





# BMJ Open How Australian First Nations peoples living in the Torres Strait and Northern Peninsula Area of Australia describe and discuss social and emotional well-being: a qualitative study protocol

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## ABSTRACT

**Introduction** Colonisation has, and continues to, negatively impact the mental well-being of Australia's First Nations peoples. However, the true magnitude of the impact is not known, partially because clinicians have low levels of confidence in using many existing screening tools with First Nations clients. In addition, many authors have critiqued the use of tools designed for Western populations with First Nations peoples, because their worldview of health and well-being is different. Therefore, the aim of the overarching study is to develop an appropriate mental well-being screening tool(s) for older adults (aged 45 and over) living in the Torres Strait that can be used across primary health and geriatric settings. This protocol describes the first phase designed to achieve the overarching aim—yarning about social and emotional well-being (inclusive of mental well-being) in First Nations peoples living in the Torres Strait and Northern Peninsula Area of Australia.

**Method and analysis** The study will be guided by decolonising and participatory action research methodologies. Yarning is an Australian First Nations relational method that relies on storytelling as a way of sharing knowledge. Yarning circles will be conducted with community members and health and aged care workers living on six different island communities of the Torres Strait. Participants will be recruited using purposive sampling. Thematic analysis of the data will be led by Torres Strait Islander members of the research team.

**Ethics and dissemination** The Far North Queensland, Human Research Ethics Committee (HREC) (HREC/2021/QCH/73 638-1518) and James Cook University HREC (H8606) have approved this study. Dissemination of study findings will be led by Torres Strait members of the research team through conferences and peer-reviewed publications.

## INTRODUCTION

Mental illness remains common among older adults but is often unrecognised and often wrongly attributed to the effects of ageing.<sup>1</sup> As a result, relatively fewer older people with

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study will use decolonising and participatory action research methodologies to explore stories about social and emotional well-being for Torres Strait Islanders living in the Torres Strait.
- ⇒ The findings will be used to codesign appropriate screening tools for mental well-being.
- ⇒ A limitation of the study is that yarning circles will not be able to be conducted on all the Torres Strait Islands.

mental illness are referred for psychiatric treatment. This results in a significant risk of missed diagnoses and treatment. This is of particular importance within Australia's First Nations communities where high rates of psychological distress have been identified in systematic reviews.<sup>2,3</sup> As high rates of dementia have also been identified in First Nations communities,<sup>4,5</sup> screening tools need to be appropriate and valid to differentiate signs and symptoms of dementia and depression in First Nations people. The consequences of missed or inaccurate diagnoses include reduced quality of life and associated decline in physical and social health, general well-being, overall functioning and increased risk of mortality as well as increased demand on healthcare services.<sup>6</sup> As the population is ageing, there will be increasing numbers of older people with mental illness, exacerbating an already significant health issue.

## Tools for screening mental well-being in First Nations peoples

Since 2007, and in response to calls for appropriate screening tools to be developed (Westerman T, Johnson A. A response to the validation of the Patient Health

Questionnaire-9 (PHQ-9) for use with Indigenous Australians), Australian research teams have been active in adapting,<sup>7-10</sup> validating,<sup>11-13</sup> developing new tools that screen for depression,<sup>14</sup> or have a component of a western developed tool for screening for psychological distress embedded in it.<sup>15</sup> In addition, a tool that screens for social and emotional well-being (SEWB), which is the preferred term used by Australian First Nations peoples and encompasses mental well-being, known as the Here and Now Aboriginal Assessment has been developed.<sup>16</sup> This work represents a significant contribution to, and acknowledgement of, different expressions of low mood and responds to calls for the use of screening tools that are appropriate for Australian First Nations peoples.

According to Russell *et al*,<sup>17</sup> data about depression and anxiety, as well as research focused on screening tools specifically for the Torres Strait Islander population living in the Northern Peninsula Area (NPA) and the Torres Strait, is lacking. For example, previous research in the Torres Strait investigating the relationship between diabetes and depression used the PHQ-9<sup>18</sup> which, the authors acknowledged had not been validated in the Torres Strait. More recently, this research team used the KICA-Dep, an adaptation of the PHQ-9 using the DSM-IV criteria for depression, and the General Anxiety Inventory to screen older adults as part of the dementia prevalence study.<sup>19</sup> Both tools were found to be inappropriate for use with Torres Strait Islanders because of different word use. In addition, questions related to self-harm in the KICA-Dep were considered offensive to some participants.

### First Nations peoples conceptualisation of health and well-being

Inherent in the critique of the appropriateness of using western tools to screen for depression and anxiety is First Nations people's conceptualisation of health and well-being.<sup>20 21</sup> Australia's First Nations peoples hold a holistic view of their health and well-being, which is interconnected and interrelated with their communities and Country.<sup>22</sup> As previously discussed, the term SEWB, which is inclusive of western conceptualisations of mental health, is preferred by Australian First Nations peoples.<sup>23</sup> This term also acknowledges that First Nations peoples well-being is determined by interactions between seven interrelated concepts: 'body, mind and emotions, family and kinship, community, culture, country, and spirituality.' (Dudgeon *et al*, p.316)<sup>24</sup> Consequently, the multi-dimensional nature of SEWB is broader than Western conceptualisations of mental health and its associated disorders. It also focuses on a strengths, rather than deficit-based approach to viewing mental health.<sup>22</sup> For these reasons, the concept of SEWB in relation to mental well-being will be explored in this study.

### Setting

The setting for this study is the Torres Strait (Zendath Kes) and NPA at the tip of Cape York in Far North

Queensland, Australia. The Torres Strait consists of over 200 islands, of which 17 are permanently inhabited, located in a vast geographic area of over 44000 km<sup>2</sup> between the top of the eastern Australian mainland and Papua New Guinea.<sup>25 26</sup> (figure 1)<sup>27</sup> Census data indicated that approximately 7403 people lived on the islands of the Torres Strait in 2016, 80% of whom identified as Torres Strait Islanders. People that identified as Australian Aboriginal constituted 2% of the population living on Torres Strait Islands. The NPA of Australia consists of five communities.<sup>28</sup> According to the 2016 Australian census, 87% of the 2796 people that live in the NPA identified as Australian Aboriginal and/or Torres Strait Islander peoples. The majority of whom identified as having Torres Strait Islander descent (48%).<sup>29</sup> There are higher proportions of people who identify as Australian Aboriginal and/or Torres Strait Islanders living in the Torres Strait Islands and NPA compared with the rest of Queensland (4%) and Australia (3%), respectively.<sup>29</sup>

As Fogarty *et al*<sup>30</sup> identified, historical and continuing impacts of colonialism on Australian First Nations peoples affects their health and health-related outcomes. For those living in the Torres Strait and NPA, health is impacted by a range of factors including their remote location, availability of health services and their associated personnel and climate change.<sup>31</sup> Despite this, 49% of First Nations Australians 15 years and over living in the Torres Strait self-assessed their health status as very good or excellent.<sup>32</sup> In contrast, 48% self-reported a current and long-term health condition and 19.6% of First Nations Australians over 18 years living in the Torres Strait reported high psychological distress. However, the Australian Institute of Health and Welfare state that the statistics related to psychological distress should be viewed with caution due to up to 15% margin of error.<sup>32</sup>

### Rationale and aims

While completing a dementia prevalence study in the Torres Strait,<sup>4</sup> the research team found that mainstream mental health screening tools and those adapted for Aboriginal communities<sup>21</sup> needed further validation before being used more widely. This was mirrored in feedback provided by Torres Strait communities and primary health partners that the tools were not appropriate in their current form.<sup>17</sup> Additionally, clinicians working in the region highlighted the need for more appropriate tools to be available. Consequently, this study responds to community and clinician concerns by developing and validating an appropriate tool(s) for clinicians and primary health services to better support SEWB, specifically mental well-being, in this population. It is anticipated that the tool(s) developed in the broader project will be available for use in health and geriatric settings across the Torres Strait. This project also aligns with a federally funded project focused on a codesigned healthy ageing framework for the Torres Strait. One of the outcomes of the Healthy Ageing in the Torres Strait project is to



**Figure 1** Torres Strait and Northern Peninsula Area of Far North Queensland, Australia.<sup>27</sup>

provide a suite of resources which could include the tool ultimately developed from the broader project.

Consequently, the aim of the broader study is to develop an appropriate mental well-being screening tool(s) for older adults (aged 45 and over) living in the Torres Strait that can be used across primary health and geriatric settings. This is of significance given high rates of psychological distress identified in Australia's First Nations peoples. Appropriate screening tool(s) will also facilitate equity within an underserved group to ensure appropriate treatment and management in this population.

This study protocol refers to the qualitative data collection using yarning circles, which is the first of five phases,

to be undertaken to achieve the broader aim of the study. Subsequent phases include: (1) Delphi process; (2) piloting of developed tool(s); (3) refinement of tool(s) based on feedback and (4) validation of tool(s). The research questions focusing this phase of the study are:

1. What words are used to describe and discuss SEWB in the Torres Strait and NPA?
2. How are signs and symptoms of poor SEWB expressed in the Torres Strait and NPA?
3. How do Torres Strait peoples interpret signs and symptoms of poor SEWB?
4. Does the experience of SEWB change with age, and if so, how?

## METHODS AND ANALYSIS

### Study design and approach

The research methodologies adopted for the proposed project are decolonising methodology<sup>33 34</sup> and participatory action research (PAR).<sup>35</sup> These approaches are in line with current research projects being undertaken by the team and are appropriate for working with Aboriginal and Torres Strait Islander communities.<sup>36</sup>

### Decolonising methodology

The aim of decolonising methodology is to broaden basic principles of knowledge beyond Western conceptualisations of knowing and understanding the world.<sup>37</sup> The research team acknowledge the historical and continuing negative impact of colonisation and research on Australia's First Nations peoples by non-Indigenous peoples. The team seek to highlight the concerns of Australian First Nations peoples by being critically reflective, enacting reciprocity, respecting the right to self-determination, and collaborating with our First Nations colleagues to transform our research practice.<sup>37</sup> For example, Thambinathan and Kinsella<sup>37</sup> (p.4) highlighted 'embracing other(ed) ways of knowing' as one of the approaches to decolonising methodology. Our approach is to foreground First Nations people's ways of knowing, being and doing. This is achieved by seeking and enacting Knowledge Circle (the team's Indigenous Reference Group) feedback and using Indigenous approaches including community codesign. First Nations team members will lead the study, including study design, data collection, data analysis and reporting.

### Participatory action research

PAR has been defined as the collective and self-reflective inquiry of coresearchers<sup>38</sup> with the intent to understand and improve the situation(s) that they find themselves in.<sup>35</sup> Self-reflective inquiry is directly linked with action and participant knowledge about the history, culture and

context in which the study takes place. It is grounded in relationships between the coresearchers. The focus of PAR is to enable action through iterative reflection cycles. This methodology also pays attention to power dynamics in research and therefore complements decolonising methodology which is the overarching approach of this phase and the wider project. For these reasons, PAR has been identified as a good methodology to use in Indigenous health research.<sup>35 36</sup>

### Governance and consultation

#### Patient and public involvement statement

The need for the broader study in which this protocol is situated arose during the conduct of the dementia prevalence study.<sup>4</sup> Consequently, the community have been involved with this study from the outset by providing verbal feedback in community forums during and after the dementia prevalence study.

The research team works with an existing Knowledge Circle (Indigenous Reference Group) that oversees research in the region. The Knowledge Circle includes Aboriginal and Torres Strait Islander academics, community members, aged care workers and healthcare staff that have expressed an interest in working with the research team on addressing health issues of adults in their communities. This project will fall under the auspices of the existing Knowledge Circle. Consequently, this protocol has been shared with members of the Knowledge Circle and the authors have acted on feedback provided by them. Projects are also conducted in partnership with local health and aged care services in the Torres Strait region.

### Participants and recruitment

Participants are outlined in [table 1](#). The purpose of the yarning circles is to develop a depth of understanding about SEWB from the perspective of First Nations peoples living in the Torres Strait and the NPA, therefore, a small

**Table 1** Summary of participants, sampling and recruitment

Participant group no and description	N (approximate)	Sampling and recruitment method
1. Torres Strait community members and community Elders	8–12 participants in each of up to six participating communities (more opportunities will be available if there is interest)	Purposive sampling via First Nations team members based in the Torres Strait and local PARAC. Information flyers distributed in services and on community notice boards.
2. Psychiatrically stable First Nation mental health clients or past clients	8–12 participants	Purposive sampling via PARAC team members. Study Information sheet provided with opportunity to register interest.
3. First Nations people with mild cognitive impairment and early dementia	8–12 participants	Purposive sampling via PARAC team members. Study Information sheet provided with opportunity to register interest.
4. Aged care and mental health service staff (may include clinicians who do not identify as an Australian First Nations person)	8–12 participants	Purposive sampling through an invitation to participate through existing relationships formed through community engagement or through flyers distributed to their services.
PARAC, Post-Acute, Rehabilitation and Aged Care.		



sample size is permissible.<sup>39</sup> Boddy<sup>39</sup> also indicated that more than 12 focus groups is a large sample size, in a demographic and geographically homogeneous population<sup>40</sup> such as the Torres Strait and NPA. However, as the yarning circles is the first of five phases which may result in the development of a questionnaire, a greater number of participants that are representative of each segment of the population is necessary.<sup>38</sup> Consequently, and to facilitate a diverse range of perspectives, the research team intend to recruit different groups including community members, psychiatrically stable current or previous mental health clients, people with mild cognitive impairment or early dementia, as well as aged care and mental health staff (see [table 1](#)).

Purposive sampling<sup>40</sup> of participants will be used to explore the dimensions of SEWB including people diagnosed with mental health conditions. A range of different strategies ranging from posting flyers on community notice boards to local Post-Acute, Rehabilitation and Aged Care Service team members identifying potential participants, will be employed. The two clinical groups will be recruited through purposive sampling which will involve healthcare staff identifying potential participants. These potential participants will be provided with an information sheet and informed they may register their interest if they wish to participate. In recognition of the potential for coercion and pressure to participate, all participants will have an opportunity to register their interest to be involved with the study. Only then will team members approach the potential participant to discuss the study further before commencing the consent process. [Table 1](#) identifies the range of intended strategies.

In line with ethical and ongoing community engagement approaches of the research team, the principles of reciprocity and mutual benefit apply to this protocol. A variety of different approaches will be used to facilitate these principles. Community members have been, and will continue to be, actively encouraged to become involved with the project as coresearchers. For example, several community members participate in our knowledge circle. Community members representing three different islands also work as research assistants on this project and will lead data collection, analysis and reporting. Simultaneously, they are mentored by more experienced team members, which builds their research capacity. By participating in this project, non-indigenous team members will benefit by deeply listening to Torres Strait Islanders stories about SEWB. Finally, the research team regularly conduct community education and feedback sessions, during which they also enquire about how they can reciprocate in communities.

### Consent

Informed consent will be obtained from all participants by members of the research team. Participants will be provided with detailed verbal and written information about the study overall and given specific details about the aspect they are being invited to participate in, in this

case yarning circles. Participants will be given the opportunity to discuss the study with others (family, friends) if they wish, before consenting to participate.

Torres Strait Islander members of the team will be available during the consent process to address any issues as they arise and provide translation into regional languages for participants whose primary language is not English. There will be provision to read the information sheet and consent form to people with limited written English literacy, so they have full understanding before consenting to participate. If a Torres Strait Islander researcher assistant is unavailable, an audio recording of information and consent for the study will be available for participants to listen to in Torres Strait Creole.

### Data collection

Torres Strait Island community members' stories about their SEWB will be gathered in yarning circles.

### Yarning

Yarning is an Australian Indigenous relational methodology<sup>41</sup> that relies on storytelling as a way of sharing knowledge.<sup>41–43</sup> Yarning, meaning 'let's talk' or 'have a conversation', can occur between individuals—or in groups,<sup>41</sup> known as yarning circles.<sup>44</sup> Bessarab and Ng'andu<sup>42</sup> identified four different types of yarning. The social yarn, where news, gossip and general information that participants choose to share is yarned about. A social yarn should precede the research topic yarn and ideally provides a way of establishing a trusting relationship between the researcher and the participant(s). The research topic yarn is initially guided by the question(s) asked by the researcher. However, it is important that yarning is not re-directed if it is thought to be 'off-topic'. While yarning, the participant has control, one of the six protocols suggested by Barlo *et al*<sup>41</sup> as being fundamental to equality and shared responsibility during yarns. Both collaborative and therapeutic yarns can take place after the research yarn has concluded.<sup>42</sup> Collaborative yarning is focused on sharing ideas. In contrast, a therapeutic yarn is focused on supporting a participant who has disclosed information that 'is traumatic or intensely personal and emotional.' (Barlo *et al*, p. 40)<sup>41</sup> As the focus of the research topic yarn for this study may result in participants sharing traumatic or personal and emotional stories about their SEWB, or that of others, the therapeutic yarn will be especially important. In addition, participants will be guided on where they can seek further support from a member of the research team or a local primary healthcare service. This protocol will use social, research and therapeutic yarning to gather participant experiences of SEWB.

A semistructured yarning guide around three key topics (see [table 2](#)) has been developed. These topics are a starting point for the yarning circles and researchers will be open to additional topics as informed by participant responses. New topics raised in previous yarns may also be included as the circles are conducted across different

**Table 2** Yarning topics

Participant group	Yarning topics
Community members	<ul style="list-style-type: none"> <li>▶ Words used to describe and discuss SEWB.</li> <li>▶ Signs and symptoms.</li> <li>▶ SEWB changes with age.</li> </ul>
Health professionals	<ul style="list-style-type: none"> <li>▶ Words clients are using to indicate that they are feeling low/down/sad/no good (depressed).</li> <li>▶ Words clients are using to indicate that they are worried (anxious).</li> <li>▶ Signs and symptoms being observed by practitioner and being described by clients.</li> <li>▶ Factors impacting SEWB.</li> <li>▶ Changes with age.</li> </ul>

SEWB, social and emotional well-being.

communities. The community yarning guide is detailed in online supplemental appendix 1 and the health professional yarning guide in online supplemental appendix 2.

It is anticipated that yarning circles will take approximately 60–90 min to complete. In line with decolonising methodology,<sup>33</sup> yarning circles may be conducted in language, where appropriate, by one of the local Torres Strait Islander team members. All participants will receive a locally redeemable gift card as an acknowledgement and reimbursement for their time and contribution to the yarning circle.

It is our preference for yarning circles to be audio recorded. Audiorecording will be transcribed verbatim with recordings translated prior to transcription if the yarning circle has taken place in language.

### Analysis

Once transcribed, data will be uploaded to NVivo (QSR international) for data management. A qualitative exploratory approach to data analysis will focus on emergent themes related to the yarning circle topics and be guided by the research questions. Thematic analysis will be used to identify themes that emerge from the data.<sup>45</sup> Initial analysis and interpretation will be conducted by Torres Strait members of the research team. They will be guided by non-indigenous members of the team with further input from the knowledge circle. This approach prioritises data analysis and interpretation from a Torres Strait Islander researcher worldview and relationality with the participants established during the yarning circles.<sup>41 46</sup>

### Ethics

This study has received ethics approval from the Far North Queensland, Human Research Ethics Committee (HREC) (HREC/2021/QCH/73 638-1518) and James Cook University HREC (H8606). Yarning circle participants will provide written or verbal informed consent. Any participant is free to withdraw from the study at any time. However, it is not possible to withdraw their

contribution to the yarning circle given the group format. Participants will be informed about this prior to providing their consent. Any potential participant who does not wish to be recorded will be given the opportunity for a one-on-one interview separately with notes being taken by the researcher.

All data will be deidentified prior to community sharing and publication. Yarning circle participants will also be asked to respect each other's privacy and not to share others' stories. However, participant anonymity cannot be guaranteed.

It is acknowledged that sharing SEWB stories during the yarning circle may elicit negative emotions and/or distress for some participants. Should any participants experience stress or negative emotions, the therapeutic yarn will provide an opportunity for further sharing and healing. Participants will be offered the opportunity to leave the circle if their distress is overwhelming. The research team includes clinicians with mental health training, who can assist with immediate distress management is that is necessary for either participants or yarning circle facilitators. Opportunities for further support after the yarning circle has concluded will be provided. All participants will receive a list of mental health services and resources or where appropriate be referred to local aged care or mental health teams.

This phase informs the subsequent tool/approach development phase which will be conducted via a Delphi process. Consequently, any further development including a conceptual framework and/or domains that will underpin the tool or approach will be shared with participants where possible. Feedback will also be sought from the knowledge circle and project partners.

### Dissemination

Robust engagement has been undertaken in the communities that have participated in the project. Dissemination approaches such as feedback and feed-forward through regional council members as well as through key health services and agencies will be conducted. As this is the first phase of a five-phase project, continuous community engagement, including requesting feedback from health practitioners and community members through dissemination meetings, will be conducted. Additionally, one community-based approach that we would like to trial in this project is dissemination through podcasts. Consequently, dissemination through local radio as well as sharing through social media will be trialled for this project.

Peer-reviewed publications and presentations will also be used to disseminate the findings of this phase of the project. To support research capacity building, dissemination will be led by Torres Strait Islander members of the team. Publications will conform with the consolidated criteria for strengthening reporting of health research involving Indigenous peoples (the

CONSIDER Statement)<sup>47</sup> and the consolidated criteria for reporting qualitative research.<sup>48</sup>

## CONCLUSIONS

This study will gather stories about SEWB from First Nations people living on the Torres Strait Islands and NPA. It is the first of a five-phase project that intends to develop an appropriate tool or approach for screening mental well-being in this population. It is guided by decolonising and PAR methodologies. Data collection, analysis, interpretation and dissemination will be led by Torres Strait Islander members of the research team.

The project's findings aim to assist clinicians and/or other research teams who are interested in developing tools to screen mental well-being in Australian First Nations populations. It may also improve knowledge of the cultural understandings of SEWB, and words used by Torres Strait Islanders, a culturally distinct Australian First Nations population, to express distress.

**Acknowledgements** Ownership of Aboriginal and Torres Strait Islander knowledges and cultural heritage will be retained by the participant.

**Contributors** SR, RQ and ES conceptualised the study. SR and RQ wrote the initial protocol for ethics approval. KM further developed the protocol and drafted the initial manuscript. EA, BS, TW, CW, RQ and SR contributed to the manuscript. BS, TW and CW provided feedback on the cultural appropriateness of the protocol. All authors reviewed and approved the final version.

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**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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