33–0.78) were significantly associated with less risk of probable depression explaining most of the model variance (18%). In the matched pair analysis, feelings of belonging were associated with reduced depression risk over time for flooded respondents (Table 6).

In summary, in the final models, ongoing distress two years post-flood was explained mostly by flood-related stressors (persistent flood damage/insurance dispute). Probable PTSD and anxiety were mostly explained by socio-demographic factors, post-flood persistent home/business damage and general life stressors and trait optimism. Feelings of belonging and trait optimism were important factors reducing risk of probable depression post-flood. After assessing changes in self-reported mental health outcomes for flooded respondents between survey timepoints, the social capital concepts of informal social connectedness, feelings of belonging and optimism were key with respect to reducing risk for probable PTSD, anxiety and depression.

Table 5: Multiple hierarchical logistic regression models predicting mental health outcomes of respondents two years post-flood.

Model block	Still distressed (N=452)				Probable PTSD (N=453)				Probable Anxiety (N=451)				Probable Depression (N=445)			
	OR	99%CI	ΔD	D	OR	99%CI	ΔD	D	OR	99%CI	ΔD	D	OR	99%CI	ΔD	D
A. Socio-demographics			-	0.04			-	0.17			-	0.08			-	0.13
Age	1.00 (0.98-1.02)				0.98 (0.96-1.01)				0.98 (0.95-0.99) *				0.97 (0.95-0.99) *			
Gender (male)	0.77 (0.44-1.36)				0.80 (0.35-1.79)				1.02 (0.49-2.12)				1.61 (0.73-3.55)			
Relationship status (single)	0.73 (0.41-1.29)				1.37 (0.64-2.92)				0.98 (0.47-2.04)				1.29 (0.59-2.85)			
Education level (non-university level)	1.50 (0.90-2.51)				2.52 (1.17-5.45) *				1.49 (0.75-2.97)				1.73 (0.80-3.77)			
Employment status (not in employment)	1.34 (0.61-2.97)				2.65 (1.07-6.55) *				2.59 (1.06-6.32) *				3.89 (1.53-9.89) **			
Income support (receives income support†)	2.09 (0.90-4.86)				2.98 (1.16-7.65) *				1.69 (0.64-4.42)				1.60 (0.58-4.42)			
B. Flood exposure			0.09	0.13			0.04	0.21			0.01	0.09			-	0.13
None / Indirect disruption	1.00 (reference)				1.00 (reference)				1.00 (reference)				1.00 (reference)			
Flooded	4.38 (2.39-8.00) ** ^				6.15 (2.00-18.84) **				2.52 (1.11-5.69) *				2.05 (0.85-4.89)			
C. Post-flood stressors			0.12	0.25			0.12	0.33			0.09	0.18			0.03	0.17
Persistent damage from flood	3.89 (2.10-7.19) ** ^				3.44 (1.47-8.02) ** ^				2.34 (1.11-4.95) * ^				1.78 (0.79-4.02)			
Insurance dispute from flood	3.71 (1.27-10.86) * ^				2.08 (0.71-6.10)				0.75 (0.24-2.34)				1.34 (0.43-4.14)			
Other life stressors#	1.95 (1.08-3.52) *				4.81 (1.99-11.62) ** ^				4.20 (1.96-9.04) ** ^				2.95 (1.31-6.63) *			
D. Post-flood social capital			0.03	0.28			0.12	0.45			0.13	0.31			0.18	0.35
Informal social connectedness	1.02 (0.74-1.41)				0.88 (0.55-1.39)				1.13 (0.74-1.72)				0.95 (0.60-1.51)			
Feelings of belonging	1.08 (0.77-1.51)				0.52 (0.32-0.85) * ^				0.70 (0.45-1.07)				0.60 (0.38-0.96) * ^			
Sense of belonging	0.80 (0.52-1.23)				1.46 (0.81-2.63)				0.96 (0.57-1.60)				0.83 (0.48-1.44)			
Trait optimism	0.72 (0.52-0.99) * ^				0.51 (0.33-0.78) ** ^				0.48 (0.33-0.72) ** ^				0.51 (0.33-0.78) ** ^			

† In receipt of the following income support: single parent payment; unemployment allowance (Newstart); youth allowance; disability support; carer payment. # Other stressors experienced in last 18 months: relationship problems; major illness or injury; close family member died; neighbour disputes; impacted by another weather-related disaster. D = Tjur's coefficient of discrimination. * $p < 0.01$; ** $p < 0.001$; ^ Predictor made an independent significant contribution in the fourth and final model.

Table 6: Matched pair analysis assessing influence of social capital concepts over survey timepoints on changes in mental health outcomes for flooded respondents (n=299).

| Mental health outcome | | Flooded respondents | | |
Social capital construct	Obs	OR	99%CI	*p*-value
Still distressed				
Informal social connectedness	126	0.78	(0.44-1.36)	0.25
Feelings of belonging	126	0.59	(0.31-1.14)	0.039
Sense of belonging	126	0.53	(0.23-1.21)	0.048
Trait optimism	126	0.63	(0.24-1.62)	0.20
Probable PTSD				
Informal social connectedness	96	0.41	(0.18-0.97)	0.008
Feelings of belonging	98	0.38	(0.16-0.93)	0.005
Sense of belonging	98	0.53	(0.24-1.19)	0.043
Trait optimism	96	0.05	(0.00-0.73)	0.004
Probable Anxiety				
Informal social connectedness	134	0.99	(0.63-1.56)	0.97
Feelings of belonging	136	0.57	(0.32-1.03)	0.015
Sense of belonging	136	0.79	(0.47-1.32)	0.23
Trait optimism	134	0.48	(0.24-0.97)	0.007
Probable Depression				
Informal social connectedness	108	0.48	(0.22-1.02)	0.013
Feelings of belonging	106	0.33	(0.13-0.84)	0.002
Sense of belonging	108	0.53	(0.26-1.08)	0.022
Trait optimism	108	0.39	(0.15-1.00)	0.01

Discussion

Our respondent group at two years was highly impacted by the 2017 floods in the northern NSW region, with two-thirds experiencing direct inundation of flood waters in their homes/yards and/or businesses (including farms). Our findings indicate minimal improvement in mental health outcomes for these respondents two years after extensive flooding. Persistent flood damage to homes and/or businesses and insurance disputes were associated with increased rates of still being distressed about the flood. Respondents who were flooded were more likely to report ongoing distress, probable PTSD and anxiety compared to those who were indirectly disrupted or non-disrupted. However, the relationship between being flooded and PTSD and anxiety were confounded by experiences of post-flood persistent home/business damage and general life stressors (such as major illness/injury, which flooded respondents were more likely to report). While there was little change in social capital measures over time, respondents with higher levels of feelings of belonging and optimism

reported less harm to their mental health after two years compared to those with lower levels of personal social cohesion.

Our findings support the few studies examining long-term impact of flooding on mental health that have also shown persistent adverse outcomes for several years particularly for flooded participants (9, 29). In a longitudinal cohort study spanning three years in England, there were significant reductions in prevalence of probable PTSD, anxiety and depression in flooded participants. In our study, there were small reductions in the proportion of flooded respondents reporting probable PTSD, anxiety and depression although these changes were not statistically significant. In contrast, the single measure of post-disaster distress (that differentiates flood-event related stress from other forms of anxiety) increased significantly within flooded participants. The secondary flood-related stressors experienced by those who were flooded (almost 50% reported persistent home/business damage after two years) contributed to their ongoing distress, probable PTSD and anxiety.

Our study implies that long-term psychological morbidity is strongly associated with both secondary flood-related stressors (persistent home/business damage) and other general life stressors experienced after the flood-event. It is well known that housing and health are inextricably linked with recent studies highlighting the association between improved housing quality and positive mental health (30, 31). The exact causal link between quality housing and mental health and wellbeing is complex and can be related to a number of factors beyond physical health effects, such as social stigma from living in poor quality housing, overcrowding and energy cost worries, relying on landlords for repairs etc. The cumulative effect of such stressors may exponentially increase the risk of poor mental health outcomes and lead to a cycle of risk where income earning capacity is reduced limiting housing affordability (31). Accumulations of stressors are often greatest in socio-economically marginalised groups who resided in most of the flood footprint in the 2017 northern NSW flood (32). The critical importance of quality stable housing is evident in studies that have demonstrated a relationship with mental health after accounting for other social factors (30).

In relation to business/farm owners in our respondent group, the most commonly reported persistent issue two years after the flood was reduced income. This may occur through increased expenses due to repair or replacement as well as disruptions to business activity. Lower employment opportunities for the broader community compound the impact of reduced business activity. Northern NSW has extensive agricultural and horticultural industries with primary production covering over 10% of employment in the region (33). In the Australian

agricultural sector, extensive floods can lower agricultural production by 4.5% on average both in the year of the disaster and the next (34). These types of problems are likely to require different interventions to those addressing other post-disaster mental health needs, such as evidence-based counselling interventions to prevent PTSD (10).

Given the impact of persistent flood-related housing and business damage prolonging negative mental health that this study has shown, increased focus on rapid financial assistance programs for housing/business repair and improvements may be warranted, including for residents in rental or social housing. These are important considerations for local preparedness and response planning, ensuring appropriate intervention and support services are in place during the post-disaster phase to ameliorate stressors and facilitate timely recovery. For the northern NSW region, a range of mental health support mechanisms was established immediately after the flood in 2017, from telephone/online help lines to specific face-to-face counselling services. However, anecdotally, we are aware that these were not well utilised (6). While there are government financial assistance programs aimed at supporting residents and businesses affected by the flood, the majority of business owners who accessed this support felt that their needs were not met at the time (35). Further assessment of the type of health support services available in the intervening period and the degree to which they met participant needs in our study will be forthcoming.

We previously demonstrated the positive association between social capital and mental health within diverse sectors of the northern NSW community following the 2017 flood (8). In particular, feelings of belonging and inclusivity through informal community connectedness were strong predictors of positive mental health including those from socio-economically marginalised groups. Our matched analysis of changes in respondent social capital and mental health outcomes between six months and two years supports this earlier finding. Previous qualitative longitudinal research in England following major floods has shown a nuanced relationship between belonging, social networks and mental health where recovery processes are non-linear and context dependent (36). There were changes in the type of social capital that mattered most depending on phase of the recovery period. In the immediate aftermath, through shared trauma, new relationships were formed and established relationships were consolidated. However, the quality and nature of these relationships were found to change positively or negatively depending on recovery experience. For example, divisions may be created if government responses are perceived to be unfair or improve protection in one part of community over another. Overall, solidarity and the importance of fairness in the

distribution of resources and mitigation action were key to community wellbeing (36). In our study, post-flood action and recovery experience may have played a role in the significant reduction in sense of belonging reported by flooded participants, inferring a reduced sense of inclusiveness and perceived access to social supports that comes with group membership. These findings indicate that to bolster recovery processes, community needs assessments are required at regular intervals post-disaster to canvas unanticipated secondary stressors contributing to poor mental health and determine most appropriate responses to immediate needs (10). While processes focused on social inclusion and empowerment or improving housing quality may not fall within the scope of mental health service delivery, they are likely to have a much larger beneficial impact on wellbeing compared to counselling services alone, emphasising the importance of a multi-sectoral approach to disaster preparedness and response planning.

Strengths and limitations

The study design limits our ability to generalise findings to other settings or the broader population. Participants in the two-year survey were a highly flood-impacted group with a small number of cases in the non-disrupted group. Within the non-disrupted and indirectly disrupted groups, there were low numbers reporting mental health issues (for e.g., seven cases reporting probable PTSD) limiting precision and our ability to detect other findings of potential significance and importance. The majority of missing data related to employment status of respondents from the indirectly disrupted and flooded groups. Their exclusion is likely to bias estimates towards positive changes in mental health after two years, however we expect this bias to have minimal impact on study findings considering the highly impacted nature of our respondent group. While we lacked a mental health baseline prior to the flood, we included two measures specifically related to the flood and we adjusted for socio-demographic factors known to predict mental health. We were also able to track change in mental health and social capital in individuals over an 18-month recovery period. Our findings are consistent with other longitudinal studies showing persistent mental health issues following flooding and we add new knowledge on the impact of secondary stressors and importance of belonging and optimism in ameliorating mental health impacts in the longer-term after flood events.

Conclusion

Understanding the scope and scale of mental health impacts associated with extreme weather events is an important first step to developing and implementing services designed to treat or

prevent these impacts. While delivery of services in response to acute impacts may appear to be of greater priority directly after the event, development of appropriate services over the longer term targeting secondary impacts on mental health are equally important. The variation in impacts, particularly those experienced by flooded participants, makes planning support services difficult. To ensure the right type and timing of mental health and wellbeing support is provided, continual dialogue with affected communities is required to: a) learn lessons from past experience; b) co-design future processes during preparedness and response planning; and c) monitor and evaluate disaster responses well after the trigger event.

Acknowledgements

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Appendix 1: Northern Rivers Community Recovery after Flood – Follow up Survey 2019:
Research Protocol

Northern Rivers Community Recovery after Flood – Follow up Survey 2019

Research Protocol v2.0
February 2019

Community Recovery after Flood Follow-up Survey - Protocol Version 1.0 – February 2019   1

SYNOPSIS

There is a shortage of research into the mental health effects on communities from fluvial (river) flooding, particularly in the longer term, in rural contexts and for specific sectors of the population including older people, young adults, Aboriginal people, farmers, business owners and people living with disadvantage. This project follows on from the *Northern Rivers Community Recovery after Flood Project*, where (using a community-academic partnership approach) the University Centre for Rural Health purposively surveyed a broad cross-section of community (including hard-to-reach population groups) six months after April 2017 when devastating flooding occurred in the Northern Rivers. This project forms a second cross-sectional data collection point (two-years post-flood) thus establishing a prospective longitudinal cohort study (with additional data collection points at 3 and 5 years post-flood). The aim of the cohort study is to monitor the longer-term impact of flood experience on mental health and wellbeing to inform strategies to improve disaster preparedness, resilience and adaptability to climate change.

Analysis from the six-month survey showed the 2017 flood had profound mental health impact, particularly for respondents still displaced after 6 months and for socio-economically marginalised groups, such as respondents on income-support. Indirect disruptions (such as loss of access to health and social services) were also associated with increased risk of adverse mental health outcomes compared to respondents who were unaffected. Having greater social connections and a sense of community belonging decreased risk of mental health issues. The UCRH is looking to build on this knowledge with a two-year survey of respondents who agreed to be followed-up (n=1,265) to assess changes in mental health status over time and associated needs.

The objectives of the study are to:
1. describe changes in the mental health, wellbeing and resilience characteristics of survey respondents 2 years post-flood;
2. identify patterns of use and gaps in the nature, timing and/or duration of mental health and wellbeing support services used post-flood
3. explore the associations over time between mental health and wellbeing, distress and
   a) level of flood exposure and financial, health and social support services received post-flood
   b) levels of community and personal resilience
4. stratified analysis for key interest groups including: the business community; the farming community; respondents on low income; Aboriginal communities; LGBTIQ community; people 75 years and older; and young adults (16-25 years)

Table of Contents

1 PROJECT GOVERNANCE

Research team

Name	Role & Affiliation	Responsibilities
Prof Ross Bailie	Coordinating Principal Investigator University Centre for Rural Health – North Coast (UCRH)	Oversee coordination of all project activities including stakeholder engagement; design of research and data analysis.
Prof James Bennett-Levy	Co-investigator, UCRH	Overall leadership on mental health and wellbeing aspects of the research; conduct stakeholder engagement.
Dr Veronica Matthews	Co-investigator, UCRH	Overall coordination of the project; protocol development and questionnaire design; stakeholder engagement; undertake quantitative analysis.
Dr Jo Longman	Co-investigator, UCRH	Provide advice on study design, questionnaire development and analysis of results; stakeholder engagement.
Ms Maddy Braddon	Project Support, UCRH	Coordinate stakeholder/community engagement; provide general project support.
A/Prof Megan Passey	Co-investigator, UCRH	Provide advice on study design, questionnaire development and analysis of results.
A/Prof Geoff Morgan	Co-investigator, UCRH	Provide advice on study design, questionnaire development and analysis of results.
Dr Margaret Rolfe	Co-investigator, UCRH	Provide biostatistical advice.
Dr Sabrina Pit	Co-investigator, UCRH	Stakeholder engagement; provide advice on questionnaire development and analysis of results.
Prof Helen Berry	Co-investigator, UCRH	Provide advice on study design, questionnaire development and analysis of results.
Dr John McKenzie	Co-investigator, UCRH	Provide advice on study design, questionnaire development and analysis of results.
Mr Dominic Peel	Co-investigator, Canberra University	Provide advice on data management.
Ms Aimmee Waddell	Research Assistant, UCRH	Research Assistant.
Ms Alex Grantham	Project Manager, UCRH	Provide overall project support.

Research Advisory Group
The Research Advisory Group will provide timely, high level advice that informs the development and implementation of the Community Recovery after Flood – Follow-up Survey project. They will also take opportunities to act as champions for the project.

Name	Affiliation	Expertise
Prof Helen Berry	University of Sydney	Expertise in flood research and role of social capital and online survey research.
Prof Tony Capon	School of Public Health, University of Sydney	Professor of Planetary Health at University of Sydney. Public health and environmental health expertise.
A/Prof Joel Negin	School of Public Health, University of Sydney	Head of the School of Public Health at University of Sydney. Public health and health planning expertise.
Malcolm Robertson	Office of Environment & Heritage	Climate change adaptation policy advisor
Katrina Haselton	NSW Ministry of Health	Mental health policy advisor
Ben Roche	Southern Cross University	Partner university to UCRH
Dr Robyn Vines	Western Sydney University	Partner university to UCRH
Prof Ian Wilson	University of Wollongong	Partner university to UCRH

Community Advisory Groups
Community Advisory Groups (CAGs: one in Lismore and one in Murwillumbah) played a vital role in the community-academic partnership approach used in the baseline survey. For this project they will continue to shape the research aims, objectives, research questions and design, and will facilitate multi-stakeholder engagement in the project. Findings from the research will be reviewed with the CAGs, and future directions agreed. The CAGs will provide governance of the project, reviewing progress and adherence to the approved protocol, and advice and guidance throughout. The CAGs offer technical expertise, extensive and essential

community linkages, networks and current projects which will be leveraged for effective collaboration, stakeholder buy-in, relevance, innovation, impact and sustainability. Broad representation of end users on the CAGs will create and deepen linkages across a range of stakeholders.

Organisation Type	Organisation examples
Community organisations	Lifeline; Salvation Army; Social Futures; Winsome Soup Kitchen; Red Cross, Rekindling the Spirit
Other non-government organisations	Primary Health Network
Local business operators	Lismore Business Chamber; Godfreys
Local Government	Lismore City Council; Tweed, Byron, Ballina Shire Councils
State Government	Emergency Services, Local Health District
Universities	Southern Cross University

2 PROJECT BACKGROUND AND RATIONALE

In 2015, the economic cost of natural disasters in Australia was estimated to exceed $9 billion with the social cost (e.g. impact on health and wellbeing, education, employment) contributing an equivalent or larger component than physical infrastructure costs[1]. Modelling suggests that this annual cost is estimated to double by 2030 and this is without incorporating potential impacts of climate change[1]. Floods are the most expensive natural disaster experienced in Australia and their frequency is expected to increase in the future due to the estimated effects of climate change[2].

Floods have significant negative health and social impacts on people of all ages. While the most immediate effects of flooding (injuries, infections, chemical hazards, and disruption to health and social services) are well documented, the longer term effects of floods are not as well understood[3]. In high income countries such as Australia, floods generally cause few immediate deaths. However, there is a durational impact on mental health and wellbeing as indicated in a recent study from the United Kingdom (UK) that estimated mental health problems are responsible for 80% of all Disability Adjusted Life Years (DALYs) attributable to floods[4].

There are several risk factors linked to psychosocial health issues following natural disasters such as the degree of exposure, previous flood experience and disaster preparedness[3]. Prevalence of depression, anxiety and post-traumatic stress (PTSD) were elevated amongst flooded participants compared to non-flooded participants one year after major flooding in the UK[5]. Mental health impacts, however, extended beyond those whose homes were flooded. People whose lives were disrupted without flood inundation (such as interruption to household utilities and difficulties accessing employment, education and health care facilities) also had elevated levels of PTSD. Controlling for severity of flooding, people who were displaced were significantly more likely to have higher scores on depression, anxiety and PTSD scales and lack of evacuation warning also led to higher scores for depression and PTSD[6]. In the second data collection point in this cohort study (two years following flooding), the prevalence of probable psychological morbidity was still elevated amongst those who had experienced flooding[7].

Psychological effects of floods appear to disproportionately affect females, older people, children and groups with greatest underlying vulnerability including people living with disadvantage and those living in rural and remote areas[8-10]. While there are high proportions of Aboriginal people living in rural and remote Australia, there is a limited evidence-base regarding trauma and distress they may experience from natural disasters. For older adults (60 years and over), those personally affected from flood had higher rates of PTSD and anxiety compared to those not affected and lack of social support was a determinant for poorer mental health[11]. Social support and connectedness appears to have an inverse relationship to level of mental distress following disasters due to psychosocial needs being met from close relationships with family, friends and communities[2, 12]. Often these social support mechanisms are missing for homeless people who are also at risk due to the marginal areas they occupy likely to be more affected by natural disasters[10].

Rural communities often do well at connectedness but are vulnerable to poor health due to socioeconomic disadvantage, reduced access to health services and a culture of stoicism that puts people off seeking help[9]. Inherent stresses related to farming have manifested in poorer mental health and wellbeing in

farmers compared to non-farm workers in rural and remote areas[13]. The addition of climate uncertainty and adverse weather events exacerbates that stress.

Risk of climate change effects and adverse impacts are known to exacerbate existing inequalities in all countries regardless of their level of development[14, 15]. Landmark international agreements, such as the United Nations' Agenda 2030 (Sustainable Development Goals) and the Sendai Framework for Disaster Risk Reduction (2015–2030), recognise the need for complementary action on climate change mitigation and adaptation, with inequality a key global challenge to creating sustainable and resilient communities[16, 17]. The Sendai Framework advocates a community-centred preventive approach to disaster risk. It recommends that government agencies be multi-sectoral and inclusive in designing and implementing policies by engaging all relevant stakeholders, including women, children, seniors, people with pre-existing health conditions, people with low socio-economic status and Indigenous communities. In this way, understanding and managing disaster risk encompasses all dimensions of exposure, vulnerability and capacity of individuals and communities in formulating regional and local risk reduction policies[17].

Northern Rivers flood, April 2017
Rainfall from ex-Tropical Cyclone Debbie in late March/early April 2017 resulted in unprecedented water rises in the Tweed and Wilson River that affected many residents in the Northern Rivers area of New South Wales. Almost all of the extreme rainfall from ex-Tropical Cyclone Debbie fell within 24 hours. Australia is not currently experiencing La Nina conditions, which have historically formed the backdrop to severe flooding in eastern Australia.

There is high confidence that the intensity of extreme rainfall experienced in eastern Australia, including northern NSW will increase due to global warming. Tropical cyclones are projected to be less frequent but more intense on average. Increases in the intensity of the heaviest rainfall events are likely to increase flash flooding, leading to strains on water infrastructure such as sewerage and drainage systems, particularly in population centres.

Northern Rivers Community Recovery after Flood – Follow-up Survey Project
A recent systematic review concluded that there is a shortage of research into the mental health effects on communities from river flooding caused by heavy rainfall in catchment areas (as opposed to coastal inundation or flooding due to direct impact from cyclones, typhoons and hurricanes)[2]. Following our baseline survey 6 months after the flood, this follow-up survey will examine changes in the mental health and wellbeing of communities in the Northern Rivers region two years following fluvial flooding in April 2017. It will examine in a rural context the degree of mental health distress by different exposure groups (flooded/ disrupted without flooding/unaffected); and by understudied groups including people experiencing homelessness, older people, young adults, Aboriginal people, farmers and other business owners, and people who respond to others' needs in the aftermath of disasters. As with our baseline survey, validated clinical diagnosis tools will be used to measure anxiety, depression and PTSD to better inform the type of interventions required in response to flood events. The study will be conducted using a community-academic partnership approach with relevant local government and community organisations to enable real time feedback on intervention gaps that emanate from the aggregate community analysis.

The study is the second data collection point in a longitudinal cohort study to assess the longer term mental health and wellbeing needs of Northern Rivers' communities affected by flood, the first of its kind within Australia looking at a broad cross-section of a rural community.

3. AIMS AND OBJECTIVES

This project aims to measure the change in impact on mental health and wellbeing of residents in Northern Rivers' communities from six months to two years post the April 2017 flood. It will examine relationships between different elements of a conceptual framework (*Figure 1: Flood Impact Framework*) that proposes mental health and wellbeing to be influenced by: the degree of flood impact; the subsequent natural disaster relief service response (government, community and insurance organisations); level of personal and community resilience; and perceptions of the adequacy of the relief response and pre-flood mitigation/warning systems.

Figure 1: Flood impact framework
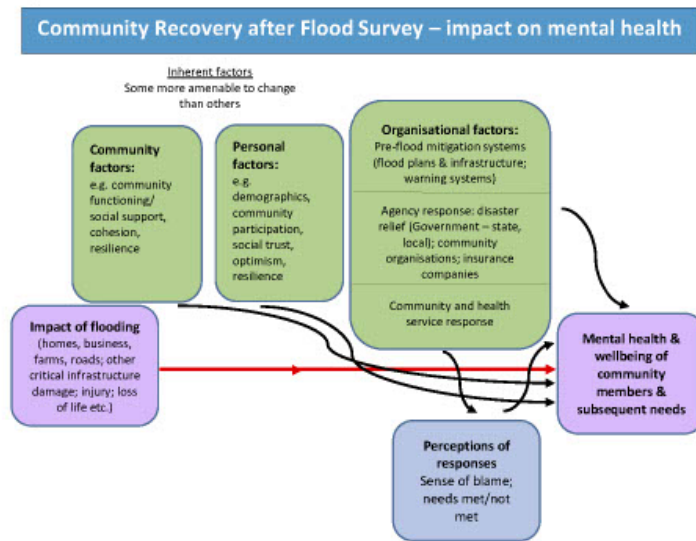
The objectives of the study are to:
1. describe changes in the mental health and wellbeing and resilience characteristics of survey respondents 2 years post-flood;
2. identify patterns of use and gaps in the nature, timing and/or duration of mental health and wellbeing support services used post-flood
3. explore the associations overtime between degree of mental health and wellbeing distress and
   a) level of flood exposure and financial, health and social support services and activities received post-flood
   b) levels of community and personal resilience
4. stratified analysis for key interest groups including: the business community; the farming community; respondents on low income; Aboriginal communities; LGBTIQ community; people 75 years and older; and young adults (16-25 years)

The findings will inform current mental health and wellbeing interventions and policy and service response mechanisms for future preparedness planning for natural disaster events.

4. RESEARCH DESIGN

4.1. Study location

Six Local Government Areas (LGAs) within the Northern Rivers region were included in the initial survey: Ballina Shire, Tweed Shire, Richmond Valley, Kyogle, Byron Shire and Lismore City (Figure 2). The estimated residential population was 247,806 in 2016 [18]. From the ABS 2016 census estimates (5 year age groups), 82% of this population was 15 and over (203,723)[19]. The region has higher proportions of older people and Aboriginal people compared to state averages and the region has experienced recent high population growth driven by coastal migration and counter-urbanisation. A diverse range of industry underpins its economic base, including tourism, retail, human services, horticulture and agriculture[20].

Figure 2: Map of the Northern Rivers region

4.2. Study design

The project is a cross-sectional analysis of the mental health and wellbeing status of residents in the Northern Rivers region approximately two years following the flood of April 2017 and eighteen months following the baseline survey.

The questionnaire used in the baseline survey included the following question:

Can we contact you in the future about possibly taking part in further research about the flood? If so, please let us know how best to contact you. If you change your mind later on, or if you want more information before making a final decision, that's ok. Just let us know when we contact you next.

Name:
Mobile:
Email:
Address:

And online the response options were "yes", "possibly" or "no".

Of the 2,530 respondents to the baseline survey, 1,265 (50%) left us their contact information.

The survey (*Community Recovery after Flood – Follow-up Survey*) questionnaire has been developed to function as a follow-up survey and has responded to substantial feedback provided from respondents to the Baseline survey (primarily in the final 'free text' opportunity in the questionnaire requesting feedback). It contains measures to quantify the relationships hypothesised in *The Flood Impact Framework* (Figure 1). The survey will include measures from the first six-month baseline questionnaire: socio-demographic characteristics, mental health indicators; and community participation and social cohesion variables. It will include questions about different support services/activities sought and accessed over the two-year period (Table 1). The questionnaire will take approximately 15 minutes to complete. The online questionnaire will be developed using Qualtrics software. A paper version of the questionnaire will be available to accommodate potential participants unable or unwilling to access the survey online.

Table 1: Justification of measures in the Community Recovery after Flood Follow-up Survey

Measure/s	Justification	Source (where relevant)
Unique identifier	To link to baseline survey and future surveys in the cohort study	Anonomised code generated in the baseline survey.
Residential circumstances – ongoing displacement and disruption, regain full use of facilities	Persistent disruption and compromised housing status 2 years after the flood are likely to be significant stressors.	Adapted from baseline survey.
Socio-economic and demographic variables – age, sex, cultural and language diversity, Indigenous status, marital status, education level, employment status, housing tenure and composition, income level and social support available.	Most socio-demographic factors were captured in baseline survey. Will ask some question again that may have changed over time i.e. relationship status, employment status, income level, housing tenure. Where socio-demographic data is missing from the baseline survey, respondents will be provided an opportunity to complete if they wish. (online participants n=65).	From baseline survey.
Business/Farm operators/owners	Farmers and business owners are key interest groups. Retain question to see if still own/operate business/farm to understand stressors, economic hardship etc. Clarify membership of these important cohorts that were not explicitly captured in the baseline survey	Adapted from baseline survey.
Mental health status – probable anxiety, depression and/or post-traumatic stress disorder (PTSD), suicidal ideation.	To assess change in mental health status.	From baseline survey. Validated scales for anxiety, depression & PTSD (PHQ-2, GAD-2 and PCL-6) drawn from the UK 2013/14 flood[5]. Suicide risk questions adapted from the Screening Tool for Assessing Risk of Suicide[21].
Insurance and other financial support	Insurance and financial support issues are strong predictors of mental health stress. This will form an update on questions from baseline survey on perceptions of adequacy of disaster relief and insurance support received at six months.	New -we will specifically ask respondents if they had insurance cover, whether a claim was made, if that claim was denied, disputed, paid and whether insurance was paid (no/partially/fully).
Other factors associated with mental health status	Other important factors related to mental health stress such as the life events register (i.e. in the last year: your spouse died? You were dismissed from your job? You suffered major illness etc)	From baseline survey.
Mental health services sought and accessed	To capture nature and timing of service use (e.g. GPs, counselling support, public mental health services etc) as well as access issues.	New
Personal (coping strategies, social capital and support networks) and community resilience measures.	To assess change in personal social and community resilience two years after the flood.	From baseline survey. Drawn from previous research measuring association between social capital and mental wellbeing in Australia[23, 24]
Post-traumatic growth measure.	Qualitative question to capture information on positive transformation experiences following the flood.	From baseline survey.

The questionnaire therefore contains sensitive questions which we highlight at the start. There is no obligation to complete questions if participants find the content uncomfortable. There will be contact information provided on the first and each relevant page of the survey for counselling services such as Beyond Blue, Lifeline and headspace.

4.3 Participants, survey recruitment and methodology

This is exploratory research investigating the relationship over time between flood impact, subsequent financial, health and social service assistance and community and personal resilience factors on the mental health and wellbeing of various sectors of the Northern Rivers community. Participation in the survey is voluntary and confidential.

The questionnaire will be disseminated on the two-year anniversary of the 2017 flood (first week of April) and will remain open for a two week period (due date Monday 15th April). If required, the survey period will be extended by one week. Timing of reminders is outlined in Table X with the follow-up strategy dependent on the type of contact information provided by respondents. Each respondent will be contacted no more than three times over the extended survey period.

Table 2:

Contact info	Initial contact	Reminder	Attempt to contact using a different method/final reminder
Respondent provided email address and phone number	By Email	1 week later by email	If respondent provided phone number we will attempt to contact by phone (questionnaire can be completed on a mobile phone) and if no answer by text
Respondent provided email address and mailing address	By Email	1 week later by email	Send paper questionnaire by post with return postage-paid envelope
Respondent provided email address only	By Email	1 week later by email	1 week later by email
Respondent provided phone and mailing address	By phone (questionnaire can be completed on a mobile phone) and if no answer by text	1 week later by phone or text	Send paper questionnaire by post with return postage-paid envelope
Respondent only provided mailing address	Send paper questionnaire by post with return postage-paid envelope	1.5 weeks later send reminder letter	1 week later send reminder letter
Respondent only provided phone	By phone (questionnaire can be completed on a mobile phone) and if no answer by text	1 week later by phone or text	1 week later by phone or text

Correspondence to the study cohort regarding the survey will be personalised and staff involved in the project will maintain a positive and caring attitude which will aid in maximising retention[25].

Table 3 a,b outline demographic and other characteristics of the follow-up study cohort compared to baseline respondents. Proportions of respondents across different exposure and outcome categories and socio-demographics are broadly equivalent across the baseline and follow-up cohorts.

Table 3 a: Demographics of baseline cohort (N=2,530) and respondents willing to be followed-up (N=1,265)

		First Survey	Second Survey Candidates
Demographics		Number (%)	Number (%)
Age Group	16-24	323 (12)	163 (13)
	25-49	969 (38)	529 (42)
	50-69	965 (38)	521 (41)
	70+ years	93 (4)	44 (3)
	Not Stated	180 (7)	8 (1)
Gender	Women	1617 (64)	884 (70)
	Men	735 (29)	363 (29)
	Other	11 (1)	8 (1)
	Not Stated	167 (7)	10 (1)
Aboriginal & Torres Strait Islander status	Indigenous	83 (3)	41 (3)
	Non-ndigenous	2271 (90)	1207 (95)
	Not Stated	176 (7)	17 (1)
LGBTIQ	Yes	139 (5)	74 (6)
	No	1191 (47)	581 (46)
	Not Stated	217 (9)	85 (7)
	Not Asked	983 (39)	525 (42)
Relationship status	Single	756 (30)	401 (32)
	In a relationship	1581 (62)	851 (67)
	Not Stated	193 (8)	13 (1)
Education level	University degree	1026 (41)	595 (47)
	Other	1325 (52)	663 (52)
	Not Stated	179 (7)	7 (1)
Employment status	Paid employment	737 (29)	379 (30)
	Not Employed/Retired	1612 (64)	876 (69)
	Not Stated	181 (7)	10 (1)
Income support	Yes	743 (29)	397 (31)
	No	1576 (62)	842 (67)
	Not Stated	211 (8)	26 (2)

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Table 3 b: Other Characteristics of baseline cohort (N=2,530) and respondents willing to be followed-up (N=1,265)

	First Survey	Second Survey Candidates
	Number (%)	Number (%)
Flood exposure		
Unaffected	290 (11)	133 (11)
Suburb damage	1913 (76)	982 (78)
Home of significant other	1572 (62)	816 (65)
Non-liveable areas	1178 (47)	624 (49)
Liveable areas	528 (21)	267 (21)
Evacuated	380 (15)	194 (13)
Displaced <6mth	259 (10)	126 (10)
Displace >6mth	92 (4)	53 (4)
Business damaged	420 (17)	221 (17)
Evacuate business	358 (15)	180 (14)
Mental health, 1st survey		
Still distressed	543 (21)	318 (25)
PTSD	363 (14)	212 (17)
Anxiety	384 (15)	219 (17)
Depression	374 (15)	195 (15)
Suicidal ideation	171 (7)	98 (8)

Consent will be implied if participants agree to continue with the survey following presentation of the Participant Information Sheet on the first page. If participants require assistance to complete the survey, they will be able to contact the research team who in turn will direct them to the most appropriate service, for example, where they can access a computer (e.g. public library, neighbourhood centres) or personal assistance via a relevant community organisation.

As an incentive, various prizes (gift vouchers with value of $100 to spend within local businesses) will be offered to all who participate through a lottery style draw. There will be 20 prizes available. The same incentive was effective in encouraging responses to the baseline survey. In order to participate in the prize draw, at the end of the survey participants will be directed to a separate site where they can leave contact details (name, phone number, email) so they can be contacted if they win one of the prizes in the draw. In this way, it will not be possible to link identifiable information about that participant to their survey responses. This part of the paper survey will be detached and stored separately from the survey responses.

At the end of the survey, participants will be asked again if they would be willing to be contacted in the future to participate in further research about the flood. Any contact information provided will be stored separately to survey responses. Through a series of personal questions at the start of the survey (the first letter of their first name, the last letter of their last name, the day of the month they were born e.g. 05 for the fifth day of the month, and if they are Left, Right or Both handed), the participant will generate for themselves a unique identifier. The purpose of this unique identifier is to continue to connect longitudinal information if participants agree to be part of the next data collection point in the cohort study.

4.4 Pilot evaluation
We will establish face validity of the questionnaire by seeking review from colleagues and the project's CAGs. Through the CAGs, we will recruit 5-10 volunteers representing a cross-section of community to pilot test the survey. Feedback will be sought on item clarity, ambiguity and length. Accurate estimates of the time required to complete the questionnaire will be obtained. This information will be used to modify the questionnaire where required. Any changes are expected to be minor and will be submitted to Ethics as an amendment.

4.5 Data analyses

Following data cleaning, we will undertake initial descriptive analyses including means and standard deviations, frequencies and proportions, for all social and mental health variables. These statistics will be calculated separately for the sample as a whole and for the exposure groups (flooded/disrupted without flooding/non-exposed) and the key interest groups (people on low income/people 75 years and over/young adults/Aboriginal people/LGBTIQ community/business owners and farmers).

We will examine the mental health (anxiety, depression and PTSD) across each of the exposure groups and key interest groups. Those claiming no flood impact (non-exposed) will form a control group for comparison to groups which reported impacts. Proposed protective factors for mental health (such as level of individual and community resilience) will be analysed within flood affected groups.

Multivariate analyses will be performed to determine associations between flood experience and mental health and wellbeing relative to non-exposed participants (controlling for confounding socio-demographic variables) and to determine the effect of mediating factors such as level of assistance received, as well as individual and community resilience characteristics. Conditional logistic regression models for repeated measures will also explore statistical significance in psychological morbidity between six-months and two years post-flood across socio-demographic groups.

4.6 Research timeframe and resources

The collection of data for this study is planned to commence in early April 2019 (two years following the flood) and continue over two to three weeks (Table 4). Funding for this stage two of the project ($20,000) has been secured from internal sources within the University Centre for Rural Health.

Table 4. Flood research timeline

Finalise protocol including methods and tools	February 2019
Ethics and governance approval process	February-March 2019
Pilot survey	March 2019
Data collection (2-3 weeks)	April 2019
Data analysis	May 2019-May 2020
Feedback to community and services	May 2019-Dec 2020
Report and paper writing	May 2019-Dec 2021

5   ETHICAL CONSIDERATIONS

5.1   Recruitment and selection of participants

Participation in the survey is voluntary. Potential participants are those who participated in the baseline survey. We will ask relevant local organisations (via our CAGs) to support members of the community wishing to participate but unable to access the internet or whose literacy level presents a barrier to participation (via assisted survey completion).

As a sign of appreciation, we will be offering the chance to win a gift voucher ($100) purchased from local businesses, via a lottery style draw for participants who choose to enter the draw. There are multiple benefits to this approach – a chance at winning a small gift voucher for survey participation as well as economic benefit for local businesses affected by the flood.

Participant contact information will only be provided by participants if they wish to participate in the draw or are willing to participate in future research. If contact information is provided, it will be stored separately from survey responses to protect confidentiality.

All correspondence with the study cohort regarding the survey will be personalised and staff involved in the project will maintain a positive and caring attitude which will aid in maximising retention. Invitation to participate will be sufficient to ensure the cohort is able to take part should they wish, but will not be bothersome.

5.2 Confidentiality and Privacy

Our project collects data via an online and paper based questionnaire. We will be using the Qualtrics platform to distribute the online survey and to capture data. The Qualtrics service is hosted by a data centre in Sydney that is independently audited using the industry standard SSAE-16 method. Qualtrics servers are protected by high-end firewall systems and scans are performed regularly to ensure that any vulnerabilities are quickly found and patched. Complete penetration tests are performed yearly. Complete backups are performed nightly. For security and confidentiality reasons, access to systems is severely restricted to specific staff, whose access is monitored and audited for compliance. Qualtrics uses Transport Layer Security (TLS) encryption (also known as HTTPS) for all transmitted data. Questionnaires are protected with passwords and HTTP referrer checking.

The UCRH subscription to Qualtrics is guarded by a strong account password limited to two authorized research staff who will download and confidentialise data for analysis purposes.

All participant data collected using the software is stored in the secure data centre. The UCRH retains data ownership of the survey information collected. Qualtrics employees do not view survey data and there is regular monitoring of security compliance by a limited number of staff with access to servers as described above.

Completed paper surveys will be returned to the UCRH using a pre-paid envelope. The project data will be stored in individually re-identifiable form to facilitate future follow up with those respondents willing to participate in further research. The code information which will enable re-identification of survey responses in cases where participants have specified they are willing to participate in further research, will be accessible by project team members named on this ethics application only.

Participants will be assured of confidentiality. No individual will be identified during survey analysis and no individual information will be disseminated, only reports of aggregate information.

5.3 Data storage and record retention

As outlined above, online survey data will be collected and stored at the Qualtrics secure data centre. All paper-based data will be collected and stored in a locked filing cabinet at the UCRH in Lismore (contact information will be coded with the individual ID code and stored separately from the completed survey). Two authorized research staff named on this application will download and confidentialise the online data for analysis purposes. Potentially re-identifiable project data will only be accessible by project staff with appropriate ethics approval from password protected computers. Only research staff named on this ethics application will have access to the locked filing cabinet. All data analysts with access to confidential (re-identifiable) information will sign/have signed an Acknowledgement of Confidentiality Declaration before the Chief Investigator will grant approval for their data access.

All electronic and paper-based data files will be stored for seven years after data publication. This will provide sufficient time for potential follow up of mental health and wellbeing following the flood. After 7 years post publication of results, electronic files will be erased and paper based data dealt with as confidential waste and disposed of accordingly.

6 OUTCOMES AND SIGNIFICANCE

The study is novel with respect to the collection of longitudinal data, and data from rural Australia. Project findings will describe any changes to the mental health and wellbeing of respondents, identify characteristics of the most vulnerable and the most resilient members of the community (and what is associated with being vulnerable or resilient), improve our understanding of vulnerability following a natural disaster (testing a *Flood Impact Framework*), and the extent to which mental health and wellbeing needs were/are being met.

The study will be conducted in partnership with relevant local government and community organisations to enable feedback on service gaps that are highlighted from the aggregate analysis. In addition, the survey results will also inform the strengthening of flood preparedness plans and disaster response. These learnings from the project may be applied to other regions within Australia and internationally that are prone to natural disasters.

The overall results of this research project will be disseminated in a final report format, plain language briefs (general communication back to the Northern Rivers community), policy briefs for government and community services as well as academic publications and conference presentations. Dissemination of results will be undertaken in a respectful way, presenting results to the CAGs regularly during the project to seek their input and insight on the interpretation of results.

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A bit more about this questionnaire

In 2017, you were one of 2,500 people who took part in the 'Community Recovery After Flood' survey. THANK YOU – the findings from that survey have been incredibly useful in helping us understand the needs of the community. Early findings were sent out to those who requested a copy and are available from the UCRH website: https://ucrh.edu.au/after-the-flood. From this first survey, you told us you might be willing to take part in future studies.

It has been two years since the flood. This follow-up questionnaire asks about

* How you are doing now
* What flood-related issues you are still dealing with
* What it's like living in the community now

Your answers will help our understanding about longer-term impacts of the flood and will help plan future responses to disasters. If you know of others who completed the first questionnaire and didn't receive this follow-up survey, please contact us at northern-rivers.flood@sydney.edu.au' or 02 6620 7570

All returned questionnaires will go into the prize draw (unless you don't want to).

Important: You do not have to fill in this questionnaire

This questionnaire is completely voluntary. If you do start filling it in, you can stop at any time. Or if you don't want to answer a question, you can skip it and go to the next one. Your other answers will still be useful.

If you fill in this questionnaire and return it to us, we will take that to mean that you have freely consented to do so.

Your information is completely confidential. You will not be identified and none of your personal information will be reported.

Send in your questionnaire by Monday 15th April. Post it in the reply paid envelope.

We recognise that many people have experienced significant losses because of the flood and we sincerely apologise for any distress completing this questionnaire may cause.

This questionnaire is part of a research project being conducted by the University Centre for Rural Health which is a collaboration between the University of Sydney, Western Sydney University, Wollongong University and Southern Cross University.

If you have any questions about the research, please phone 02 6620 7570 or email: northern-rivers.flood@sydney.edu.au

If you have any concerns or complaints about the ethical conduct of the project, please contact the Ethics Administration Officer of the Human Research Ethics Committees which have reviewed and approved this project:

University of Sydney Ethics Committee
human.ethics@sydney.edu.au
Phone: 02 9036 9161

Aboriginal Health & Medical Research Council
ethics@ahmrc.org.au
Phone: 02 9212 4777

ACON Ethics Committee
research@acon.org.au
Phone: 02 9206 2000

We sincerely thank the National Centre for Flood Research at Southern Cross University for their financial support. The project also receives advice, practical help and support from a large number of organisations on our Community Advisory Groups and Research Advisory Group. We thank all our contributors.

Do you want to talk to someone confidentially about the flood or how things are going now?

Please call Lifeline: 13 11 14
or BeyondBlue: 1300 224 636
Or talk to your doctor about how you are feeling to ensure you are getting the appropriate support you need.

For young people (12 to 25 years) call your local headspace office (Mon-Fri, 9am-5pm): 02 6625 0200 (Lismore) or 07 5589 8700 (Tweed Heads) or there's an online counselling service eheadspace: www.eheadspace.org.au (daily between 9am - 1am). Outside of these hours, please call Lifeline: 13 11 14 or BeyondBlue: 1300 224 636

First, to ensure confidentiality, we ask you to write your own personal code using the instructions below. This will help us link your story to what you told us about 18 months ago.

☐	☐	☐ ☐		☐

The **FIRST letter** of your **FIRST name**   The **LAST letter** of your **LAST name**   The **DAY** of the month that you were born on (e.g., '05' for the fifth day of the month)   Are you left or right-handed? (L, R, Both)

Instructions for filling out the questionnaire

Most questions are either ☑ Tick a box OR Circle a number   1   2   ③   4   5

If a question is not relevant for you, please tick ☑ Not applicable (N/A)

In some questions, you are asked to write in some words, e.g: Where is your current postcode? e.g. 2480

Part 1 About the flood and your wellbeing now

1. Was your home or yard flooded during the 2017 flood?

    ☐ Yes   ☐ No > Go to Q4

2. If you had to move home because of the 2017 flood, which best describes your current situation?

    ☐ Moved back into original home at the time of the 2017 flood
    ☐ Moved permanently into new home
    ☐ Temporarily living elsewhere
    ☐ Other (Please specify):
    ☐ N/A

3. If your current home was flooded in 2017, have you been able to resume use of all liveable rooms (e.g., bedroom, living room, kitchen, bathroom) in your home as normal?

    ☐ Yes   ☐ No   ☐ N/A

4. Is your current home affected by any ongoing problems caused by the flooding in 2017? (Please tick all that apply)

    ☐ No, not affected
    ☐ Visible mould in liveable rooms (e.g., bedroom, living room, kitchen, bathroom)
    ☐ Structural damage
    ☐ Sewage (drains) backing up and flooding
    ☐ Problems with septic tank
    ☐ Problems with other utilities (drinking water, gas, electricity, etc.)
    ☐ Other (please specify what other problems have continued):
    _____
    _____
    _____

5. At the time of the flood, were you working as..?

    A farmer?   ☐ Yes   ☐ No
    Other business owner?   ☐ Yes   ☐ No

6. Are you currently working as..?

    A farmer?   ☐ Yes   ☐ No
    Other business owner?   ☐ Yes   ☐ No

7. Was your business or farm affected during the 2017 flood?

    ☐ Yes   ☐ No >Go to Q9   ☐ N/A >Go to Q10

8. If your business or farm was flooded, which best describes your current situation?

    ☐ Still operating out of the same business/farm address at the time of the 2017 flood
    ☐ Moved business/farm permanently elsewhere
    ☐ No longer operating as business owner or farmer
    ☐ Other (Please specify):
    _____
    _____

    ☐ N/A

9. Is your current business or farm property affected by any ongoing problems caused by the flooding in 2017? (Please tick all that apply)

☐ No, not affected

☐ Reduced income compared to before the 2017 flood

☐ Structural damage to buildings

☐ Damage to property such as stock, fences, machinery etc.

☐ Damage to land and road infrastructure e.g. landslips

☐ Sewage (drains) backing up and flooding

☐ Problems with other utilities (water supply, gas, electricity, etc.)

☐ Other (please specify what other problems have continued):

_____

_____

10. Are you still distressed about what happened in the 2017 flood?

☐ Yes   ☐ No

11. Have any of the following happened since the last questionnaire (about 18 months ago)? (Please tick all that apply)

☐ Relationship problems (e.g. arguing with partner/friends/children)

☐ Disagreements/arguments with neighbours

☐ You are more worried about climate change than you used to be

☐ A close family member died

☐ You suffered a major injury or illness

☐ You were dismissed from your job

☐ You went to prison

☐ You got divorced

☐ Your spouse or long-term partner died

☐ You separated from your spouse or long-term partner

☐ You were impacted by another natural disaster (e.g., bushfire, drought, flood)

☐ None of the above

12. At the time of the flood, what type of insurance policies did you have (Please tick all that apply):

a) Business / business contents   ☐ Yes ☐ No ☐ N/A
b) Home and/or home contents   ☐ Yes ☐ No ☐ N/A

13. Did you make a business / business contents insurance claim in relation to damage from the 2017 flood?

☐ Yes   ☐ No > Go to Q14   ☐ N/A > Go to Q14

If yes: Has your business insurance claim been processed, approved and paid?

Insurance claim not yet assessed	Claim not approved	Claim approved, not yet paid	Approved, some money paid, still some outstanding	Approved, fully paid
☐	☐	☐	☐	☐

14. Did you make a home and/or home contents insurance claim in relation to damage from the 2017 flood?

☐ Yes   ☐ No > Go to Q15   ☐ N/A > Go to Q15

If yes: Has your home insurance claim been processed, approved and paid?

Insurance claim not yet assessed	Claim not approved	Claim approved, not yet paid	Approved, some money paid, still some outstanding	Approved, fully paid
☐	☐	☐	☐	☐

15. Which of the following financial assistance programs did you apply for relating to 2017 flood damage in your home and/or farm/business? (Please answer each one)

a) Local Government Flood Appeal Assistance (e.g., Tweed Mayoral Flood Appeal; Lismore City Council Flood Appeal etc)

☐ Yes   ☐ No > Go to Q15b   ☐ N/A > Go to Q15b

If yes: Was your application approved and paid?

Application not approved	Application approved, not yet paid	Approved, some money paid, still some outstanding	Approved, fully paid
☐	☐	☐	☐

b) State Government Disaster relief grant for replacing essential household contents

☐ Yes   ☐ No > Go to Q16c   ☐ N/A > Go to Q16c

If yes: Was your application approved and paid?

Application not approved	Application approved, not yet paid	Approved, some money paid, still some outstanding	Approved, fully paid
☐	☐	☐	☐

c) State Government Disaster relief grant for essential structural repairs

☐ Yes   ☐ No > Go to Q16d   ☐ N/A > Go to Q16d

If yes: Was your application approved and paid?

Application not approved	Application approved, not yet paid	Approved, some money paid, still some outstanding	Approved, fully paid
☐	☐	☐	☐

d) *Category B or C funding (disaster relief funding for small business, primary producers not for profit organisations)*

☐ Yes   ☐ No > *Go to Q17*   ☐ N/A > *Go to Q17*

If yes: Was your application approved and paid?

Application not approved	Application approved, not yet paid	Approved, some money paid, still some outstanding	Approved, fully paid
☐	☐	☐	☐

e) *Other disaster relief funding*
   *Please specify:*_____

☐ Yes   ☐ No > *Go to Q16*   ☐ N/A > *Go to Q16*

If yes: Was your application approved and paid?

Application not approved	Application approved, not yet paid	Approved, some money paid, still some outstanding	Approved, fully paid
☐	☐	☐	☐

The next few questions ask about your health and wellbeing, including services and support you may have needed and/or accessed since the 2017 flood.

16. Because of the 2017 flood, did you try to seek support from any of the following? Please answer each one.

a) *Doctor (GP)*

☐ Yes   ☐ No > *Go to Q16b*

If Yes: did the service meet your needs?

No	Partially met my needs	Fully met my needs	Don't know
☐	☐	☐	☐

b) *Psychologists and other counsellors*

☐ Yes   ☐ No > *Go to Q16c*

If Yes: did the service meet your needs?

No	Partially met my needs	Fully met my needs	Don't know
☐	☐	☐	☐

c) *Public mental health services (psychiatry; community mental health hospital mental health)*

☐ Yes   ☐ No > *Go to Q16d*

If Yes: did the service meet your needs?

No	Partially met my needs	Fully met my needs	Don't know
☐	☐	☐	☐

d) *Mental Health Flood Support Line and other helplines (e.g., Lifeline, BeyondBlue, headspace, Mensline etc)*

☐ Yes   ☐ No > *Go to Q16e*

If Yes: did the service meet your needs?

No	Partially met my needs	Fully met my needs	Don't know
☐	☐	☐	☐

e) *Community support networks (e.g., disability support networks; parent support networks; Tropical Fruits etc)*

☐ Yes   ☐ No > *Go to Q16f*

If Yes: did the support network meet your needs?

No	Partially met my needs	Fully met my needs	Don't know
☐	☐	☐	☐

f) *Housing and accommodation support*

☐ Yes   ☐ No > *Go to Q16g*

If Yes: did the service meet your needs?

No	Partially met my needs	Fully met my needs	Don't know
☐	☐	☐	☐

g) *Other supports and services (please specify)*

_____

☐ Yes   ☐ No > *Go to Q18*   ☐ N/A > *Go to Q17*

If Yes: did the service meet your needs?

No	Partially met my needs	Fully met my needs	Don't know
☐	☐	☐	☐

17. Were any of the following issues a challenge for you in accessing support for your health and wellbeing? (Tick all that apply)

☐ Cost
☐ Service availability
☐ Lack of cultural safety*
☐ Stigma/shame
☐ Transport
☐ Not sure what is available
☐ Other (Please specify):_____
☐ None of the above
☐ N/A

*Cultural safety means that when you are accessing support, you are treated with respect and you feel safe and secure in your identity & culture.

3

18. In general, would you say your health is..?

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

19. Please rate the following statements according to how true the statement is for you: (Please circle one per line)

a) Since the flood, I tend to be hard on myself

Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly Agree
1	2	3	4	5	6	7

b) Since the flood, I've made a special effort to take care of myself

Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly Agree
1	2	3	4	5	6	7

20. Over the past four weeks, how often have you been bothered by any of the following problems? (Please tick one per line)

	Not at all	Several days	More than half the days	Nearly every day
a) Little interest or pleasure in doing things	☐	☐	☐	☐
b) Feeling down, depressed or hopeless	☐	☐	☐	☐
c) Feeling nervous, anxious or on edge	☐	☐	☐	☐
d) Not being able to stop or control worrying	☐	☐	☐	☐

21. Below is a list of complaints that people sometimes have after severe rain and flood. Please indicate how much you have been bothered by each complaint in the last four weeks. (Please tick one per line)

	Not at all	A little bit	Moderately	Quite a bit	Extremely
a) Repeated, disturbing memories, thoughts, or images	☐	☐	☐	☐	☐
b) Feeling very upset when something reminded you of the event	☐	☐	☐	☐	☐
c) Avoiding activities or situations because they remind you of the event	☐	☐	☐	☐	☐
d) Feeling distant or cut off from other people	☐	☐	☐	☐	☐
e) Feeling irritable or having angry outbursts	☐	☐	☐	☐	☐
f) Having difficulty concentrating	☐	☐	☐	☐	☐

22. Sometimes when people experience a stressful event, they can think about ending their life. Do you know of anyone in the community who has thought about or attempted to end their life since the flood?

☐ Yes   ☐ No

23. Over the past four weeks, have you personally had any thoughts about ending your life?

Not at all	Several days	More than half the days	Nearly every day
☐	☐	☐	☐

24. Can you comment on any actions taken by yourself and/or others since the 2017 flood to help you prepare for future floods?

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25. What could be improved to help our community better prepare for future floods?

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When disaster strikes, long-term community recovery is really important. This part of the questionnaire is mostly about your community and what it's like living there.

The following questions are about how much time you spend connecting with different people and groups in the community in which you live.

26. What sorts of things do you do in your community? Please say to what extent you agree with the following statements? [Circle one per line]

	Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly agree
a) I chat with my neighbours when I see them	1	2	3	4	5	6	7
b) I volunteer locally (e.g., Meals on Wheels, school fete, Rural Fire Service)	1	2	3	4	5	6	7
c) I make time to keep in touch with my friends	1	2	3	4	5	6	7
d) I take part in sports activities or groups	1	2	3	4	5	6	7
e) I spend time with extended family members (relatives who don't live with me)	1	2	3	4	5	6	7
f) I take part in community-based clubs or associations (e.g., Rotary, CWA, book club, Lions)	1	2	3	4	5	6	7
g) I am active on social media (e.g., facebook, snapchat, instagram)	1	2	3	4	5	6	7
h) I get involved with political activities (e.g., through interest groups, public meetings, rallies)	1	2	3	4	5	6	7
i) I attend community events such as farmers' markets, festivals and shows	1	2	3	4	5	6	7
j) I attend services at a place of worship or I go to prayer meetings	1	2	3	4	5	6	7
k) I go to arts or cultural events	1	2	3	4	5	6	7

27. Over the past year, have you been doing everything you normally do? To what extent do you agree with the following statements?

	Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly agree
a) I go about my daily activities as usual (e.g., around the house, work, shopping)	1	2	3	4	5	6	7
b) I walk places as often as I used to	1	2	3	4	5	6	7
c) I go outdoors for leisure just as much as before (e.g., go to playgrounds, parks, local sports fields)	1	2	3	4	5	6	7
d) I've been as physically active as usual	1	2	3	4	5	6	7

5

The following questions are about what it's like spending time in the community in which you live and what other people are like there these days.

28. What is it like living with other people in your community? To what extent do you agree with the following statements? (Please circle one per line)

	Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly agree
a) I enjoy the time I spend with others socially	1	2	3	4	5	6	7
b) When I feel lonely there are several people I could call and talk to	1	2	3	4	5	6	7
c) I feel like an outsider	1	2	3	4	5	6	7
d) I have family or friends I can confide in	1	2	3	4	5	6	7
e) I would like to spend more time with people socially	1	2	3	4	5	6	7
f) I feel that I belong	1	2	3	4	5	6	7
g) I feel that I'm on the fringe in my circle of friends	1	2	3	4	5	6	7
h) There are people outside my household who can offer help in a crisis	1	2	3	4	5	6	7
i) I don't often get invited to do things with others	1	2	3	4	5	6	7
j) I feel included	1	2	3	4	5	6	7

29. Generally speaking, what are most people like around where you live? (Please circle one per line)

	Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly agree
a) People in my area make everyone feel welcome	1	2	3	4	5	6	7
b) Most people around here succeed by stepping on others	1	2	3	4	5	6	7
c) Some people are left out here	1	2	3	4	5	6	7
d) Most people tell the truth when they're sorting out a problem	1	2	3	4	5	6	7
e) People are mostly well-off around here	1	2	3	4	5	6	7
f) Most people keep their word	1	2	3	4	5	6	7
g) There is a lot of ethnic diversity here	1	2	3	4	5	6	7
h) Most people do what they say they'll do	1	2	3	4	5	6	7

30. Thinking about people in general (not just people in your community), how do they tend to behave? (Please circle one per line)

	Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly agree
a) Most people, try to be helpful	1	2	3	4	5	6	7
b) Most people look out for themselves	1	2	3	4	5	6	7
c) You can't be too careful with some people	1	2	3	4	5	6	7
d) Most people can be trusted	1	2	3	4	5	6	7

6

...A few last questions about what things have been like personally for you.

31. When it comes to alcohol and to bacco, has anything changed over the last year?

	Probably have	Don't think so	N/A
a) I smoke more than I used to	☐	☐	☐
b) I drink more than I used to	☐	☐	☐
c) I've been worried about my smoking or drinking	☐	☐	☐

32. When it comes to spending time with friends, has anything changed over the last year? I spend...

Much less time with friends	A bit less time with friends	About the same time with friends	A bit more time with friends	Much more time with friends
☐	☐	☐	☐	☐

33. To what extent do you agree with the following statements? (Please circle one per line)

a) Overall, I expect more good things to happen to me than bad

Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly Agree
1	2	3	4	5	6	7

b) In uncertain times, I always expect the best

Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly Agree
1	2	3	4	5	6	7

c) If something can go wrong for me, it will

Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly Agree
1	2	3	4	5	6	7

d) I'm always optimistic about my future

Strongly disagree	Disagree	Disagree somewhat	Neither agree or disagree	Agree somewhat	Agree	Strongly Agree
1	2	3	4	5	6	7

34. Thinking back, has the 2017 flood resulted in you being able to make any positive changes in your life?

☐ Yes   ☐ No   ☐ Not sure

If yes: Could you give an example of your positive changes?

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35. Is there anything else you want to add about your experience since the 2017 flood, what things are like for you now and/or what may be needed into the future to better prepare for floods? (you can use the space on the very back page if you need more room)

_____

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Finally, an update about you and your household. This information is important for planning purposes to ensure relevant support services reach the right people and places.

36. How old are you? ☐ [years]

37. Where were you born?
☐ Born in Australia ☐ Born overseas

38. What language do you speak at home?
☐ Mainly English ☐ Mainly a language other than English

39. Are you of Aboriginal or Torres Strait Islander origin?
☐ Yes, Aboriginal ☐ Yes, both Aboriginal and Torres Strait Islander
☐ Yes, Torres Strait Islander ☐ No

40. Are you...?
☐ Female ☐ Male ☐ Non-binary/gender fluid
☐ Different identity (please state):

_____

41. What is your relationship status?
☐ Single ☐ Married or other formal commitment
☐ In a relationship, but not living together
☐ Living together (in a defacto relationship)

42. Do you consider yourself to be:
☐ Straight or heterosexual ☐ Lesbian, gay or homosexual
☐ Bisexual ☐ Queer
☐ Different identity (please state):

_____

43. Have you completed any formal education? (Please tick all that apply)
☐ Year 10 certificate (or equivalent)
☐ Year 12 certificate (or equivalent)
☐ Diploma or trade (e.g. child care, hairdresser, chef)
☐ University degree
☐ Other (please specify): _____
☐ None of the above

44. Are you currently in paid work? (Please tick all that apply):
☐ Part-time work ☐ Full-time work
☐ Shift-work ☐ No
☐ Casual work (hours very and are not set)

45. Which of the following describes what you do (if you are in paid work, some of these won't apply)? (Please tick all that apply)
☐ At school or in full time education
☐ Unable to work due to long-term sickness or disability
☐ Looking for paid work
☐ Regular unpaid volunteer work
☐ Looking after your home or family
☐ Retired from paid work
☐ Other (please specify): _____
☐ N/A

46. What is your housing situation now?
☐ Renting ☐ Own home outright
☐ Have a mortgage
☐ Other (please specify): _____

47. Who are you living with now? (Please tick all that apply)
☐ Living alone ☐ Spouse or partner
☐ Parent/s ☐ Unrelated adults (eg flatmates)
☐ Children ☐ Other (please specify): _____

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48. Are you currently responsible for the care (in your home) of: [Please tick all that apply]

- [ ] No-one
- [ ] Children under 5
- [ ] Children aged 5-12
- [ ] Teenage children
- [ ] Elderly adult
- [ ] Child or adult with a disability or long-term illness
- [ ] Pet(s)
- [ ] Other (please specify): _____

49. Are you currently receiving any income support from the government? [Please tick all that apply]

- [ ] Age-related pension
- [ ] Youth allowance
- [ ] Newstart
- [ ] Disability support pension
- [ ] Parenting payment (single)
- [ ] Parenting payment (partnered)
- [ ] None of these
- [ ] Other (please specify): _____

50. What is your approximate total household income per year before tax?

- [ ] Under $50,000
- [ ] $50,000-$100,000
- [ ] Over $100,000
- [ ] Prefer not to answer

51. Suppose you only had one week to raise $2,000 for an emergency, do you think you could do it?

- [ ] Yes, I think so
- [ ] No, I don't think so

This is the end of the questionnaire Thank you very much for taking part!

If you want to enter the prize draw, please complete the blue section on this page. Your contact details will be detached from your survey responses

Do you want to talk to someone confidentially about the flood or how things are going now?

Please call Lifeline: 13 11 14 or BeyondBlue: 1300 224 636

Or talk to your doctor about how you are feeling to ensure you are getting the appropriate support you need.

For young people (12 to 25 years) call your local headspace office (Mon-Fri, 9am-5pm): 02 6625 0200 (Lismore) or 07 5589 8700 (Tweed Heads) or there's an online counselling service eheadspace: www.eheadspace.org.au (daily between 9am - 1am). Outside of these hours, please call Lifeline: 13 11 14 or BeyondBlue: 1300 224 636

9

Just a couple of final things, including the prize draw ....

Feedback

If you have any queries, suggestions or feedback, please use the space below (you can use the space on the back page if you need more room).

_____

_____

_____

_____

_____

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If you would like to speak to one of the research team, please call 02 6620 7570 or email: northern-rivers.flood@sydney.edu.au.

Would you like to receive a summary of the results?

- [ ] No
- [ ] Yes (Please provide your mail address or email address):

_____

Taking part in future studies

Do you give permission for us to contact you again in the future about possible participation in further research about the flood? If so, please let us know how best to contact you. If you change your mind later on, or if you want more information before making a final decision, that's OK. Just let us know when we contact you next.

Name: _____

Mobile: _____

Email: _____

Address: _____

Prize draw*

One last thing! If you would like to enter the draw, please leave your contact details here:

- [ ] As above/or:

Name: _____

Mobile: _____

Email: _____

The draw will be held on Friday 10 May 2019 and the winners will be contacted directly. The winners' first names and suburbs will also be published on the project website www.uorh.edu.au

THIS PART WILL BE STORED SECURELY & SEPARATELY FROM YOUR QUESTIONNAIRE RESPONSES

Office use only: _____

Still distressed (N=452)	Block A		Block B			Block C			Block D		
	OR	99%CI	OR	99%CI		OR	99%CI		OR	99%CI	
Socio-demographics											
Age	1.00	(0.98-1.02)	1.00	(0.98-1.02)		1.00	(0.98-1.02)		1.01	(0.99-1.03)	
Gender (male)	0.77	(0.44-1.36)	0.79	(0.44-1.44)		0.67	(0.36-1.31)		0.61	(0.32-1.20)	
Relationship status (single)	0.73	(0.41-1.29)	0.82	(0.45-1.49)		0.75	(0.39-1.44)		0.67	(0.34-1.32)	
Education level (non-university level)	1.50	(0.90-2.51)	1.32	(0.77-2.28)		1.16	(0.64-2.10)		1.01	(0.55-1.87)	
Employment status (not in employment)	1.34	(0.61-2.97)	1.43	(0.62-3.30)		1.08	(0.44-2.67)		0.99	(0.38-2.57)	
Income support (receives income support†)	2.09	(0.90-4.86)	1.61	(0.67-3.86)		2.05	(0.77-5.47)		1.83	(0.67-5.02)	
Flood exposure											
None / Indirect disruption			1.00	(reference)		1.00	(reference)		1.00	(reference)	
Flooded			4.38	(2.39-8.00)	**	2.27	(1.16-4.44)	*	2.14	(1.09-4.22)	*
Post-flood stressors											
Persistent damage from flood						3.89	(2.10-7.19)	**	3.72	(1.98-7.00)	**
Insurance dispute from flood						3.71	(1.27-10.86)	*	4.27	(1.41-12.91)	*
Other life stressors#						1.95	(1.08-3.52)	*	1.72	(0.92-3.20)	
Post-flood social capital											
Informal social connectedness									1.02	(0.74-1.41)	
Feelings of belonging									1.08	(0.77-1.51)	
Sense of belonging									0.80	(0.52-1.23)	
Trait optimism									0.72	(0.52-0.99)	*

† In receipt of the following income support: single parent payment; unemployment allowance (Newstart); youth allowance; disability support; carer payment. # Other life stressors experienced in last 18 months: relationship problems; major illness or injury; close family member died; neighbour disputes; impacted by another weather-related disaster. * $p < 0.01$; ** $p < 0.001$

Probable PTSD (N=453)	Block A		Block B		Block C		Block D	
	OR	99%CI	OR	99%CI	OR	99%CI	OR	99%CI
Socio-demographics								
Age	0.98	(0.96-1.01)	0.98	(0.95-1.01)	0.99	(0.96-1.02)	1.01	(0.97-1.05)
Gender (male)	0.80	(0.35-1.79)	0.83	(0.36-1.93)	0.70	(0.29-1.73)	0.54	(0.20-1.47)
Relationship status (single)	1.37	(0.64-2.92)	1.65	(0.75-3.64)	1.86	(0.79-4.40)	1.29	(0.49-3.38)
Education level (non-university level)	2.52	(1.17-5.45) *	2.26	(1.02-4.99) *	2.52	(1.06-6.00) *	2.59	(0.97-6.89)
Employment status (not in employment)	2.65	(1.07-6.55) *	2.86	(1.13-7.25) *	2.56	(0.94-6.99)	1.79	(0.59-5.46)
Income support (receives income support†)	2.98	(1.16-7.65) *	2.39	(0.91-6.28)	2.50	(0.86-7.23)	2.50	(0.78-8.09)
Flood exposure								
None / Indirect disruption			1.00	(reference)	1.00	(reference)	1.00	(reference)
Flooded			6.15	(2.00-18.84) **	3.55	(1.01-12.49) *	3.42	(0.86-13.55)
Post-flood stressors								
Persistent damage from flood					3.44	(1.47-8.02) **	3.82	(1.48-9.86) **
Insurance dispute from flood					2.08	(0.71-6.10)	2.38	(0.69-8.13)
Other life stressors#					4.81	(1.99-11.62) **	3.96	(1.48-10.64) **
Post-flood social capital								
Informal social connectedness							0.88	(0.55-1.39)
Feelings of belonging							0.52	(0.32-0.85) *
Sense of belonging							1.46	(0.81-2.63)
Trait optimism							0.51	(0.33-0.78) **

† In receipt of the following income support: single parent payment; unemployment allowance (Newstart); youth allowance; disability support; carer payment. # Other life stressors experienced in last 18 months: relationship problems; major illness or injury; close family member died; neighbour disputes; impacted by another weather-related disaster. * $p < 0.01$; ** $p < 0.001$

Probable anxiety (N=451)	Block A OR	99%CI		Block B OR	99%CI		Block C OR	99%CI		Block D OR	99%CI	
Socio-demographics												
Age	0.98	(0.95-0.99)	*	0.97	(0.95-0.99)	*	0.98	(0.95-1.01)		1.00	(0.97-1.03)	
Gender (male)	1.02	(0.49-2.12)		1.05	(0.50-2.22)		0.95	(0.43-2.07)		0.79	(0.33-1.87)	
Relationship status (single)	0.98	(0.47-2.04)		1.06	(0.50-2.23)		1.05	(0.48-2.29)		0.74	(0.31-1.78)	
Education level (non-university level)	1.49	(0.75-2.97)		1.36	(0.68-2.74)		1.42	(0.68-2.96)		1.17	(0.52-2.66)	
Employment status (not in employment)	2.59	(1.06-6.32)	*	2.64	(1.08-6.47)	*	2.39	(0.93-6.13)		1.84	(0.64-5.30)	
Income support (receives income support†)	1.69	(0.64-4.42)		1.46	(0.55-3.87)		1.17	(0.42-3.27)		1.02	(0.33-3.16)	
Flood exposure												
None / Indirect disruption				1.00	(reference)		1.00	(reference)		1.00	(reference)	
Flooded				2.52	(1.11-5.69)	*	1.56	(0.62-3.90)		1.27	(0.47-3.47)	
Post-flood stressors												
Persistent damage from flood							2.34	(1.11-4.95)	*	2.29	(1.00-5.23)	*
Insurance dispute from flood							0.75	(0.24-2.34)		0.71	(0.20-2.49)	
Other life stressors#							4.20	(1.96-9.04)	**	3.35	(1.45-7.75)	**
Post-flood social capital												
Informal social connectedness										1.13	(0.74-1.72)	
Feelings of belonging										0.70	(0.45-1.07)	
Sense of belonging										0.96	(0.57-1.60)	
Trait optimism										0.48	(0.33-0.72)	**

† In receipt of the following income support: single parent payment; unemployment allowance (Newstart); youth allowance; disability support; carer payment. # Other life stressors experienced in last 18 months: relationship problems; major illness or injury; close family member died; neighbour disputes; impacted by another weather-related disaster. * $p < 0.01$; ** $p < 0.001$.

Probable depression (N=445)

	Block A			Block B			Block C			Block D	
	OR	99%CI		OR	99%CI		OR	99%CI		OR	99%CI	
Socio-demographics												
Age	0.97	(0.95-0.99)	*	0.97	(0.94-0.99)	*	0.98	(0.95-1.01)		1.00	(0.96-1.03)	
Gender (male)	1.61	(0.73-3.55)		1.67	(0.75-3.70)		1.57	(0.69-3.53)		1.48	(0.58-3.79)	
Relationship status (single)	1.29	(0.59-2.85)		1.39	(0.62-3.09)		1.41	(0.62-3.23)		0.92	(0.35-2.42)	
Education level (non-university level)	1.73	(0.80-3.77)		1.61	(0.73-3.54)		1.63	(0.72-3.66)		1.41	(0.56-3.54)	
Employment status (not in employment)	3.89	(1.53-9.89)	**	3.95	(1.55-10.08)	**	3.53	(1.34-9.26)	*	2.65	(0.86-8.17)	
Income support (receives income support†)	1.60	(0.58-4.42)		1.43	(0.51-3.99)		1.31	(0.45-3.82)		1.07	(0.32-3.61)	
Flood exposure												
None / Indirect disruption				1.00	(reference)		1.00	(reference)		1.00	(reference)	
Flooded				2.05	(0.85-4.89)		1.37	(0.52-3.65)		1.21	(0.39-3.71)	
Post-flood stressors												
Persistent damage from flood							1.78	(0.79-4.02)		1.52	(0.60-3.82)	
Insurance dispute from flood							1.34	(0.43-4.14)		1.43	(0.38-5.36)	
Other life stressors#							2.95	(1.31-6.63)	*	2.08	(0.82-5.27)	
Post-flood social capital												
Informal social connectedness										0.95	(0.60-1.51)	
Feelings of belonging										0.60	(0.38-0.96)	*
Sense of belonging										0.83	(0.48-1.44)	
Trait optimism										0.51	(0.33-0.78)	**

† In receipt of the following income support: single parent payment; unemployment allowance (Newstart); youth allowance; disability support; carer payment. # Other life stressors experienced in last 18 months: relationship problems; major illness or injury; close family member died; neighbour disputes; impacted by another weather-related disaster. * $p < 0.01$; ** $p < 0.001$

Chapter 4: Recurrent Outbreaks of Acute Post-Streptococcal Glomerulonephritis (APSGN) in the Northern Peninsula Area, Queensland in 2019

Preface

In the first half of 2019, there were two outbreaks in quick succession of acute post-streptococcal glomerulonephritis (APSGN) in the Northern Peninsula Area (NPA) of Queensland. The NPA is comprised of five inter-connected Aboriginal and Torres Strait Islander communities (Bamaga, Seisia, New Mapoon, Injinoo and Umagico) within the Torres and Cape Hospital and Health Service (TCHHS).

During the second outbreak in May-June 2019, Queensland Health (QH) requested field assistance through the MAE program. I was subsequently invited to join the outbreak control team, the hub of which was located within the Bamaga Primary Health Care (PHC) Clinic, a QH facility. I travelled to Bamaga where I spent eight days (19th – 28th June 2019) helping the Information Coordination team manage screening and treatment data of children and young adults across the five NPA communities. This involved designing and then maintaining excel spreadsheet information as screening and treatment occurred, preparing and discussing daily follow-up lists with the screening and treatment teams prior to their departures for field work in each community and presenting status reports at daily outbreak control team meetings.

My role meant having access to individual patient information and as a non-QH employee, I should have signed a confidentiality agreement prior to my participation. I was unaware of this, not realising until after my field assignment. This administrative oversight required me to return all data I held for the purpose of the MAE outbreak chapter. After negotiation, I was able to re-apply for access via a QH research ethics process. This process took seven months to complete. Final approval from the Cairns and Hinterland Hospital and Health Service Human Research Ethics Committee and the Torres and Cape Hospital and Health Service coincided with the escalation of COVID-19 in early March 2020. Due to this emergent priority, I was unable to receive the data in time for my thesis submission. Hence, this chapter does not include an epidemiological analysis of the APSGN outbreak data, nor a planned analysis of qualitative feedback from staff involved in both the first and second outbreaks. Instead, I reflect on my experience during the second outbreak response, drawing on meeting notes from team meetings and staff debriefing sessions.

Lessons Learnt

Beyond the invaluable experience of being at the heart of data management during an outbreak (lessons outlined in Discussion section), a significant lesson learnt as an external person joining the outbreak team was to ensure adherence to data security/confidentiality procedures (and any other protocols) prior to participation. A simple signature on a QH confidentiality agreement form would have saved much concern about breaching patient confidentiality and much time in preparing ethics applications. Other lessons learnt during the outbreak response are outlined in the Discussion below.

Public Health Implications

APSGN results from the body's response to repeated *Streptococcus pyogenes* (a group A streptococci - GAS bacteria) infection. GAS bacteria are transmitted via skin or upper respiratory tract infections typically in low resource settings (1, 2). Depending on the strain of GAS, immune reactions can damage kidneys (nephritis) or the heart (carditis – acute rheumatic fever (ARF)). Repeated episodes of ARF can destroy heart valves leading to rheumatic heart disease (RHD) (1, 3). APSGN cases usually recover but episodes experienced during childhood are thought to contribute to chronic renal failure later in life (4).

Cases of APSGN and RHD are completely avoidable, as GAS infections generally result from poor environmental conditions where there is overcrowding, lack of resources and/or faulty hardware essential for appropriate hygiene. They are considered diseases of social injustice (5). Primordial prevention of these diseases requires attention to social and economic determinants of health such as improved housing and sanitation facilities and increased access to quality education, employment and health services (6). Primary prevention involves regular health promotion activities to increase awareness of the link between skin and throat infections and the potentially adverse results from the body's response to that infection. Treating scabies infestations and skin/throat infections with topical aids (e.g., permethrin cream) and penicillin respectively will interrupt the progression to APSGN disease (6).

Disturbingly, incidence rates of APSGN within Aboriginal and Torres Strait Islander communities are among the highest reported globally (7, 8). Much disease inequity and burden experienced by Aboriginal and Torres Strait Islander communities could be alleviated through the preventive measures described above (5, 6). This outbreak investigation centred on the control of GAS spread through the treatment of skin and throat infections in children aged 12 months to <17 years across the five NPA communities. The outbreak response was successful in its aims for high screening and treatment coverage of the child population in the NPA. The success of the screening response was largely a result of good coordination,

collaboration and cooperation between QH clinic sites and external agencies (such as other health care facilities and schools) and consistent communication from trusted sources to community on the importance of screening and treatment for the wellbeing of their children. Challenges included lack of workforce and a complete population information database to use for monitoring screening and treatment.

Abstract

Background

Acute post-streptococcal glomerulonephritis (APSGN) is an auto-immune complication from repeated infection with *Streptococcus pyogenes* (a type of Group A streptococci – GAS bacteria). GAS is transmitted between children primarily through skin or throat infections. In 2019, there were two successive APSGN outbreaks within 6 months in the Northern Peninsula Area (NPA) of Queensland that prompted separate community-wide screens of children and young adults aged from 12 months to 17 years. During the screens, children were checked for skin and throat conditions and other symptoms of APSGN.

Methods

Due to data access issues, this chapter comprises a reflective analysis of the second outbreak response based on my field experience in the NPA while assisting with the response and notes from the daily Outbreak Control Team meetings.

Discussion

A number of lessons were learnt from the recurrent APSGN outbreaks in the NPA region. APSGN re-emergence may have occurred due to population movement or missed screening and treatment of GAS infected children during the first outbreak. Effective responses require ambitious coverage targets, a sufficiently resourced, well-coordinated multi-disciplinary team with a mix of local knowledge and external expertise. Data systems with accurate population information need to be established prior to commencement of community screening. Having APSGN mandated as a notifiable condition would assist with early identification of outbreaks and analysis of long-term trends.

Conclusion

The second response was effective in controlling GAS spread and further cases of APSGN. To prevent future outbreaks, sustained health promotion programs delivered in an integrated community partnership approach (incorporating environmental health, public health and primary health care) is required to minimise the occurrence of skin conditions that can lead to GAS infection. In the long term, improved socio-economic conditions, community infrastructure and reductions in overcrowded households will reduce current inequities in GAS

infections (and APSGN) between Aboriginal and Torres Strait Islander and non-Indigenous populations.

Background

APSGN disease

Acute post-streptococcus glomerulonephritis (APSGN) is a rare immune-mediated kidney disease that may occur two to three weeks after repeated infection by nephritogenic strains of *Streptococcus pyogenes* (Group A streptococci - GAS) (9). GAS bacteria are transmitted via skin or upper respiratory tract infections typically in low resource settings (1, 2). The body's auto-immune response leads to deposition of immune complexes at the glomerular basement membrane of the kidney causing inflammation (glomerulonephritis) (10). The typical latent period for APSGN following throat or skin GAS infection is around 10 days and 3 weeks respectively (9). Symptoms of APSGN include facial and/or peripheral swelling (oedema), high blood pressure and haematuria (blood in urine) (2). It most commonly occurs in children between the ages of 12 months to 17 years and usually has a relatively benign prognosis, however, is associated with increased risk of chronic kidney disease (8).

Global incidence of APSGN has been reduced substantially over the last half-century due to improved socio-economic conditions, sanitation infrastructure, health care and a reduction in household crowding (5). However, it remains a significant disease in less developed countries and in certain resource-poor areas of high-income countries, such as remote Aboriginal and Torres Strait Islander communities (7, 8). For example, in the Northern Territory (NT), the annual incidence of confirmed APSGN in Aboriginal children under 14 years over the period 2009 to 2016 was 124 per 100,000 person-years, exceeding previous global APSGN median incidence estimates in children (6 – 24.3 per 100,000 person-years) (7, 8).

Molecular *emm* typing has shown much genomic heterogeneity in GAS isolates (3, 11) with serotypes that cause APSGN observed not to be associated with ARF/RHD (12). Within this diversity, certain M protein types are considered to be more nephritogenic (1), making M typing useful to inform epidemiological investigations tracking APSGN outbreaks (13). Compared to other high-income countries in Europe and the United States of America where recurrent invasive GAS disease outbreaks have been associated with M type 1 or 3, there is no dominant type consistently responsible for APSGN outbreaks in Northern Australia (3). Studies in the NT have shown several *emm* types (49, 42, 2, 57, and 60) as common etiological agents inducing APSGN (14). In addition, there have been other GAS isolates in the NT (e.g. 55) that have appeared during outbreaks that have not been seen within community prior or subsequently (14). Similar genotype diversity has been found in Western Australian APSGN

outbreaks (41 different *emm* types from 216 isolates with most common *emm*49, 75 and 108) and in a cross-sectional study of child skin infections swabs in North Queensland (22 different *emm* types out of 84 isolates with *emm*54 being the most common) (15, 16). This serotype diversity has made vaccine development difficult (11).

GAS bacterial infections in tropical areas of northern Australia typically involve skin rather than throat infections (2, 17, 18). Research has shown that almost half of all children living in remote communities having a skin infection at any one time (19). The high incidence and prevalence rates of skin infections are largely driven by socio-economic factors, poor housing infrastructure, overcrowding and reduced access to health care. Complicating the treatment of skin infections is the co-occurrence of *Staphylococcus aureus* and GAS. Typically, the first line of treatment is targeted at the anti-biotic resistant *S. aureus*, which will not clear GAS infection requiring penicillin (20).

APSGN is a notifiable condition in the NT with electronic data collection beginning in 1991 (14). Longitudinal trends of NT notification data have showed roughly five yearly cycles of APSGN outbreaks, however most recently there has been more consistent case numbers across years with outbreaks less frequent (8). Similar data is not available for other parts of northern Australia, because it is not notifiable in Queensland or Western Australia. In the Torres and Cape Hospital and Health Service (TCHHS) region of Queensland, there have been outbreaks recorded previously in 2005, 2008 and 2013.

APSGN outbreak detection, treatment and prevention

The NT Government has published a standard protocol for APSGN prevention, outbreak detection and response (2).

For outbreak detection, **confirmation of a case** requires either:

1. laboratory definitive evidence (renal biopsy suggestive of APSGN)

OR

2. laboratory suggestive evidence (all of the following: haematuria on microscopy; positive GAS swab from skin or throat; reduced complement protein C3 level)

AND

clinical evidence (at least two of the following: facial oedema, moderate haematuria on dipstick, hypertension or peripheral oedema).

Probable cases require clinical evidence only.

Possible cases require laboratory suggestive evidence only.

Outbreak criteria includes when either of the following conditions have been met:

1. two cases, either probable or confirmed living in the same community and have an onset within a week of each other; at least one case has a low C3; and the cases are not contacts of each other;

OR

2. one confirmed case and two probable cases living in the same community and have onset within one month of each other; and none are contacts of each other.

The NT protocol outbreak criteria has been adopted by QH and included within its Primary Clinical Care Manual (PCCM) (21).

In APSGN outbreak responses, goals are to find and treat undetected APSGN cases and to reduce the prevalence of GAS transmission in the affected communities (2). Therefore, in addition to investigating and treating case contacts, the NT APSGN protocol recommends community-wide screening (children aged 1 to <17 years) and treatment programs to reduce prevalence and transmission of GAS. Where skin sores are present, provision of intramuscular (IM) benzathine penicillin is recommended to eradicate the GAS bacteria (preventing its spread) and for scabies infestations (which can lead to skin breaks and secondary GAS infections), two doses (one week apart) of topical permethrin or oral ivermectin.

Long-term prevention of APSGN requires improved housing infrastructure to reduce overcrowding and improved household facilities (particularly running water and washing infrastructure) as well as regular surveillance through skin health community education programs (2). Where there are instances of scabies and skin sores, more immediate prevention measures include prompt treatment and health promotion to encourage regular washing to limit spread of GAS bacteria (21).

Queensland 2019 APSGN outbreaks

Setting

Approximately 3,000 people live in the Northern Peninsula Area (NPA) in Queensland with >85% Aboriginal and/or Torres Strait Islander (22). The NPA is comprised of five inter-connected Aboriginal and Torres Strait Islander communities (Bamaga, Seisia, New Mapoon, Injinoo and Umagico) within the jurisdiction of the Torres and Cape Hospital and Health Service (TCHHS) (Inset - Figure 1). The NPA is ranked as one of the most socio-economic disadvantaged areas in Australia with higher proportions of low-income earners and high

unemployment (22). Within the NPA, Aboriginal and Torres Strait Islander people experience greater levels of economic vulnerability compared to non-Indigenous residents, with 24% unemployed (compared to 5% of non-Indigenous residents), 36% of households earning under $400/week (considered below the poverty line - compared to 6% non-Indigenous NPA households) and 32% living in overcrowded houses (compared to 4%) (22). In terms of health infrastructure, TCHHS operates a hospital and primary health care (PHC) centre in Bamaga with outposts in the communities of Seisia, New Mapoon and Umagico. An Aboriginal and Torres Strait Islander community-controlled organisation, the NPA-Family and Community Service (FACS) also operates a PHC centre next door to the QH Bamaga PHC facility with an outpost at Injinoo.
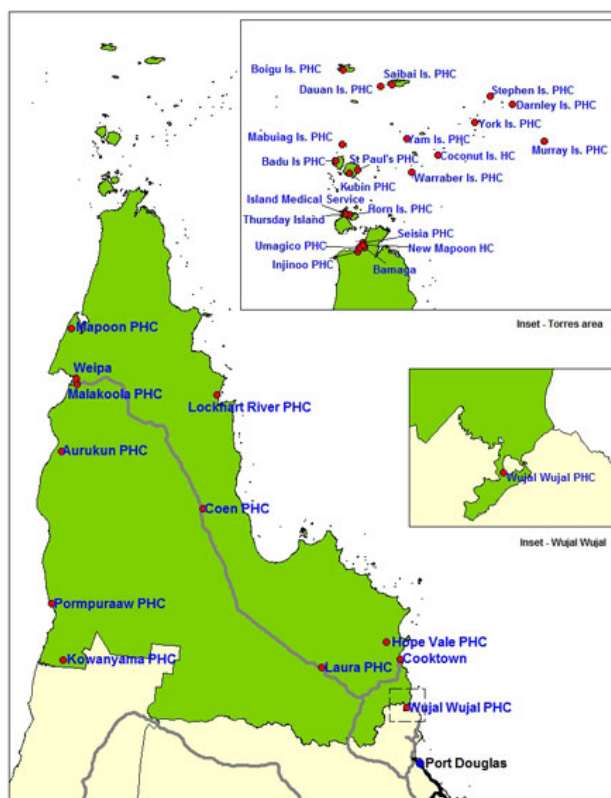
Figure 1: TCHHS Communities in the Northern Peninsula Area & Cape York region, Queensland.

Outbreak detection

Between December 2018-February 2019, an outbreak (eight confirmed and three probable cases in total) occurred in the Northern Peninsula Area (NPA) on the tip of Cape York Peninsula. A broad community screen was initiated in late January to identify undiagnosed cases and provide preventive treatments for at-risk children (with skin sores and/or scabies) aged 12 months to less than 17 years. The coverage target was at least 85% of children screened within one week of commencement. The screening target was not met within the

specified timeframe and three more confirmed cases (non-contacts) appeared within three weeks of each other in late May/early June 2019 meeting the NT protocol's definition of an outbreak. A definitive reason behind the APSGN re-emergence was unknown, hence, a subsequent outbreak response strategy incorporated stricter treatment guidance (e.g., long-acting bicillin treatment on presentation of sore throat as well as skin sores) and greater coverage targets (≥90%) of children aged 1-<17 years within the five NPA communities.

Second outbreak investigation and response

Planning for the second outbreak investigation began on 10 June 2019 with the QH Public Health Units in Cairns organising the critical operational resources required before the field work began. This included seconding additional public health and data analysis expertise to assist with the response. However, the majority of the outbreak control team were local PHC and hospital staff who, in addition to conducting screening and treatment, took responsibility for logistics, management, administration and finance support, information management, health promotion and communications (outbreak control team structure - Appendix 1). The operational hub of the APSGN outbreak response was situated in QH's PHC centre in Bamaga.

The community screening exercise commenced on 18 June 2019. During the response, I participated in daily morning meetings that were held to outline the screening and treatment strategy for the day ahead. Nursing and Aboriginal and Torres Strait Islander health staff comprised screening teams assigned to each community. The NPA-FACS team joined these meetings, assisting the screening teams across the region, beyond their usual service area. The teams were equipped with 'tally sheets' based on the community screening form proforma included within the NT APSGN protocol (Appendix 2) (2). Details recorded included the name, sex and date of birth of each child screened, screening outcomes, treatment provided and GP referral if required. To inform priority actions at these morning meetings, up-to-date screening and treatment data was essential. It was the responsibility of the information management team to collate the tally sheets, enter all screening/treatment data from the day prior and provide the teams with a list of children still to be screened/treated per community. At the end of each day, an outbreak control team meeting was held with members present representing all core components of the outbreak response: logistics, communications, information and screening teams. QH public health executives would also join this meeting for everyone to report and debrief on progress. It was at these meetings that the tally sheets from the day would be collated. The information was entered overnight, rapidly turning around the data in preparation for the morning strategy meeting to guide priority actions.

Screening strategies included undertaking assessments while children were at school or day care centres. The timing of the outbreak crossed over into the start of school holidays hence it was crucial to take advantage of school hour screens while children were congregated in the one location. Additionally, information about the outbreak and screen was broadcast via local radio and posted on social media, encouraging families to attend their nearest PHC facility for skin check-ups. PHC centres extended their opening hours to allow working parents to visit out of office hours. Towards the end of the response, home visits were implemented to follow-up children that missed screening or needed treatment.

By the beginning of July, 93% (945/1,020) children were screened in total (Table 1). Treatment rates exceeded 95% except for scabies (full treatment of which requires two treatments, one week apart). By the end of the outbreak investigation, there were six confirmed cases of APSGN (including the initial three).

Table 1: Northern Peninsula Area APSGN screening results as at 3 July 2019 (N=1,020 children aged between 12 months & <17 years).

Screening	Number screened	945
	% children screened	93%
Skin sores	Number with skin sores	608
	% children with skin sores	64%
	% children with skin sores treated	96%
Sore throat	Number with sore throat	23
	% children with sore throat	2%
	% children with sore throats treated	100%
Scabies	Number with scabies	70
	% children with scabies	7%
	% children with scabies 1st treatment complete	81%
	% children with scabies all treatment complete	11%

Aim

The original aim of this project was to conduct a comparative analysis of public health responses across both APSGN outbreaks in the NPA, using the experience of staff involved to document what worked well and not so well to inform policy recommendations for future events. Due to hurdles encountered as described in the Preface, the staff survey (Appendix 3) and data analysis were unable to be carried out. Therefore, the following discussion of issues is based on my experience working with the team during the second outbreak utilising meeting notes and personal reflections.

Discussion

Lessons learnt during outbreak response

My 8-day involvement in the second APSGN outbreak response was a thoroughly rewarding experience, where I learnt first-hand the hard work and team effort required to minimise spread of outbreak infections. I learnt the importance of having pre-established processes and protocols, a multi-disciplinary team with diverse skills and adequate resources and the need for cooperation within the team, with community and across health and external facilities. The days were long and the team (made up of mostly local staff) commitment was evident. By the end of the outbreak response, the team achieved the target, screening 95% of all children across the NPA community. The critical issues encountered during the response are highlighted below, and included tasks I was directly involved in and others encountered by the broader team.

1. Close cooperation between QH and external health and education facilities made the response more comprehensive and efficient

The success of the screening response was a result of good coordination, collaboration and cooperation between QH clinic sites and external agencies (such as NPA-FACS, day care centres and primary and high schools). Examples of collaboration included:

- A combined population list of children from all health partners was necessary to enable systematic screening and data collection. An established MoU between QH and NPA-FACS enabled the sharing of patient information and the development of a comprehensive listing.
- Schools and day care centres allowing outbreak response teams to attend facilities for mass screening exercises. As the response spanned school semester and holiday periods, there was a priority to undertake most screening while students were congregated together. This proved the most efficient way to ensure comprehensive screening, in combination with provision of absentee lists by the schools for those days that the screening was conducted.
- NPA FACS staff assisting with the outbreak response beyond their own clinic facilities when there were shortages of health worker staff to undertake screening/treatment in other communities. Secondment of other QH Aboriginal and Torres Strait Islander health workers from with TCHHS and other jurisdictions.

2. Clear, regular communication with community

The outbreak control team had a dedicated communications manager to drive information sharing with community and stakeholders. A mix of strategies utilising multiple media platforms to reach diverse local audience (23). Initial consultation occurred with key stakeholders, including traditional owner groups, the Mayor and local council and school principles. Early on, information sheets were disseminated to staff within the TCHHS to inform them of the APSGN outbreak and providing facts and key messages framed appropriately for community. Similar information was passed out at interagency meetings within the NPA, where representatives from government agencies operating in the region share updates and information. Regular press releases were prepared by the QH media team, keeping the public informed about progress with the response. Senior members of the outbreak control team and local respected figures (for example, the Mayor) gave interviews on radio encouraging families to attend their local PHC clinic for screening. Audio advertisements (in both English and Creole) were regularly played about APSGN and control measures. Locally tailored posters and brochures were prepared about skin health and sore prevention (Appendix 4). In general, there was positive feedback about the messaging, resulting in most of the population following public health recommendations to attend screening (Table 1). Locally developed communications plan, delivered by authoritative health professionals and trusted local figures in a caring, open and honest way generates trust and credibility, enhancing communities' adherence to public health messaging (23).

3. Workforce skills and resourcing

Strong, collaborative multi-disciplinary teams were required, as indicated by the array of tasks and responsibilities needed to meet logistics, clinical, stakeholder engagement, data management and communication components of the APSGN outbreak response. In the context of Aboriginal and Torres Strait Islander communities, it was crucial that most of the team were local health workers who know and are trusted by community. With their knowledge and skills, local staff were best placed to inform and mobilise communities, child care facilities and schools. They were also key in the refinement of an accurate population list, particularly as the NPA is a highly transient region. It was realised during the outbreak intervention that additional staffing resources were needed, including public health nurses and Aboriginal and Torres Strait Islander health workers. Given the geographic size of the screening exercise covering five communities across 48,000 square km, extra cars also were hired to enable separate screening teams to simultaneously travel to different communities.

4. Queensland's APSGN surveillance system

QH's PCCM includes specific advice regarding the reporting of APSGN to local public health units. It is understood that not all early suspected cases may have been promptly reported. Hence, there have been discussions to make APSGN case notifications mandatory within Queensland to allow for better disease surveillance and timely responses, however, to date, there has been no official recommendation. Mandatory notifications would also allow trends to be documented over time, building on existing epidemiological knowledge of APSGN activity in the region.

5. Inefficiencies in data management processes

Upon my arrival the day after screening commenced, I was asked to develop an excel spreadsheet to record and monitor the community screening and treatment intervention. This was at odds with an established plan to utilise the PHC facility's clinical information system with specifically designed 'auto-fills' to assist data entry. From my understanding, there were some hurdles preventing the immediate use of the system for recording outbreak screening and treatment data including lack of trained staff and delays in executing reports due to a need to seek off-site assistance. In addition, network connectivity was poor making data entry slow. A spreadsheet model was therefore considered a necessary approach to provide more immediate data capture and reporting. While necessary, the process was inefficient as screening/treatment data was entered twice, first into the spreadsheet and then into the clinical information system.

The spreadsheet listed all children aged between 1 and 17 years living in the NPA for documentation of skin/throat infection screening and treatments as they occurred. There wasn't a ready-made population list, therefore, in the initial set-up, patient lists were taken from both the Bamaga PHC and the NPA-FACS clinical information systems and cross-checked. The combined list was shared with local health workers conducting the fieldwork, seeking input to inform currency of residential locations. Some children were known by different names, therefore the knowledge of local health workers was invaluable with respect to accurately recording population lists. This was crucial, as accuracy prevented double-up of screening/treatment effort and lessened burden on staff, children and their families, particularly with respect to provision of painful bicillin injection treatments.

The spreadsheet was designed with separate tabs for each community and a pivot table that automatically produced data summaries showing number and percent screened and treated by community. With this design, the outbreak control team could monitor progress towards screening targets and community population list print-outs could easily be generated for field

teams to show those children yet to be screened/treated. Tally sheets were entered on a daily basis to monitor progress towards screening targets. As the outbreak response spanned into school holiday period, a separate list was generated that included children living away in boarding schools. This allowed screening staff to follow-up with these children when they returned for holidays.

An oversight in the design of the tally sheets and spreadsheet was the inclusion of a column to note second treatment for scabies. As a result, screening teams were not provided information to follow-up those children one week after receiving their first dose of Ivermectin or application of Lyclear. This is likely to have contributed to the low percentage of children that received their second treatment and reinforced the benefit of using the local clinical system to manage outbreak data with its recall alert capabilities.

Data collection processes should be streamlined to support field investigations rather than be laborious, diverting staff time away from other activities (24). In this respect, utilisation of the existing clinical information system would have been more ideal in guiding and monitoring the outbreak response, particularly if screening teams were able to enter information directly into the system to enable access to data in near–real time. This would have increased data security, efficiencies in staff time and resources and timeliness and completeness of data collection. In addition, the screening and treatment provided to children is important clinical information for health care providers, especially with respect to in-depth case management and follow-up treatment which may need to occur post outbreak response.

Recommendations from an information management perspective include:

- having a clear consistent system of data capture throughout the outbreak process, from standardised tally sheets that contain all required screening and treatment steps to a well-designed database system developed preferably prior to outbreak scenarios that enables efficient data entry and timely reporting;
- ensuring an adequate number of staff are trained in all aspects of the database system (i.e., data entry, report generation) that is intended to hold outbreak information; and
- regularly updating and maintaining an accurate population list of the service region.

6. Post-outbreak preventive measures

Towards the end of the outbreak intervention, an environmental health team (including local environmental health workers) conducted housing and community infrastructure audits throughout the NPA with respect to hygiene and sanitisation control. Any pest infestation, hygiene or sanitation issue was addressed. There was also discussion about the need for

regular healthy skin programs similar to what has been developed in the Northern Territory that involve community education and active surveillance for scabies and skin sores (25). Skin infection rates within the NPA recorded during the APSGN outbreaks were comparable to studies in other remote Northern Australia locations showing prevalence of childhood skin infections to be as high as 70% (14).

Skin examinations are included in annual health checks for both children and adults. However, the high prevalence of skin infections in communities can lead to normalisation of this condition and complacency amongst families and health care providers to treat, instead prioritising other health issues. Healthcare provider education about correct diagnosis and treatment of skin infections is therefore required, aided by a recently published national guideline (26). A service-based integrated response to an APSGN outbreak in the Kimberley region in Western Australia resulted in a significant decrease in scabies presentations at the local PHC clinic (27). It comprised a partnership between environmental health (improvements in health hardware, sanitation facilities, drainage etc), health promotion (increased community awareness about the link between skin infections and other diseases), public health and PHC clinic staff (conducting population wide skin checks and initiating treatments).

7. Links between first and second outbreaks

There is no definitive explanation for the re-emergence of APSGN three months after the first outbreak response in early 2019. Possible mechanisms for the recurrent outbreaks are outlined below.

a) *Continued transmission of GAS due to population movements between communities on Cape York Peninsula.* GAS bacteria may have been transmitted between NPA and areas further south in Cape York from regular movement of residents due to family and community connections that exist. This is supported by subsequent confirmed cases after the NPA outbreaks in late 2019 and 2020 within the Weipa-Napranum-Mapoon region and Kowanyama respectively that triggered similar community-wide screens (28).

b) *Undetected endemic level of APSGN disease in the region*. Long term surveillance of APSGN in the NT has shown regular cycles of five yearly outbreaks up until 2006 (8). However, in more recent years, there has been consistent numbers of notifications each year with less frequent outbreaks (8). This may suggest an underlying endemic rate of APSGN disease due to persistent high rates of skin infections and circulation of GAS bacteria in remote communities. While data is not systematically captured in Queensland, the outbreak information available for the NPA/Cape York region indicates similar patterns with

previous outbreaks documented in 2005, 2008 and 2013. The outbreaks in 2019 continue this trend, however confirmed cases in Cape York communities in 2019 and 2020 may also indicate a change from sporadic outbreaks to consistent annual notifications. In addition, the increased notifications may be due to greater reporting by medical officers from heightened awareness and increased knowledge of the condition within the region. Continued surveillance is required to determine long-term epidemiological trends which would be aided by legislating APSGN as a notifiable condition.

c) *Not enough children screened and treated during the first NPA outbreak in early 2019.* A population coverage target of at least 85% of in-community children screened during the first week was set during the initial outbreak (aligning with the NT APSGN protocol recommendations (2)). Approximately 80% of children were screened during the first response. Missed children requiring treatment for infected skin or throats may have been the catalyst for the second outbreak. A more ambitious target of >90% of children screened within the NPA was met during the second response and appeared to have been more effective in halting transmission of GAS.

Consistent molecular *emm* typing across both outbreaks may have provided clues into the source of the re-emergence of APSGN. While all of the above hypotheses may have contributed, a key reason for ongoing APSGN outbreaks is the lack of a sustained preventive health approach. Attention to socio-economic determinants, environmental health and health promotion activities focused on healthy skin education would address not only GAS related diseases (APSGN and RHD) but also other debilitating conditions resulting from chronic infections including otitis media and permanent hearing loss.

Limitations

The reflections in this chapter are based on staff discussions recorded in meeting notes and my recollections during participation in the second outbreak response. A more systematic collection of diverse perspectives from those involved in both outbreaks was planned, however, due to an administrative oversight and subsequent ethics process, I was unable to access screening, treatment and case data nor collect timely qualitative data to conduct a comparative analysis of the two outbreak responses.

In relation to MAE competencies, this outbreak investigation is atypical in terms of the chronic nature of underlying condition leading to APSGN. I was not involved in outbreak detection or other aspects of outbreak investigation beyond my information management role. Irrespective of these limitations, I have strengthened my understanding of factors important to an

outbreak response and contributed as part of the outbreak team to the broader goal of minimising GAS transmission within and across NPA communities.

Conclusion

A number of lessons were learnt from the recurrent APSGN outbreaks in the NPA region. Effective outbreak responses require ambitious coverage targets, enabled by a coordinated contribution of a number of different workers with clearly defined roles and responsibilities, that are sufficiently resourced and guided by clear protocols. In addition, efficient outbreak interventions require a locally produced communication plan with tailored messaging delivered by trusted sources.

Coordination of data activities across multiple locations needs to be established prior to commencement of community screening. Initial plans involved the use of the existing clinical information system, however, issues around lack of a well-maintained population list, staff training and system report generation hindered near-real time collection and reporting of screening and treatment information. During the response, population lists were refined and the clinical information system was updated to more easily and consistently record screening and treatment history. It will be important to maintain population lists, particularly in the NPA context where communities are highly transient.

An integrated community partnership approach incorporating environmental health, health promotion, public health and primary health care is required to minimise the occurrence of skin conditions that can lead to GAS infection. At the very least, adequate and recurrent funding for basic skin health programs are necessary, otherwise, communities will face future APSGN outbreaks with severe, and much more costly, long-term health outcomes.

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Appendices

Appendix 1: Outbreak control team structure based in Bamaga, Torres and Cape Hospital and Health Service (TCHHS) with external Queensland Health support
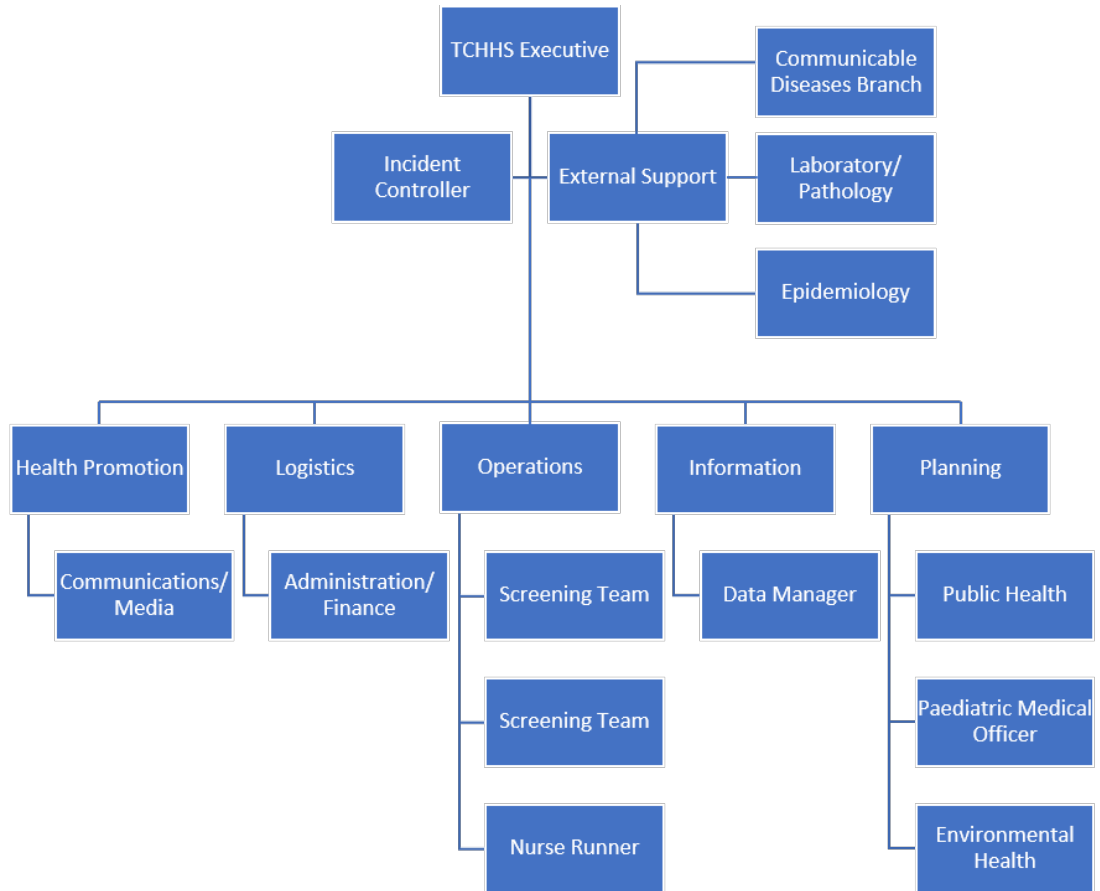
Appendix 2: Queensland Health Northern Peninsula Area 2019 APSGN community screening form (all children aged 12 months up to 17 years)

Screening site:				Name of staff screening:					Date of screen:		

DEMOGRAPHICS					HISTORY AND EXAMINATION					APSGN CLINICAL ASSESSMENT Only if oedema or dark / red urine			GAS TREATMENT		REFER
Surname	First name	DOB	Sex M/F	Ethnic TSI/A/O	Oedema Y/N	Dark / red urine Y/N	Scabies Y/N	Skin sores Y/N	Sore throat Y/N	BP	Weight kg	Urine dipstick: Blood?	LA Bicillin Y/N	Lyclear or Ivermectin Ly or Ivm	Date if referred PHC / MO
1		/ /								/					
2		/ /								/					
3		/ /								/					
4		/ /								/					
5		/ /								/					
6		/ /								/					
7		/ /								/					
8		/ /								/					
9		/ /								/					
10		/ /								/					

Staff feedback online survey: public health responses during recurrent outbreaks of APSGN in the NPA (Jan-Jul 2019).

Participant information and consent

You were sent this brief survey as you participated in one or both public health responses to the APSGN outbreaks in the NPA in 2019. It includes up to 5 questions about your experiences during planning and implementation of the outbreak response/s. Your answers will add to information already collected through staff debrief sessions. This survey provides an opportunity for further input in a confidential way and will take up to 25 mins to complete.

Your answers will help improve public health response planning in case of future outbreaks.

You do not have to fill in this survey. **It is completely voluntary and confidential**. None of your personal information will be collected or reported. If you do start filling it in, you can stop at any time. Or if you don't want to answer a question or part of a question, you can skip it and go to the next one. Your other answers will still be useful. If you complete this survey and submit online, we will take that to mean that you have freely consented to do so.

This survey is part of a quality assurance activity being conducted by Veronica Matthews (Masters of Applied Epidemiology student from the Australian National University) in conjunction with the Torres and Cape Hospital and Health Service and the Tropical Public Health Unit.

If you have any queries about the survey, phone Veronica on 02 6620 7224 or email: veronica.matthews@sydney.edu.au

If you have any concerns or complaints about the ethical conduct of the project, please contact the Ethics Officer of the Far North Queensland Human Research Ethics Committee which has reviewed and granted ethics review exemption for this project:

Email: Cairns_Ethics@health.qld.gov.au

Phone: (07) 4226 5513

Survey questions via survey monkey

Q1 Which APSGN outbreak response/s were you involved in the NPA this year? (select all that apply)

☐ 1ˢᵗ outbreak Jan-Feb 2019   ☐ 2ⁿᵈ outbreak response May-Jul 2019

Skip logic will take respondents through relevant questions depending on participation in outbreak/s

Q2 From your experience during the 1ˢᵗ outbreak (Jan – Feb 2019), please think about the following issues & provide comment (where you can) on what worked well and what did not work so well:

Issue:	What worked well?	What didn't work so well?
1.Availability of APSGN protocol/resources to help identify outbreak & develop response strategies		
2.Workforce issues & organisation of resources required to do the response		
3.Internal communication & planning within the outbreak team		
4.Communication with communities about the outbreak & what was needed to stop APSGN		
5.Strategies to engage community in screening and treatment		
6.Data collection & reporting to support screening & treatment activity		
7.Any other issue?		

Q3 From your experience during the <u>2nd response (May – Jul 2019)</u>, please think about the following issues & provide comment (where you can) on what worked well and what did not work so well:

Issue:	What worked well?	What didn't work so well?
1.Availability of APSGN protocol/resources to help identify outbreak & develop response strategies		
2.Workforce issues & organisation of resources required to do the response		
3.Internal communication & planning within the outbreak team		
4.Communication with communities about the outbreak & what was needed to stop APSGN		
5. Strategies to engage community in screening and treatment		
6.Data collection & reporting to support screening & treatment activity		
7.Any other issue?		

Q4 For each of these issues, what were your lessons learned, or things you would do differently to improve response strategies in case of future outbreaks?

Issue:	What would you do differently if APSGN outbreak happens again?
1.Availability of APSGN protocol/resources to help identify outbreak & develop response strategies	
2.Workforce issues & organisation of resources required to do the response	
3.Internal communication & planning within the outbreak team	
4.Communication with communities about the outbreak & what was needed to stop APSGN	
5.Community screening and treatment strategies	
6.Data collection & reporting to support screening & treatment activity	
7.Any other issue?	

Q5 To understand your role in the outbreak, please indicate parts of the response that you contributed to? (select all that apply)

☐ Logistics and operations management

☐ Screening and treatment teams

☐ Promotion and communication

☐ Data collection and reporting

☐ Other? Please specify:

Torres and Cape
Hospital and Health Service

HEALTH ALERT
Sores & Kidney disease in children

Northern Peninsula Area, June 2019

Bad sickness going around NPA Communities called 'Acute Post-Strep Glomerulo-Nephritis' or the short name APSGN. This sickness can cause sudden kidney trouble after infection with germs called 'Strep'.

If your **child** has:
- Skin sores
- Scabies itch or rash
- Puffy face, arms or legs
- Dark or red urine
- Swollen feet

Please take them to your local PHC immediately!

Puffy Face

Swollen Feet

KIDNEY SICKNESS

Poison from the sores gets into the body and may cause KIDNEY SICKNESS

Infected sore

Kidney

Scabies
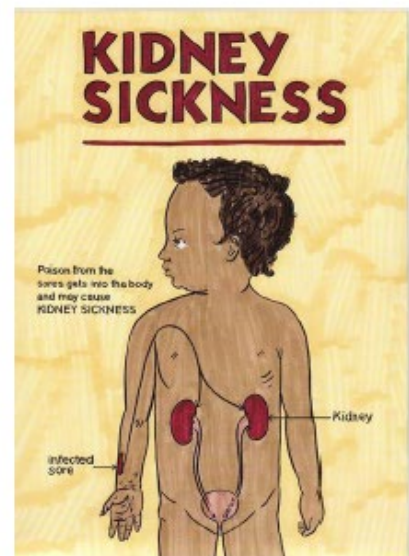
Skin Sores

Washing hands can prevent skin sores

Queensland Government

Take a bath everyday with SOAP

WASH HANDS often to keep GERMS away

STOP

Cover up sores with a BAND-AID

Wash SHEETS and TOWELS

Show the HEALTH WORKER, NURSE or DOCTOR

Version 2, Dec 2014

Chapter 5: Tuberculosis Surveillance in New South Wales: Developing Data Systems for Effective Contact Investigations

Preface

In July 2018, I was asked by the North Coast NSW Local Health District (LHD - Public Health Unit) and the NSW Tuberculosis (TB) Program Manager in Health Protection NSW to assist with developing a generic TB contact investigation module for the NSW Notifiable Conditions Information Management System (NCIMS). NCIMS is the primary surveillance tool used to monitor epidemiology of TB and other communicable diseases. Currently, TB Coordinators within each of the eight LHDs manage contact tracing data in their own excel spreadsheets, locally recording contact demographics, risk factors, exposure dates, screening events and outcomes for contacts as they proceed through screening processes. From these data tools, TB Coordinators enter summary statistics into NCIMS for reporting such as number of contacts screened by different risk categories. Health Protection NSW recognised the need for a module for central collation and recording of contact investigation data to promote a systematic and coordinated approach to contact tracing covering a range of exposure settings (e.g. air travel, prisons, healthcare facilities).
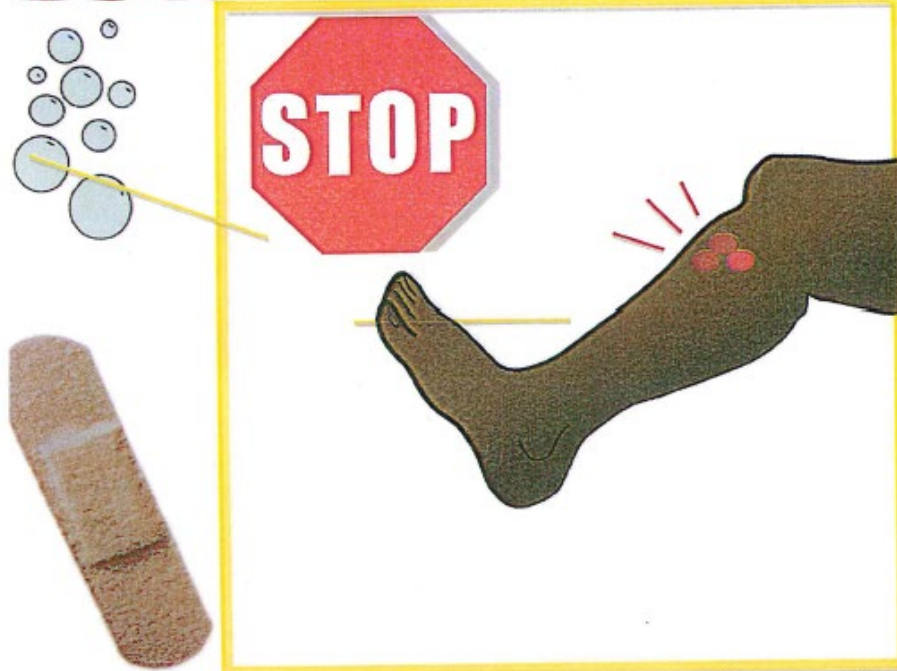
My role in the project was to lead the engagement with TB Coordinators within each LHD, evaluating the current contact investigation data system by assessing gaps and developing data specifications for a new NCIMS module that would meet their needs for effective contact tracing and reporting. Once the module was developed, I would use international guides on evaluating surveillance systems to test its functionality by both: a) retrospectively entering data (related to a TB cluster in Aboriginal communities within the North and Mid-North Coast LHDs (1)); and b) prospectively tracking contacts from a recently notified TB case.

Lessons Learnt

There were extraneous factors that significantly impacted the timely progress of this project. The evaluation of the current system and development of new data specifications for the TB contact tracing module occurred within six months by Dec 2018/Jan 2019. However, there were delays in the technical development of the new module. As the NCIMS surveillance database covers all notifiable conditions, other priorities took precedence including a freeze to all modifications to allow for a technical upgrade of NCIMS in May/June 2019. The upgrade subsequently resulted in significant performance issues which required another two-months to rectify.

As discussed in this chapter, there were other technical hurdles to overcome which were not initially envisaged, including accounting for the multiple end-states for TB contacts and cases (i.e., active TB, latent TB, no TB). The NCIMS team within NSW Health were eventually able to identify a solution with the NCIMS software vendor that would allow contacts to be managed consistently across conditions (i.e., no TB/ active/latent and case/contact). However, the required NCIMS changes would take time and would likely require financial investment. During 2020 (beyond the timeframe of this project), the work from this project allowed fast tracking of NCIMS changes to manage contacts of COVID-19. The practical application for COVID-19 contact tracing, in turn, provided useful insights into the possible adaption for TB.

So, while proposed changes to the TB surveillance system appeared simple on the surface, it had implications for other conditions that were not necessarily obvious from an NCIMS' user perspective. Implementing desired fields into a NCIMS question package is straight forward however managing the process and flow of a TB contact through the database was not as simple requiring amendments to the underlying architecture of NCIMS and associated financial costs.

Public Health Implications

Globally, TB remains a disease of high morbidity and mortality. In Australia, TB surveillance and control procedures have resulted in TB cases being relatively rare (incidence rate 6.3 per 100,000 population) in comparison to high incidence countries (2). Despite Australia adopting the WHO End-TB Strategy, aiming to eliminate the disease by 2050, our incidence level has remained stable in the last number of years. Our close proximity to neighbouring countries with higher incidence means a consistent TB threat, requiring an effective and efficient contact tracing system as part of a suite of control strategies.

Outbreaks within Australia are a public health concern due to the: severity of health impact for infected individuals; anxiety that arises within community when aware of a TB threat; and resourcing required to treat and monitor cases. Treatment costs of cases with drug susceptible active pulmonary TB disease is generally over $11,000 per case (3), therefore, contact investigations play a critical role in early detection and intervention to reverse or slow down progression of disease and minimise its spread through community (4).

Inefficient data management and infrastructure systems are barriers to effective contact tracing (5). There is currently no systematic data collection infrastructure for TB contact tracing in NSW. There are separate electronic medical systems operating in each LHD. While NCIMS is a state-wide database, it only allows aggregate summary information to be entered post contact investigation

for cases including the: number of contacts identified and screened; number of contacts with positive screens; and number of contacts in preventive treatment. As a result, TB teams across the state have developed their own bespoke data collection tools (such as excel spreadsheets) to manage contacts separately to cases and capture comprehensive information about risk assessment, screening and treatment action related to contact networks of individual cases. As a result, there is a lack of consistency in the type of data collected and there is limited capacity to efficiently share the information across LHDs impacting TB staff ability to efficiently conduct contact investigations. The disparate nature of TB and clinical information systems limits the ability to undertake programmatic evaluation of contact tracing systems within NSW.

Abstract

Tuberculosis (TB) disease is the world's top infectious killer and remains a leading cause of mortality and morbidity in low- and middle-income countries. While incidence of active TB is comparably low in Australia, proximity to and migrant intake from high-incidence countries presents an ongoing risk. Active TB is a notifiable condition in Australia with strong surveillance systems managed by state public health authorities. In New South Wales, TB surveillance data is captured in the Notifiable Conditions Information Management System (NCIMS), a cover-all data system for all notifiable diseases. A recognised gap within NCIMS is the ability to systematically capture TB contact investigation data. Working with TB Coordinators across NSW, a set of data specifications was developed for integration into NCIMS. A subsequent desktop assessment of the new contact tracing module compared to the current system of uncontrolled bespoke spreadsheets managed separately within Local Health Districts indicated improved simplicity, timeliness, usefulness, acceptability and data quality and completeness. Due to delays in the technical development of the module, testing and evaluation of the new contact tracing system will need to occur once operationalised.

Background

Tuberculosis disease

Mycobacterium tuberculosis is a bacterium that causes active tuberculosis (TB) disease which most often affects the lungs. It is transmitted through the air when respiratory infected TB cases expel the bacteria through coughing, sneezing or spitting. TB is an infectious disease that commonly occurs in marginalised populations experiencing health, social and economic inequalities, such as insecure employment and unstable housing (6). Despite development of chemotherapeutic drugs, TB is the world's top infectious killer and remains a leading cause of mortality and morbidity

particularly in low- and middle-income countries. In 2018, there were an estimated 10 million new cases of TB worldwide and 1.2 million deaths, with eight countries accounting for around two-thirds of the global burden: India, China, Indonesia, the Philippines, Pakistan, Nigeria, Bangladesh and South Africa (7). With timely diagnosis, new cases can be effectively treated with six months of antibiotics limiting onward transmission. However, effectiveness of pharmaceutical treatments have been compromised by the emergence of multi-drug resistant (MDR-TB) and extensively drug resistant TB (XDR-TB) (7).

Only around 5-10% of people exposed to *Mycobacterium tuberculosis* will get infected by the disease (8, 9). Some groups are more susceptible to infection and active TB disease than others, such as people that are immuno-comprised (for example, people with HIV; diabetes; chronic renal failure; receiving anti-cancer treatments; children <5 years of age; and the elderly) (9). Risk of transmission depends on duration and intimacy of contact, number and infectivity of TB bacilli discharged, adequacy of ventilation and exposure of bacilli to sunlight and opportunities for aerolisation and airborne transmission(9, 10). Increased risk of exposure includes: those in close contact with a TB case; travellers from high incidence countries; and people living in institutions or overcrowded accommodation. For pulmonary TB, common symptoms include: chronic cough with haemoptysis, fever and night sweats; weight loss; and general feelings of tiredness and illness (9). Dependent on the host immune response, the infection may be successfully contained but not necessarily eliminated (termed Latent Tuberculosis Infection - LTBI) or may progress to active disease (11). With LTBI, there is an absence of clinical symptoms and it is not transmissible. The estimated lifetime risk of TB reactivation is 10%, with around half of that risk occurring within 1-2 years after infection (11). Several factors can trigger reactivation of TB, with HIV immunosuppression being the greatest single risk factor for adults (11).

In 2014, World Health Organisation (WHO) member states adopted The End-TB Strategy, endorsing the implementation of three pillars (integrated patient-centred care and prevention; bold policies and supportive systems; and intensified research and innovation) monitored by key progress milestones and targets to end the global TB epidemic by 2050 (12). Australia is a relatively low-incidence country making elimination of TB (defined as <1 case per million population) feasible by 2050 (13). However, the rate of new TB infections has remained stable over the past few decades due to close proximity and migrant intake from high-incidence regions such as south-east Asia and the Pacific (13). In 2019, the TB notification rate was 6.0 per 100,000 population per year, equating to 1,513 individual notifications (2). The majority of new TB cases diagnosed in Australia were people born overseas (approximately 90%) and 1-2% of cases were

classified as MDR-TB which is low in comparison to international rates (14). Low local transmission in Australia implies that the vast majority of overseas-born TB cases result from reactivation of LTBI acquired prior to arrival in Australia (15). There is also a disproportionate burden within the Aboriginal and Torres Strait Islander population having six times higher incidence compared to the non-Indigenous Australian born population (14). Increased risk for Aboriginal and Torres Strait Islander people is largely due to adverse social and health factors such as overcrowding and high rates of chronic disease that enable TB infection, or in the case of chronic lung disease, can confound diagnosis (9). Pre-elimination strategies for Australia therefore focus on strengthening immigration TB control and working with Aboriginal and Torres Strait Islander communities to reduce transmission and the disparity in TB rates between Indigenous and non-Indigenous Australian born populations (13).

Tuberculosis surveillance in Australia

In Australia, each state and territory has responsibility for jurisdictional implementation of TB surveillance and control procedures that are maintained and monitored nationally by the Communicable Diseases Network Australia (CDNA) (16). Active TB is a nationally notifiable condition where health professionals and public health laboratories are required to report cases to jurisdictional health authorities (9).

The CDNA confirmed active TB case definition is as follows:

3. **laboratory definitive evidence**:

    a. isolation of *Mycobacterium tuberculosis* (*M.tuberculosis M.bovis* or *M.africanum* excluding *M.bovis* var BCG) by culture

    OR

    b. detection of *M.tuberculosis* complex by nucleic acid testing EXCEPT where this is likely to be due to previously treated or inactive disease

OR

4. **clinical evidence**: histopathology finding consistent with TB and diagnosed by experienced clinician including clinical follow-up assessment to ensure a consistent clinical course.

Contact tracing is a critical component of TB prevention and control and is key to achieving Australia's surveillance objectives as set by the CDNA (9):

- To identify and treat infectious cases of TB in a timely manner.

- To identify infected contacts and reduce their risk of developing active TB.

- To monitor the epidemiology of TB in Australia to better inform prevention strategies.

- To identify and monitor drug resistance.

- To identify and monitor TB-HIV co-infection.

As part of the development of a national strategy on LTBI diagnosis and treatment, the National Tuberculosis Advisory Committee (NTAC) of the CDNA is currently considering whether LTBI should also become nationally notifiable. NTAC recognises that to achieve elimination of TB, comprehensive testing for LTBI should be carried out in high risk population groups including close (household) contacts of pulmonary TB cases; migrants from high incidence countries; and healthcare workers from settings with high incidence (15).

Tuberculosis in New South Wales

Thirty-nine percent of TB notifications in Australia in 2019 were in New South Wales (NSW; n=597)(2). Similar to national trends, the majority of NSW cases are born overseas and for Australian-born NSW cases, Aboriginal people on average have 3.5 times the notification rate compared to Australian born non-Indigenous Australians (17). First identified in 2003, there has been persistent TB outbreak within Aboriginal communities of the North and Mid North Coast Local Health Districts (LHDs) (1, 18). Both sociocultural and individual risk factors are contributing to this ongoing transmission such as extensive family and community connections and socio-economic circumstances that lead to poor living conditions (1). In response to the cluster, local public health TB services within these districts have been working in partnership with Aboriginal communities and health services to develop culturally appropriate methods for screening, treatment and contact tracing (19).

Current tuberculosis surveillance resources and processes in NSW

The key goals and strategies of the New South Wales (NSW) TB Control Program are case finding, early diagnosis and effective treatment in order to identify, minimise and eliminate local transmission (20). NSW has a strong surveillance system in place, whereby all patients diagnosed with active TB are notified to a public health unit in accordance with the NSW Public Health Act 2010. Case details are then entered into a central registry, the Notifiable Conditions Information Management System (NCIMS) (20) (Figure 1). NCIMS plays a crucial role in this system, enabling early identification of outbreaks and monitoring long term trends in incidence (21).
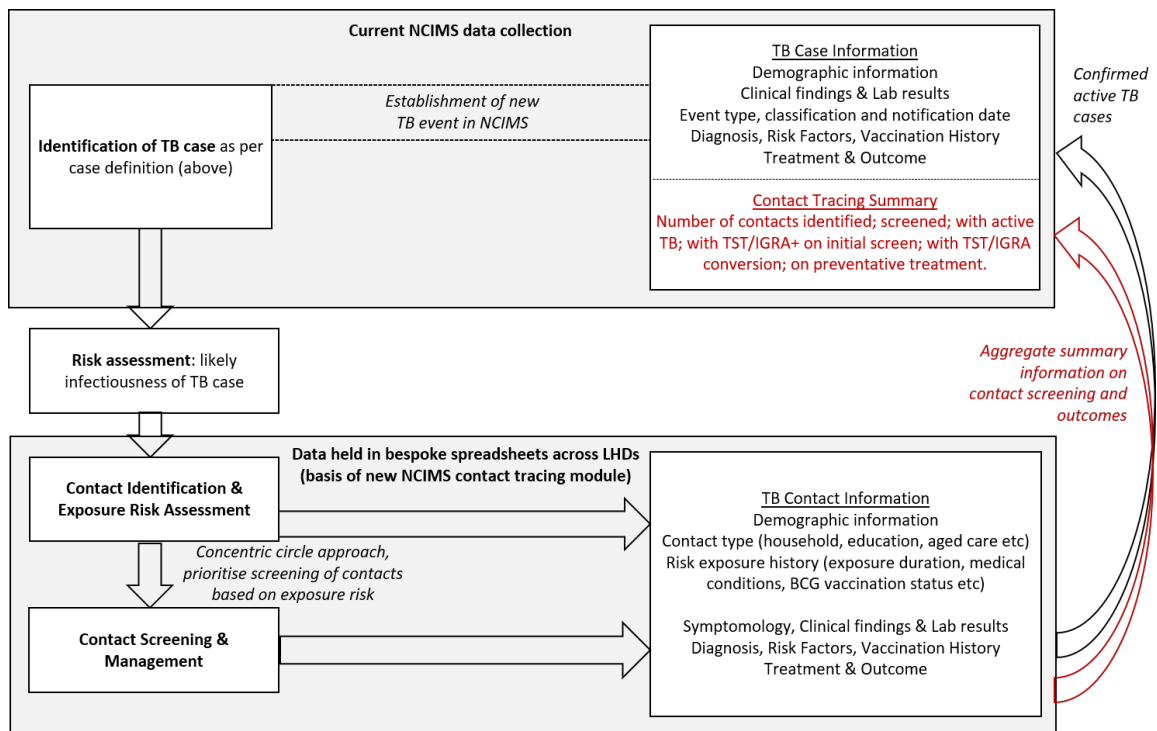
Figure 1: Current flow of NSW TB surveillance information and data collection.

The NSW TB Program within Health Protection NSW is the central coordinating hub, providing guidance to LHDs to implement specialised TB prevention and control activities across NSW. There are TB Coordinators in each LHD who, as part of prevention and treatment services, collect and enter TB case data into NCIMS including diagnosis, treatment and risk information. Recent guidelines have been developed for TB contact investigations in NSW with the following aims:

- identify and treat cases of TB disease among those in contact with the index case including identification of a possible source case;
- identify persons who have LTBI and offer treatment for LTBI or monitoring by chest radiography (CXR);
- provide timely treatment, education and support for persons identified with evidence of disease or infection, and;
- provide education and support for all persons identified as having exposure risk.

The guidelines outline important information required for identifying and prioritising assessment and screening of contacts and incorporates specific protocols for at-risk groups. NCIMS, however, currently does not have the capability of recording this type of information - it only allows

aggregate information to be entered about contact tracing post-investigation including the: number of contacts identified and screened; number of contacts with positive screens; and number of contacts in preventive treatment.

Because of the lack of centrally housed contact tracing data, TB teams across the state have developed their own bespoke data collection tools (such as excel spreadsheets) to manage contacts separately to cases and capture comprehensive information about risk assessment, screening and treatment action related to contact networks of individual cases. As a result, TB health information management of contacts is fragmented; there is a lack of consistency in the type of data collected and limited ability to efficiently share the information across LHDs, which is problematic when TB contact investigations often occur across LHD boundaries. Due to the lack of systematic TB contact tracing data collection, there is limited ability to undertake programmatic evaluation of this component of the TB surveillance system in NSW.

This project aims to draw on a number of sources (including an existing NCIMS template for contact investigations in the correctional system; other data tools used by TB Coordinators across the state; and best practice national and international TB contact tracing systems) to develop a generic TB contact tracing module for NCIMS that captures necessary information for a number of settings (e.g., residential care, health, educational settings). The module will then by evaluated using relevant international frameworks (4, 22) to assess how effectively and efficiently it performs in facilitating best practice public health responses to TB cases.

Aim and Objectives

The aim of the project was to use international guidelines on evaluation of surveillance systems to assess the current data collection system for TB contact investigations in NSW and develop and evaluate a module for NCIMS (or future electronic medical system) that aligns with best practice protocols and procedures for TB surveillance (23).

The objectives were to:

- review documented best practice TB surveillance procedures in Australia and internationally;
- review NCIMS as it is currently used for TB contact investigations in NSW and understand its strengths and limitations;
- engage with TB Coordinators from each LHD and the State TB Coordinator and other TB health workers where appropriate to gather information on:

- o implementation of TB surveillance protocols across NSW and consistency and understanding of data definitions;
- o current data collection tools (including interview tools) used in contact investigations;
- o key features of a data module to enable efficient and effective TB contact investigations; and
- o minimum data requirements and reporting features to meet the needs of the TB coordinators;
- based on the above, make recommendations on a standardised data collection tool/structure for TB contact investigations to be integrated within NCIMS and/or future electronic medical systems;
- once developed, test the module by using retrospective data (from cluster of TB cases in the North/ Mid North Coast LHDs) and prospective data (from a newly notified TB case); and
- assess the TB contact tracing module against the CDC Framework for Evaluating Public Health Surveillance Systems for Early Detection of Outbreaks and the WHO framework for monitoring and evaluating surveillance systems.

Methods

Document review

International and Australian national and state TB contact tracing guidelines were compared to document key common best-practice protocols. This was used as a basis for consultation with TB coordinators on a minimum dataset for integration into NCIMS that would meet specific TB contact investigation and reporting needs.

Engage relevant stakeholders in co-design of NCIMS TB contact investigation module

TB Coordinators from across NSW were consulted during a state-wide TB meeting held in Sydney in October 2018. Minimum data specifications (based on guideline comparison) were presented and discussion focused on existing processes for contact investigation and identification of issues relevant to data capture and implementation of contact tracing protocols. Following discussion, data specifications were then refined and taken to the NCIMS team by the TB central coordinating hub within NSW Health Protection to configure a contact tracing module that could be developed reasonably efficiently within the confines of the existing database.

Evaluation of module specifications

Once developed, the original plan was to operationally test the module using retrospective data from a TB project in the North/Mid North Coast LHDs and prospective data using new

notifications. However, due to prolonged delays in the technical development of the module, a desk-top evaluation was instead conducted to assess and compare the current contact tracing data collection system and the new NCIMS module design against key characteristics of effective surveillance systems (4, 22).

Results

Document review and stakeholder consultation

A review of TB contact tracing guidelines was undertaken to compile a summary of best practice protocols from leading international and national authorities. Public Health England initiated a new model for management of TB contact investigations in London, to support local TB clinics with incidents in congregate settings (24). The London TB Extended Contact Tracing team (LTBEx) undertakes mass screenings in response to local outbreaks where there is risk of transmission beyond household contacts. They also maintain the only contact tracing database in London where information on risk assessment of TB incidents, contacts identified, screening method used and outcome of screening is collated and analysed. The LTBEx team shared their data dictionary with NSW Health for the purpose of this project. Other international TB contact tracing protocols consulted included the National Institute for Health and Care Excellence in the United Kingdom (10) and the United States Centre for Disease Control (25). In Australia, the national guidelines for public health management of TB and state and territory protocols were drawn upon (9, 23, 26, 27). These best-practice guidelines highlight the importance of accessible, consistent and timely information for public health staff undertaking contact investigations. Appropriate data systems will enable both the efficient and effective management and follow-up of individual cases and contacts and the monitoring and evaluation of investigations. Table 1 presents the common key elements of these best-practice contract tracing guidelines. Alongside each element are the associated data requirements to enable implementation of each critical step in an investigation including identification, risk prioritisation, screening and clinical management processes.

Table 1: Key elements of contact tracing guidelines for TB (10, 23, 25-27).

Aims	Detect and treat cases of TB among contacts, including possible identification of source case and/or other index cases. Prevent future cases through: 1) education and support for persons identified as having exposure risk and persons with LTBI; and 2) preventive treatment or CXR surveillance for persons found to have LTBI (especially those highly susceptible to development of active TB)
Contact identification & risk assessment	Contacts identified and risk assessment performed based on infectiousness of index case (high/medium/low) and the likely infectious period (at least 3 months prior to date of symptom onset). Prioritise contacts (high/medium/low) based on exposure risk (duration and proximity of contact, environmental factors – ventilation, room size etc) and susceptibility/vulnerability. **Data required: contact type/setting (e.g., household, education etc), clinical symptoms, & risk exposure history (exposure date and duration, medical conditions, previous history of TB disease & BCG vaccination).**
Contact assessment, screening & management/ surveillance	In a concentric circle approach, screen all **high-priority** contacts first (i.e., highest level of exposure to highly infectious cases and high vulnerability regardless of exposure risk classification): 1) household & other close contacts of pulmonary & laryngeal TB cases that should be screened immediately (baseline screen within 2 weeks) of index case diagnosis and again at 8-12 weeks (break of contact screen); and 2) vulnerable contacts (children <5 years; immune-suppressed) Where transmission from index case to high-risk contacts is found to have occurred, contact investigation should be widened to **medium-priority** contacts, particularly those susceptible to active TB disease progression. **Data required: screening dates and outcomes (CXR, sputum smear/culture, TST/IGRA), symptom assessment at various timepoints and start/end dates of preventive therapy (for LTBI).**
Susceptible groups	Children <5 years; immune-compromised contacts; pregnant women; MDR-TB cases **Data required: demographics, medical conditions.**
Special situations	Hospital settings; correctional facilities; aged care facilities; airflights (>8 hours) while infectious; Aboriginal people & communities. **Data required: setting information, demographics.**

TST – Tuberculin Skin Test; CXR – Chest X-Ray; IGRA – Interferon Gamma Release Immunoassay; LTBI – latent TB infection; BCG - Bacille Calmette-Guérin vaccination; MDR-TB – multi-drug resistant TB, 'Index' case is the individual with active TB that prompts the contact investigation. 'Contact' is an individual who has a risk of acquiring TB because the person has shared the same environment with the index case. 'Source' case is the TB case that infected the index case.

Protocols and guidelines vary depending on exposure setting. Although the general TB contact tracing principles apply, contacts in congregate settings (such as school, workplace, nursing home or prison) may be more vulnerable to infection and disease progression. In addition, TB contact investigations within Aboriginal communities must occur with respect and trust, requiring rapport to be established with cases, their families and communities(1, 23).

NCIMS contact tracing module specifications

The proposal to develop a contact tracing module for NCIMS along with a spreadsheet of proposed data elements (based on best practice guidelines collated in Table 1) was presented to a meeting

of NSW LHD TB coordinators. There was general agreement and support about the usefulness of developing the module as it would: exclude the need for separate data systems across LHDs and enable the sharing of information between clinics and across LHD jurisdictions during contact investigations; facilitate prioritisation of contacts and workflow actions; and become a workflow management tool, potentially incorporating calendar alerts when follow-up actions were due.

Proposed dataset elements were discussed with the TB coordinators ensuring that the data captured would facilitate recommended contact screening and management pathway processes (Attachment 1). Subsequent discussion with the NCIMS technology team finalised a minimum dataset that could be incorporated into existing NCIMS data structure without major reconfigurations that would fulfil contact investigation needs. The resulting minimum dataset is presented in Table 2.

Table 2: Data specifications for NCIMS TB Contact Tracing Module developed initially from best-practice guidelines and refined based on consultation with NSW TB Coordinators.

	Field	Description	Current NCIMS field	Field type/List of values (where applicable)	Notes
	Event ID	Index case unique identifier	Y	[Free text]	Link to index case
yuersonal details of contact	qjk	Contacts first name	Y	[Free text]	
	Last name	Contacts surname	Y	[Free text]	
	Birth date	Contacts DOB	Y	[Date field]	
	Sex	Contacts gender	Y	[Single select]/Male; Female; Transgender; Not stated	
	Indigenous status	Indigenous status	Y	[Single select]/Aboriginal; Torres Strait Islander; Both Aboriginal and Torres Strait Islander; Not Aboriginal or Torres Strait Islander; Not stated / unknown	
	Ethnicity	*Other ethnicity status*	*N*	*List of ethnicities*	*At risk migrant groups captured by 'country of birth'*
	Street	Contacts address	Y	[Free text]	
	Suburb/town		Y	[Free text]	
	State		Y	[Single select]/NSW; QLD; VIC; TAS; SA; NT; WA	
	Postcode		Y	[Numerical field]	
	Email	Email address	Y	[Free text]	
	Home phone	Contacts telephone number/s	Y	[Numerical field]	
	Mobile phone		Y	[Numerical field]	
	Work phone		Y	[Numerical field]	
	Country of birth	Country where they were born	Y	[Single select]/Standard Australian Classification of Countries (SACC) list (ABS)	

	Field	Description	Current NCIMS field	Field type/List of values (where applicable)	Notes
	Date of arrival in Australia	Contacts year of arrival	Y	[Date field]	
	Is an interpreter needed?	Language interpreter needs	Y	[Single select]/Yes; No	
	Primary language	Contacts preferred language	Y	[Single select]/List of languages	If interpreter = yes
	Event type		Y	[Single select]/Case; Contact/Exposed person	
Contact identification & risk assessment	During the period of interest, the person spent time in the following settings:	Place of exposure type	Y - (add additional values)	[Multiple select]/Hospital; School; University; Childcare; *Residential Care Facility; Correctional Facility;* Work/Office; Travel; Social; Place of worship; Household; Airline; Other [free text]	
	Place of exposure name		N	[Free text]	
	First exposure date	*Date of first contact with index case/in exposure setting*	*N*	*[Date field]*	*Length of exposure is estimated.*
	Date of last exposure		Y	[Date field]	If exposure setting = yes
	Hours of exposure	Exposure length	N	[Numerical field]	
	Contact (exposure risk) level	Estimated degree of contact with case	Y	High risk; Medium risk; Low risk	Based on duration/ proximity/ environmental factors
	Risk classification date		Y	[Date field]	
	Pregnancy status		*Y*	*Yes; No; Unknown*	*Information contained within patient medical record. Also, inclusion of HIV*
	Height	*Height in cm*	*N*	*[Numerical field]*	
	Weight	*Weight in kgs*	*Y*	*[Numerical field]*	
	BMI		*N*	*[Numerical field]*	

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	Field	Description	Current NCIMS field	Field type/List of values (where applicable)	Notes
	Smoking status			*Yes; No; Unknown*	*status will compromise confidentiality. Picked up in risk factors – 'immunosuppressive health condition'.*
	HIV status		*N*	*Yes; No; Unknown*	
	During the period of interest, did the person travel outside of the country/state/region?	Travel related risk factors (high risk countries)	Y	Yes;No;Unknown	
	Name of region/state/ country	Name of travel destination	Y	[Free text]	If travel outside = yes
	Travel dates		Y	[Date fields]	If travel outside = yes
	Has the contact ever had long-term visitors from overseas staying with them?	*Visitors with travel related risk factors (high risk countries)*	*N*	*Yes;No;Unknown*	
	TB Risks (repeatable)		Y	Born in a high risk country; CXR suggestive of old untreated TB; Child (Australian born), of parent(s) born in a high risk country; Currently or recently employed in the Australian health care industry in the last 12 months; Currently or recently employed in the health care industry overseas in the last 12 months; Ever employed in an institution (i.e. residential services such as corrections, aged care etc); Ever employed in health industry overseas; Ever employed in the Australian health care industry; Ever homeless/residing in a shelter; Ever resided in a correctional facility (excluding immigration detention); Ever resided in an aged care facility; Household member or close contact with TB;	

	Field	Description	Current NCIMS field	Field type/List of values (where applicable)	Notes
				Immunosuppressive health condition; Immunosuppressive health therapy; Other; Past residence (>=3mnths) in high risk country (other than country of birth); Previously diagnosed with TB; Risk not able to be determined; Risk not assessed	
	Has the person ever received a vaccine against this condition?	Bacille Calmette-Guérin (BCG) vaccine	Y	[Single select]/Yes; No; Not known by case or doctor	
	Date of last dose		Y	[Date field]	If vaccination = yes
	Vaccination validation		Y	[Single select]/AIR or other register; Health record; School records; BCG scar sited; Self or parental recall; Unable to validate	
Contact assessment, screening & management	Previous TB screening	Contact previously screened for TB?	N	Yes; No; Unknown	
	Test type (repeatable)	Sputum, skin or blood test or chest xray	N	Sputum; TST; IGRA; CXR	If previous TB screening = yes
	Test date	Date of the test	N	[Date field]	If previous TB screening = yes
	Result	What was the result of previous screening	N	Positive; negative	
	Did the contact have symptoms?	Symptom assessment	N	Yes; No	
	Cough (>2 weeks)	Symptom assessment	N	Yes; No	
	Haemoptysis	Symptom assessment	N	Yes; No	
	Shortness of breath	Symptom assessment	N	Yes; No	
	Fever	Symptom assessment	N	Yes; No	
	Night sweats	Symptom assessment	N	Yes; No	
	Unexplained weight loss	Symptom assessment	N	Yes; No	
	If yes, weight loss details (kg)	*Symptom assessment*	*N*	*[Numerical field]*	*Considered unnecessary detail*

	Field	Description	Current NCIMS field	Field type/List of values (where applicable)	Notes
	If yes, in how many of weeks?	*Symptom assessment*	*N*	*[Numerical field]*	
	Other symptom DETAILS:	Symptom assessment	N	[Free text]	
	Baseline assessment				
	Type of test (repeatable)		N	TST; IGRA	
	Date of test		N	[Date field]	
	Result (in mm)		N	[Numerical field - TST only]	
	Result:		N	Positive; negative; indeterminate; not read; unknown	
	Break of contact assessment				
	Type of test (repeatable)		N	TST; IGRA	
	Date of test		N	[Date field]	
	Result (in mm)		N	[Numerical field - TST only]	
	Result:		N	Positive; negative; indeterminate; not read; unknown	
	CXR		N	Yes; No; Not done; Unknown	
	Date		N	[Date field]	
	Result		N	Normal; Abnormal - suggestive of TB; Abnormal - other; Unknown; Not done	
	Outcome Result		N	Active TB; LTBI; Discharged (no evidence of infection); Declined screening; Lost to follow-up	
	NCIMS ID		Y		If screening outcome=active TB and case classification won't be updated (contact episode to active case).

	Field	Description	Current NCIMS field	Field type/List of values (where applicable)	Notes
	Commenced preventive therapy?	Has contact commenced preventative treatment?	N	Yes; No; Offered but declined; Unknown	If screening outcome = LTBI
	Preventive therapy commenced date		N	[Date field]	If commenced preventive therapy = yes
	Preventive therapy completed date		N	[Date field]	If commenced preventive therapy = yes
	CXR surveillance only		N	Yes; No; Unknown	If screening outcome = LTBI
	Result of CXR at 6 months		N	Normal; Abnormal - suggestive of TB; Abnormal - other; Unknown; Not done	If CXR surveillance = Yes
	Result of CXR at 12 months (if CXR surveillance = Yes)		N	Normal; Abnormal - suggestive of TB; Abnormal - other; Unknown; Not done	
	Result of CXR at 24 months (if CXR surveillance = Yes)		N	Normal; Abnormal - suggestive of TB; Abnormal - other; Unknown; Not done	
	Follow-up appointment date:		N	[Date field]	
	Owning chest clinic		Y	List of chest clinics	
	Notes		Y	[Free text]	

During discussion with the NSW TB teams, there was some uncertainty how NCIMS may be able to accommodate the multiple potential end-states following exposure to TB: no infection, active TB, LBTI (and subsequently active TB) without duplicating or losing information such as historical event data and laboratory results. For instance, should a notification for a contact that subsequently develops active TB be considered two separate episodes or a single episode with dates entered that demarcate the period between disease states? As an example, the Victorian Department of Health's NCIMS equivalent (Public Health Event Surveillance System - PHESS – which uses the same underlying technological infrastructure) treats an event as one episode if active TB is diagnosed in a contact within a 3-month period, and a new episode if longer. However, these data are not currently analysed systematically so it is unclear how this affects analysis and reporting of contact tracing data. This is yet to be fully resolved until testing of the new module can occur.

Discussion

Evaluation of NCIMS TB Contact Tracing Module

Due to delays in the technical development of the NCIMS module, no data entry or report generation tests could be undertaken. Hence, the following evaluation is based on a desktop analysis comparing the current data collection system to the agreed data specifications and expected functionality of the new module against surveillance system attributes as they apply to contact investigation objectives. Once developed, the practical use of the module should also be evaluated against these attributes.

Simplicity

Simplicity refers to ease of system operation related to information flow from point of generation to the end user (4, 22). From consultation with NSW TB Coordinators, the data specifications for the contact tracing module represents the minimum data elements required to be able to prioritise contacts for screening and treatment to control spread of TB disease. The module greatly improves simplicity of contact investigation system from non-standardised individual LHD contact data collection to a centrally housed standardised system where the minimum dataset only has to be entered once and where information can be shared securely and easily across jurisdictions. As a result, the simplicity of the NSW contact tracing data system will be greatly improved once the NCIMS module is operationalised. Simplicity also relates to *acceptance* and *timeliness*.

Flexibility

Flexibility refers to how easily the system can be adapted to meet changing needs (4, 22). As NCIMS is the NSW Public Health data system for all notifiable conditions, changes made to incorporate a TB contact investigation module has implications for other infectious diseases captured by NCIMS. This has limited the flexibility of the new module design, requiring modifications to align with existing data structures, definitions and validations. After consultation with the NCIMS technology team, the minimum dataset for contact tracing can be incorporated with mostly minor modifications to existing data elements (for example, event type and notification (e.g., confirmed case) changed to include information for contacts (e.g., contact - close) and concept of 'calculated onset date' being propagated to contact events to enable calculation of last contact with case date (last exposure date)). While there is a proposal to overcome the dilemma about how to manage situations where contacts become cases, this will require testing once developed ensuring records aren't duplicated while keeping important historical event notes and laboratory results. The existing classification functionality will remain unchanged with an option to merge contacts and cases automatically following a 30-day period. This replicates a similar system designed in New York for TB contact tracing by the same software vendor. So, while there is a degree of flexibility to NCIMS to incorporate these changes, the modifications will take time and are likely to incur substantial costs in the development of the module.

Data quality/completeness

Data quality refers to the completeness and validity of the surveillance data (4, 22). The contact investigation module will promote collection of standardised data across LHD jurisdictions improving aspects of data quality and completeness in comparison to current processes where LHDs have individually developed contact information forms and data systems. In addition to standardised data, the module will facilitate shared data access, which is important where investigations span different LHD areas where different TB teams may be interacting with the same contact network. The system will enable complete reporting with regularly generated reports using NSW Health's standardised performance indicators (Table 3). Finally, incorporating contact information into NCIMS will bring an additional layer of individual privacy protection and security that otherwise has the potential to be compromised by unregulated spreadsheets within LHD Public Health Units.

Table 3: NSW Health TB contact investigation key indicators.

Indicator	Definition
Initial processes - evaluated during or up to six months post diagnosis of the index case	
Proportion of cases who had a contact investigation carried out	The number of cases where the number of contacts was not blank, divided by the number of TB cases
Proportion of contacts that completed screening	The number of contacts that completed screening, divided by the number of contacts identified
Proportion of household contacts <5 years of age that completed screening	The number of household contacts <5 years of age that completed screening, divided by the number of household contacts < 5 years of age identified
Short-term processes – evaluated during or up to six months post diagnosis of the index case	
Proportion of contacts with LTBI commenced on preventive treatment	The number of contacts commenced on preventive treatment, divided by the sum of the number of contacts with TST/IGRA conversion and the number of contacts with a single positive TST/IGRA
Proportion of household contacts < 5 years of age with LTBI commenced on preventive treatment	The number of household contacts < 5 years of age commenced on preventive treatment, divided by the number of household contacts <5 years of age that tested TST/IGRA positive
Long-term outcomes - evaluated 24 months post diagnosis of the index case	
Proportion of contacts who completed preventive treatment	The number of contacts that completed preventive treatment, divided by the number of contacts commenced on preventive treatment
Proportion of household contacts <5 years of age that completed preventive treatment.	The number of household contacts <5 years of age that completed preventive treatment, divided by the number of household contacts <5 years of age commenced on preventive treatment
Proportion of contacts that completed CXR surveillance	Number of contacts that completed CXR surveillance, divided by the number of contacts commenced on CXR surveillance
TB disease in contacts not evaluated during contact investigation	Number of cases with TB disease that were not evaluated during contact investigation, identified by whole genome sequencing or subsequent epidemiological links

Acceptability

Acceptability reflects willingness of staff to participate in, use and accept the data generated from the surveillance system (4, 22). Acceptability is enhanced by engaging staff in the design and regular evaluation of the system. Data specifications and functionality of the module were developed in consultation with TB Coordinators across NSW who will be utilising the NCIMS module as a workflow management system during contact investigations and using the system for automated reporting. Co-design of the module has enhanced its acceptability over the current system that is universally recognised by TB staff as inadequate. Further testing of the new module will be required with staff once developed to ensure it meets their expectations.

Timeliness

Timeliness represents the efficiency of the system in terms of how fast appropriate action occurs between steps. In TB surveillance and control this includes recognition of symptoms, speed of diagnosis and laboratory confirmation and notification of TB cases to NSW Health Protection (4, 22). For contact investigations, timeliness refers to speedy identification of contacts based on infectious period, their risk prioritisation and screening and treatment (if required). Interviews should occur as soon as possible to identify locations where the case attended while infectious and details of known contacts. Screening and treatment processes should occur according to set timeframes (Attachment 1). Having a specific TB contact investigation module within NCIMS will promote timeliness by: facilitating standardised data entry of contact information as it comes to hand; immediate sharing of standardised data between LHDs (for cases that have travelled between districts); and more efficient use of staff time and resources avoiding the current double entry of aggregate information from local spreadsheets into the NCIMS database and facilitating automated reporting of performance indicators (Table 3).

Specificity, Sensitivity, Positive Predictive Value & Representativeness

These attributes describe the sensitivity, specificity and accuracy of true cases enabled by the system's case definition so that the proportion of actual cases detected and notified represents the distribution of all cases within the surveillance population (4, 22). While prompt notification of TB disease is also important for contract tracing, the effectiveness of the case definition, detection and notification aspects of the TB surveillance system falls outside the scope of evaluating the contact investigation module.

Usefulness

Overall, the addition of a contact investigation module will improve the usefulness of the NCIMS TB surveillance system by increasing the efficiency of contact tracing through standardised data collection and data sharing, enabling systematic automated reporting processes. Facilitating state-wide data entry and extraction should enable early identification of appropriate public health response, allow control measures to be initiated earlier and promote regular monitoring and evaluation of the effectiveness of TB control programs.

Limitations

As the new NCIMS contact tracing module could not be tested within the timeframes of this project, there remains some uncertainty with respect to its performance and value in real world contact investigations. TB disease is complex in comparison to other notifiable conditions given

the multiple end-states and lengthy screening and follow-up processes that are required in contact investigations (Attachment 1). Discussions with the TB Coordinators envisioned a system that could support these complex workflows by incorporating calendar alerts when contacts are due for screening or follow-up assessments. This ideal system functionality was not possible within the current NCIMS technical architecture. The final set of contact investigation data specifications represent what was achievable within the confines of the existing NCIMS system.

Conclusion

A clear deficiency in the current NSW TB surveillance system is the management of contact tracing data within uncontrolled spreadsheets across LHDs. Co-development of a contact tracing module with TB coordinators produced a minimum set of data specifications that could be feasibly integrated into NCIMS and that would meet their contact tracing management and reporting needs. While development of the module could not be completed within the project timeframe, a desktop assessment of the new contact tracing data management system compared to current arrangements indicated improved simplicity, data quality and completeness, acceptability, timeliness and usefulness. Some of the features desired by TB coordinators may not be realised due to existing NCIMS architecture limiting the flexibility of the system. Once developed, the contact tracing module will need to be tested and evaluated against the same key characteristics. Ultimately, a centralised contact tracing database should enable improved screening and management of close contacts of active TB cases and provide timely access to data to measure the public health effectiveness the NSW TB contact tracing system.

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Appendices

Appendix 1: NSW TB Contact Screening and Management Flow Chart (23)

Baseline

Assess:
- Current TB symptoms
- History of TB / LTBI
- TB exposure risk history
- Immunosuppression
- Cultural & linguistic needs

- No current symptoms but with a history of TB/LTBI
- Current symptoms suggestive of TB disease
- Neither current symptoms nor a history of TB/LTBI

TST/IGRA → Positive

Negative → Is the contact a child < 5yrs or highly vulnerable to disease progression?

CXR +/- TST/IGRA +/- sputa for AFB and clinical review

TB disease confirmed ** → Treatment & follow up for TB disease

TB disease excluded → History of TB disease

Neither TB disease nor LTBI

LTBI

No / Yes

Clinical review to consider window prophylaxis

Follow-up assessment / screening at break of contact

Baseline assessment / screening unable to be completed

Preventive therapy and follow up for LTBI

CXR surveillance at 6/12/24 months or as clinically indicated

Break of contact

Assess:
- Current TB symptoms
- History of TB / LTBI
- TB exposure risk history
- Immunosuppression
- Cultural & linguistic needs

- Neither current symptoms nor a history of TB/LTBI
- Current symptoms suggestive of TB disease
- No current symptoms but with a history of TB/LTBI

TST/IGRA → Negative → No follow-up unless symptoms develop

Positive ** — *If previous negative TST/IGRA, classify as a conversion (= evidence of recent TB infection)*

CXR +/- TST/IGRA +/- sputa for AFB and clinical review

Educate re. signs & symptoms of TB and to seek medical review if symptoms develop

TB disease → Treatment & follow up for TB disease

LTBI → Preventive therapy and follow up for LTBI / CXR surveillance at 6/12/24 months or as clinically indicated

>6 months

** If evidence of recent TB infection, expand screening to next risk category of contacts

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