




# BMJ Open Birang Daruganora: a protocol for a qualitative study to elicit Aboriginal and Torres Strait Islander community views about cultural needs and experiences for a new Australian health facility

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## ABSTRACT

**Introduction** To address challenges regarding the delivery of healthcare, governments and health services are focusing on the implementation of models that are flexible, person-centred, cost-effective and integrate hospital services more closely with primary healthcare and social services. Such models increasingly embed consumer codesign, multidisciplinary teams and leverage digital technologies, such as telehealth, attempting to deliver care more seamlessly and to continually improve services. This paper provides a study protocol to describe a method to explore Aboriginal and/or Torres Strait Islander consumer and healthcare provider needs and expectations for the design and development of a new healthcare facility in Australia.

**Methods and analysis** A qualitative study of consumer members' and health providers' needs and expectations. Data collection includes a short consumer-specific and provider-specific, demographic questionnaire and culturally appropriate facilitator-coordinated consultation workshops. Data will be analysed thematically (qualitatively).

**Ethics and dissemination** The results will be actively disseminated through peer-reviewed journals, conference presentations, reports to stakeholders and community meetings. This study was reviewed and approved by a health service-based Ethics Committee in New South Wales, Australia and the Aboriginal Health and Medical Research Committee.

## BACKGROUND

Aboriginal and/or Torres Strait Islander peoples (hereafter, Aboriginal) experience significant health inequities<sup>1</sup> largely driven by socioeconomic determinants and systemic discrimination.<sup>2–5</sup> Aboriginal people are twice as likely to report fair or poor health and high levels of psychological distress compared with other Australians.<sup>6</sup> Hospitalisation rates for

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study will be the first of its kind to identify Aboriginal communities' expectations and needs regarding the provision of acute care and support services in the sacred land of the Darug people to inform the development of the new health facility.
- ⇒ Study outcomes will inform the design and development of a new health facility in Sydney, Australia.
- ⇒ A key strength of the study is the use of qualitative methods and the triangulation of data from multiple sources specific to the needs of Aboriginal and Torres Strait Islander consumers and their healthcare providers.

chronic disease such as renal failure occur at a rate of 14 times higher, and life expectancy is 17 years less, than that of other Australians.<sup>7</sup> The recent New South Wales (NSW) Bureau of Health Information 2021 report 'Aboriginal people's experiences of hospital care' highlighted continuing disparities between Aboriginal and non-Aboriginal experiences when it comes to safe and respectful care in hospitals. The report revealed that Aboriginal people admitted to hospital are less likely to feel informed, feel respected and treated with dignity, and have their family included in their care.<sup>8</sup> National survey research in 2021 showed that while 23.5% of Australians reported feeling disrespected or discriminated against when receiving healthcare in the last 12 months, 81% of the Aboriginal cohort did.<sup>9</sup> This provides further support for these systemic issues within the current healthcare climate in Australia.

Jones *et al*<sup>1</sup> conducted a recent systematic review of Aboriginal peoples' healthcare experiences and found that the quality of healthcare for Aboriginal people is significantly affected by their past experience and poor trust of the health system. In Aboriginal culture, the need for trust in provision of care, and for their social, mental, spiritual and community needs to be understood holistically, is vital.<sup>1</sup> There is a growing body of evidence that vulnerable and disenfranchised communities, such as Aboriginal peoples in Australia, benefit from having a voice in their healthcare,<sup>10</sup> thereby ensuring that health services increasingly recognise their perspectives.

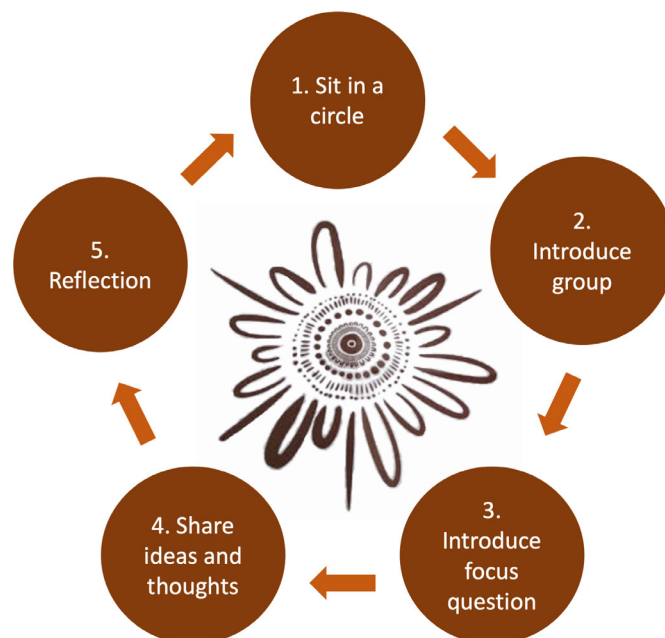
In 2021, in collaboration with the Western Sydney Local Health District (WSLHD) in Australia, research was conducted to seek views about the design and development of a new healthcare facility in Sydney, within the Darug Nation territory.<sup>11</sup> The catchment area of the new facility consists of 49 suburbs, comprising a land area of almost 500 km<sup>2</sup> and an estimated population in 2019 of approximately 300 000 residents.<sup>12</sup> The overarching goal of the research was to inform delivery of care that is more accessible, efficient and effective for healthcare providers, funders and the population. The study will contribute to understanding whether healthcare can be delivered in ways other than through a conventional hospital building.

While Aboriginal peoples make up only 0.9%<sup>13</sup> of the population in the catchment area within Darug territory, they experience a disproportional burden of ill health and difficulties accessing health services. To address this imbalance, this study aims to understand the Aboriginal communities' expectations and needs regarding the provision of acute care and support services in the sacred land of the Darug people.

This protocol describes a study that was designed by the Aboriginal research team members from the community to elicit the Aboriginal community's perspectives and cultural needs on the ideas being studied with the non-Aboriginal population. Thus, it complements and differs from the already published research.<sup>11</sup> Including Aboriginal experiences and perspectives in the current study will inform the culturally appropriate development of innovative acute and chronic care and support service delivery that address the delivery preferences and concerns of the community. This information will also provide key insights and opportunities for the WSLHD and the health facility to fulfil key components of the Australian National Safety and Quality Health Service Standards,<sup>14</sup> as they relate to Aboriginal consumers.

## METHODS

The Aboriginal Health Liaison officers of the WSLHD supported by Australian Institute of Health Innovation researchers will lead the study. Initially, the project team will meaningfully engage with stakeholders and communities to participate in the project. Existing networks will be approached through community Elders, and we will link in with service providers and media to engage



**Figure 1** The yarning circle process (adapted from qcaa.qld.edu.au).

with community to recruit participants for facilitator-coordinated workshops and follow-up interviews.

## Study design

We will conduct a qualitative study of Aboriginal consumer and provider needs and expectations in relation to innovative models of care delivery for a new health facility. As illustrated in [figure 1](#), the design involves adopting a culturally appropriate, in person method of data collection called 'yarning circles'. Yarning for Aboriginal people was, and still is, a conversational process that involves the telling of stories as a way of passing on cultural knowledge. These circles provide a safe place for all to speak without judgement. The conversations within a yarning circle have always focused on strengths of people and their stories, rather than problem-solving and criticisms. It is a collaborative way to communicate and provides a respectful place to be heard and to respond.<sup>15</sup> Today, yarning circles are used as a meeting format when Aboriginal and non-Aboriginal communities come together and provide an ideal method for conducting the workshops in this study (see [figure 1](#)). As part of the yarning process, consent will be sought, and demographic information (age, gender) and views about the new facility will be recorded.

## Study setting

The workshops will be held in public community centres. Options to attend workshops during or outside of work hours will be provided. We will follow NSW Health guidelines that are in place at the time of the workshops, such as mask wearing or social distancing, to reduce the transmission of COVID-19.

## Study procedures

The project team will reach out to the Elders first to understand their perspective on Aboriginal community needs. The project team will also share the details of the project with their networks, colleagues and workplaces, as well as reach out to the community through multiple avenues to invite the community to participate in the project. For example, the Koori Mail Newspaper and Koori Radio (Australian media written and owned by Indigenous Australians) will be approached, as well as services with Aboriginal workers in the community to disseminate the project. The newspaper posting and radio collaborations will include a phone number to ring to register interest. For those interested in finding out more information about the project, we will seek their contact information (eg, an email address or phone number) so that we can coordinate participation. The current project will also link in with the district director for the Aboriginal Health Strategy Aboriginal Service providers in the area to support engagement across the WSLHD of both consumers and providers.

In early planning for the study, project team meetings identified several potential barriers that might affect the ability of Aboriginal people to be meaningfully engaged. These include feelings of mistrust, systemic racism and a perceived lack of cultural competence among the research team.<sup>16</sup> We anticipate the communities will consist of people with diverse demographics and experience. The optimal method of meaningfully engaging people with diverse views is to meet them face to face in the community.<sup>15</sup> Aboriginal Liaison Officers of the WSLHD will visit elders groups for discussions to ensure they are appropriately consulted and play an active part in the collaborative process. In addition, the research team will undertake Aboriginal Cultural Safety Training prior to the commencement of data collection.

Up to 25 participants will be selected based on responses to verbal discussions with the community. The contact information collected during the initial discussions inviting participation will then be used to coordinate with participants the details about the location and time of the workshops (either via phone or email—as indicated as best mode of contact by participant). We will explain the study to those who register by phone or face to face and obtain verbal consent ('Are you happy to proceed and answer the demographic questions I will read to you now?'). For all participants who agree to attend a workshop, we will obtain written and verbal informed consent at the workshop prior to the commencement. We will provide participants with the information sheet beforehand, either via email or during initial face-to-face consultation, and answer any questions on the day prior to obtaining informed consent.

Disability has also been identified as a potential barrier that might impact the ability of Aboriginal people to be meaningfully engaged.<sup>17</sup> All people have a story to share and recognise that different strategies to support participation will need to be implemented depending on

disability. The team will take steps to include everyone who can provide informed consent regardless of whether their disability is physical, mental, hearing impairment or vision impairment. The team will take steps to minimise any barrier by making participation as accessible as possible. For example, Aboriginal Liaison Officers and Elders will be consulted on how best to provide project information to individuals living with disability and on how to support their participation in the project. Flexible participation options will be made available (regarding timing and place or telephone) to individuals living with disability.

## Data collection

Data in this project will include demographic information and qualitative workshop and interview data. All data will be captured using pen and paper. Audiorecording will not be used due to cultural sensitivities.

There will be two streams of workshops: one for health providers that provide care, or are likely to provide care, to community members in the health facility catchment; and the other for community members that reside in the health facility catchment. There will be two facilitators/scribes at each workshop.

Initial meetings with the community will be arranged by the Aboriginal Liaison Officers who will introduce the research team and facilitate conversations. During these visits, the research team will explain that the purpose of the workshop is to capture the needs of the community and their perspectives on the design of a new healthcare facility, and their views about different models of care (eg, virtual). Once the community consultation is completed, and relationships established, data collection will commence. Consumer participants will be informed that their experiences as patients are very valuable, but there is no obligation to disclose details of personal healthcare issues. Participants can ask questions before signing the consent form. Using a 'yarning circle' method, facilitators will guide the conversational process about experiences with healthcare and the community's wants and needs for the new healthcare facilities.<sup>15</sup> All participants in the discussion will be considered information-rich cases that will allow the research question/s to be adequately explored. See online supplemental files 1 and 2 for workshop and interview scripts.

## Length of study

Dependent on recruitment, we anticipate data collection will take place over 1–2 months. Each workshop will be planned for a 2-hour duration with a 10 min break after the first hour. Participants will not be paid for their participation but will be provided with refreshments.

## Number of participants

We seek to recruit 3–12 participants for each of the workshops (this estimation takes into consideration drop-outs). With two streams of workshops, we anticipate 6–24 participants in total. However, the number of participants

invited to each workshop will largely depend on the number of Aboriginal peoples who volunteer to be a part of it, and NSW Health COVID-19 restrictions at the time of data collection.

### Inclusion criteria

We seek to involve the Aboriginal community members (including a range of ages), throughout the process. All participants need to be able to provide verbal consent.

Community participants include Aboriginal local residents and patient representatives within the new health facility catchment as defined by the WSLHD planning team. Our inclusion criteria are broad enough to capture any adult community member.

Providers include Aboriginal healthcare workers and liaison officers within the WSLHD who will be directly affected by the new health facility. This will include general practitioners and other health providers such as community nurses and services, allied healthcare professionals, aged care facilities, community care organisations, the primary health network, community care providers, the ambulance service and other identified stakeholders. Inclusion criteria will be broad enough to capture any Aboriginal healthcare provider in WSLHD or new health facility catchment.

### Interviews

After the workshop, there will be an option for participants to volunteer for a semistructured interview. We will purposively select follow-up participants based on insights shared in the workshops and the need to capture varied responses. The purpose of these interviews is to expand on areas of interest and verify the findings from the workshop data. Interviews will last approximately 45 min and conducted via face to face, or over the telephone for participant convenience. Some volunteers may indicate that they would prefer an interview rather than attend a focus group, due to, for example, cultural sensitives and time constraints.

### Data analysis and synthesis

All data will be deidentified with a study code assigned. All participants will be advised that any information that is shared, that by law must be disclosed to a relevant authority will not be kept confidential. The study protocol, materials and all data will be stored in password-protected electronic files and backed up on OneDrive hosted by Macquarie University. All data relating to this research project will be destroyed after a 5-year storage period. This is in line with General Retention and Disposal Authority University Records (GDA 23) (2005) and the Australian Code for the Responsible Conduct of Research (2007) requirements.

The quantitative data that include demographic data will be descriptively analysed using SPSS V.22.0<sup>18</sup> and weighted against the Australian Bureau of Statistics data for the catchment, to assess the representativeness of the sample.

Consumer and provider workshop (ie, facilitator notes and key elements of the workshop recordings) and interview qualitative data will be merged into two aggregated, narrative summaries, one for consumers and one for providers. Aggregated data sets will be thematically analysed separately for consumers and providers. Two members of the research team will independently use an open coding process and will work together to resolve discrepancies. Themes will be extracted that characterise the expectations and needs of the consumers and health providers in terms of the new health facility catchment. Any variation in response, or conflicting views, will be reported. Multiple methods and data sources will be triangulated to ensure findings are comprehensive, authentic and rigorous. Information from community members participation in the workshops and semistructured interviews will be coded independently by multiple researchers. Researchers will then compare and discuss codes. The trustworthiness of the emerging concepts and themes (ie, codes) will be checked via feedback from Aboriginal and Torres Strait Islander team members.

The results will be synthesised to identify the key elements for the development of a healthcare service that meets the needs and expectations of Aboriginal consumers and providers. Findings will inform the planning decisions and feasibility of implementation of the options for development of a new health facility. Bringing together these data sources will enable us to identify the key elements for the development of a world-class solution for healthcare service delivery to the community for Aboriginal people.

### Patient and public involvement

Patients or participants will be directly involved in the current study.

### DISCUSSION

This study seeks to explore consumer and provider needs and expectations for the development of an innovative care model for a health facility, specifically for Aboriginal people who reside in metropolitan NSW, Australia. We will undertake a consultation that uses an evidence-based culturally sensitive and appropriate method led by community Aboriginal Liaison Officers to explore community perspectives on wants and needs for a new healthcare facility.

The limitations of this research may include the following: This study is limited to the local health district under investigation (WSLHD) and the specific needs of the consumer and providers in that district. Therefore, as there are a variety of Aboriginal communities across Australia, findings may not generalise to other regions. In addition, the catchment area could change as the WSLHD redefines its boundaries. As we will not be audio recording yarning circle conversations, it is possible that some information may be missed. Mitigating this, the research team

will independently make notes which will be analysed for consistency prior to analysis.

### Expected outcomes

This research will report on views and opinions from Aboriginal consumers and their healthcare providers through a cultural lens. It will aim to highlight the multiple considerations for a new healthcare facility accounting for Aboriginal perspectives. This will guide the development of the facility to help ensure that the surroundings enhance feelings of welcome and are culturally safe and appropriate. It will contribute to reducing the health inequities encountered by Aboriginal consumers and providers in metropolitan Australia.

### Ethics and dissemination

Ethics approval for conducting the study has been obtained from the Local Health District Human Research Ethics Committee (2021/PID01000) and the Aboriginal Health and Medical Research Committee. The results will be actively disseminated through peer-reviewed journals, conference presentations, reports to stakeholders and community meetings.

We will obtain written and verbal informed consent from those who agree to participate in the workshops.

For both the workshop and interviews, a researcher will present a brief verbal and written (bullet) summary of the findings from the workshops, with the opportunity for participants to ask any clarifying questions. At this stage, participants will also be reminded that participation is voluntary, and they can revoke their consent at any time during the study. The project team will also explain and make clear that participation or refusal to participate will remain unknown to others outside of the workshop and will not affect their employment or future healthcare treatment.

Should a participant withdraw from a workshop or interview, or withdraw their consent after research has commenced, their data will not be used as part of the formal analysis. We do not anticipate participant withdrawal having any impact on the study; however, should it occur, some modification of results may occur.

### Managing risk/distress

Participants will be informed as part of the workshop and interview participant information and consent forms (PICF) that there may be potential for distress as the questions relate to issues around their experiences with healthcare. They will be informed that they do not have to answer any question that makes them feel uncomfortable and are able to stop at any time. If participants do become distressed, researchers will offer to arrange for free counselling or other support. The project team will refer distressed participants to relevant support services.

Unintended impacts for Aboriginal peoples include feelings of being exploited, being unclear on what the information is being used for and the progression of the

project. Actions to mitigate or prevent these unintended impacts from occurring:

1. Be explicit about what will be done with the information. This will be conveyed through PICF.
2. Communicate the progress of the project through multiple avenues. For example, Koori Mail Newspaper (<https://koorimail.com/>), Koori radio and community meetings.
3. Acknowledge the Aboriginal involvement in the research—including the design phase, Aboriginal Liaison Officers as facilitators and the community as participants. This will be viewed as an ongoing and continuous process.

The impact of the project on Aboriginal peoples will be actively monitored and evaluated through verbal check-ins with community members at each stage throughout the project. The potential positive impact from the project is an invitation of ownership in idea creation and the potential for the recommendations generated to inform future health service development projects. This information will also be usefully documented, so that all the community can be informed about the engagement process and outcomes.

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**Competing interests** None declared.

**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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