AUSTRALIAN INSTITUTE
OF HEALTH INNOVATION

MACQUARIE
University

Birang Daruganora

Aboriginal and Torres Strait Islander community cultural and health needs for hospitals of the future

PREPARED FOR

THE WESTERN SYDNEY LOCAL HEALTH DISTRICT AND HEALTH INFRASTRUCTURE

NOVEMBER 2022

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CONFIDENTIALITY

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ACKNOWLEDGEMENT OF COUNTRY

The Australian Institute of Health Information acknowledges Aboriginal people as the traditional custodians of the lands and waters of Australia and pays respect to Elders past, present, and future. In this report, Aboriginal and Torres Strait Islander people are referred to as Aboriginal peoples in recognition that Aboriginal peoples are the original inhabitants of Australia.

IMAGE INFORMATION

The artwork featured on the cover of this report was created by Fiona Vespa, a proud Yaegal artist from Yamba. It tells the story of a family banding together to build a hut. They add small pieces of bark and wood to create a home that family far and wide can come to.

FURTHER INFORMATION

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List of Abbreviations

AIHI	Australian Institute of Health Innovation
COVID-19	Coronavirus disease of 2019
GP	General Practitioner
HI	Health Infrastructure
HITH	Hospital in the Home
HREC	Human Research Ethics Committee
NDIS	National Disability Insurance Scheme
NSW	New South Wales
WSLHD	Western Sydney Local Health District
QCAA	Queensland Curriculum and Assessment Authority

Executive Summary

INTRODUCTION

Commissioned by Health Infrastructure, in collaboration with Western Sydney Local Health District (WSLHD), the Australian Institute of Health Innovation conducted research to inform the development of a new health facility that is fit for purpose now and into the future. This collaboration included consultation with the local Aboriginal and Torres Strait Islander (hereafter Aboriginal peoples) community. The Aboriginal community member consultation project was called Birang Daruganora, meaning belonging to Darug Country, and was led by Aboriginal community members. This report provides the findings from an Aboriginal community consultation on the development of a new healthcare facility centred on Rouse Hill, a suburb in the north-west of Sydney, New South Wales (NSW), which is situated on the sacred lands of the Darug nation. The report identifies key cultural and health considerations perceived by Aboriginal community members and providers in respect of hospital care.

METHODS

Approach. Led by Aboriginal team members, two streams of yarning circles were conducted, one each for healthcare providers and community members. Yarning circles are a culturally appropriate method for data collection and involve a conversational process of telling stories, focusing on strengths and not criticisms or problem-solving.(1) Yarning circles were held in community centres and lasted up to two hours. Two providers and 18 community members (20 participants; 14 female, 6 male) aged between 21 to 60+ years. Qualitative data were analysed using high-level inductive analysis to synthesise the needs and experiences of health providers and community members.

Ethics. The Aboriginal Health and Medical Research Council of NSW Human Research Ethics Committee (HREC) approved the study (1870/21). The Western Sydney Local Health District HREC approved the study (2021/ETH00812).

RESULTS

Three primary themes emerged from the workshops. These were ‘culturally responsive spaces’, ‘systems’, and ‘models of care’.

Culturally Responsive Spaces

Yarning circle participants expressed the importance of culturally responsive spaces. The need for a welcoming, happy and healing environment (e.g., via use of colours, shape, flow, building materials, art, garden) that is co-designed with Aboriginal people was most often reported by participants. For example, these might include the provision of spaces to walk and reflect, including a garden with bush medicine plants, for families to gather, and smoking ceremonies to be conducted. For Aboriginal peoples, the time before and

following death is subject to customary practices that are sacred. A space that allows them to practice their cultural and spiritual traditions and customs without the presence of other religions or churches would enable culturally and clinically responsive care for Aboriginal patients and their families. Aboriginal families gather to support their loved ones when they are in hospitals or engaging with care services. Therefore, space within clinical settings to allow for the family to be present during care delivery, as well as culturally appropriate and accessible accommodation, offsite or outreach service options and accessibility services (e.g., shuttle transport services), would support services to meet the needs of the community.

Culturally Responsive Systems

Aboriginal peoples are not a homogenous group and must be recognised as having multiple distinctive cultures with customary practices varying between and within tribal groups. Wherever possible, care services should be co-designed with their local community to ensure appropriate, culturally responsive care. Participants specifically reported the need for systems to support accessibility (e.g., transportation, cost, timing, offline options). Representation is critical for engagement with care services. For example, the inclusion of Elders in hospital management structures, programs and pathways for Aboriginal peoples to enter care professions from High School (e.g., internships), staff retention programs, and training and recognition of qualifications and skills to allow Aboriginal health providers to work (and be remunerated) to the full scope of their abilities. Participants highlighted the need for visibility of health service providers, in particular managerial staff, to be visible to and connected with the community. Participants also highlighted the need for support roles (patient navigators), Aboriginal-specific care teams, greater numbers of Aboriginal providers (including males), and cultural awareness training that involves the local community.

Culturally Responsive Models of Care

The overarching preference was for care to be holistic, and to reflect individual and cultural needs. Participants' perspectives on six evidence-based innovative models of care were explored. These six models were derived from a literature review conducted by the researchers prior to this study.(2, 3) Table 1 summarises the perceived strengths, barriers, and enablers reported by our participants in relation to these innovative models of care.

Table 1. Six evidence-based innovative models of care.

Model	Description	Example	Strengths	Barriers	Enablers
1. Ambulatory care and diagnostic hospitals	Non-admitted services, where patient care does not involve an overnight stay and usually involves diagnosis and treatment on the same day.	Same-day joint replacement.	• More comfortable as not an inpatient	• Timeliness of care delivery • Access (parking and cost) • Transport home if family unavailable • The need for repeat visits	• Caring providers • Community transport • Patient navigator • Systems that are easy for staff to use • Streamlined care processes
2. Hospital in the home	Patient care and consultation which is typically delivered in the hospital setting are delivered to patients in their own home.	Early discharge hospital at home care for chronic obstructive airway disease managed by a community service.	• Convenient • Feel safer at home • Comfort • Care for family • Privacy	• Housing situation (set up, cleanliness) • Lack of trust	• Safety and security procedures • Clear communication • Required equipment is setup safely with 24/7 support available • Culturally sensitive skills • Resources • Communication pathways between providers and patients • Aboriginal cultural training
3. Integrated care	The multidimensional needs of the patient are delivered in a coordinated manner by an interdisciplinary team or network of healthcare professionals	Orthogeriatric fracture service.	• Effective communication between providers • Reduced wait times • Addresses multiple needs • Targeted • Confidence in care and taken seriously	• Sense of lack of control over care • Paternalistic care • Inaccuracies in patient information • Cannot see/ access a doctor • Extensive wait times • Communication gaps and exclusion	• Support person to navigate • Access to information • Aboriginal liaison • Communication systems • Patient/family involved in decisions

				• Some find it hard to trust and open up	• General Practitioners (GP) as part of the team • Succession planning for when providers retire
4. Virtual care	Patient care and consultation are delivered through telephone or video communication.	Telehealth management in patients with heart failure.	• Can be cared for remotely • The comfort of own space • Easy, fast and convenient	• Connectivity issues • No computer • Technology anxiety • Low digital literacy • No physical examination (things might be missed) • Patients with cognitive issues • Elders living alone	• Support person • Pathways to enable equity • Access to computer/ internet/ smartphone
5. Specialist hospitals and population-specific care units	Specialist hospitals provide selective care services for targeted patient groups. Population-specific care units are pathways within general hospitals dedicated to the treatment of specific conditions.	Comprehensive cancer centres.	• Things might not get missed • One-stop shop for holistic care • Targeted to needs • Expert clinician knowledge • Higher level of care	• Lack of communication • Difficulty accessing transport to/ from • Narrow care focus • No other option • Service not a good fit	• Information (accessible) • Accurate diagnosis • Access to resources to support care • Support person for patient and family
6. Digital hospitals	Hospitals that make extensive use of new technologies to provide streamlined care, improve patient safety and care quality, and improve overall care cost-effectiveness.	A machine learning algorithm for prediction of the early warning signs of cardiac arrest.	• Helps monitor health-related things • Convenience	• Patient not understanding the model • Technology failures • Technological safety – hacking and data privacy • Not suitable for all conditions and healthcare needs • Inflexible system	• Technology support • Orientation information to familiarise patients with the technology being used in their care • Shared tools for communication and health monitoring • Back-up systems

LIMITATIONS

The findings presented in this report should be considered with the following limitations:

- Only six models of care were presented in yarning circles.
- The catchment area characteristics for the new Rouse Hill hospital are not definitive and may change.
- The consultations were conducted with a limited number of residents and providers of the WSLHD.
- The consultations were conducted face-to-face so this may have restricted the opportunities for community members who were not able to travel to participate.
- Participants were adults attending community centres. Other Aboriginal community members were invited to participate in consultations.
- Consultations did not include individuals younger than 21, so this may have restricted the diversity in experiences, cultural needs, and accessibility needs reported here.

CONCLUSION

Using a co-design approach led by Aboriginal team members, the cultural and health needs were gathered from Aboriginal community members who live or work in the Rouse Hill catchment. Across the yarning circles, participants identified key cultural, strengths, limitations and enablers relevant to accessing health care in hospitals as well as making comments on the evidence-based models of care. Common themes of respect and recognition, relationships and partnering and capacity building emerged as important consumer and provider considerations when developing and evaluating care services. Participants supported a range of models citing concerns about accessibility and choice when discussing evidence-based models of care. Aboriginal community members and providers are invested in the co-creation of an innovative, well-integrated hospital that will meet the needs of the community.

Introduction

The delivery of care is evolving with the development and implementation of new technologies and models of care to adapt to increasing health challenges of under-constrained resources (e.g., funding, skilled workers) and the prevalence of complex conditions and chronic disease. Coupled with the ongoing evolution in care delivery, the COVID-19 pandemic accelerated the rollout of new models of care (e.g., telehealth) to minimise disease transmission whilst maintaining care delivery).(4) However, unintended consequences from the implementation of new models of care, as well as from existing services, result in Aboriginal and Torres Strait Islander (hereafter, Aboriginal) people experiencing significant health disparities and difficulties accessing care services.(5, 6) The Bureau of Health Information 2021 report 'Aboriginal people's experiences of hospital care' identified that Aboriginal peoples admitted to hospital are less likely than non-Aboriginal people to feel informed, feel respected and treated with dignity, and have their family included in their care.(7) Similarly, the NSW Aboriginal Health Plan 2013-2023 acknowledges the significant and continuing health disparities between Aboriginal peoples and non-indigenous people in NSW and the commitment to closing the gap.(8) To establish innovative ways of delivering hospital care for the new Rouse Hill hospital that is culturally responsive, we sought to ascertain the Aboriginal community's views about cultural needs and experiences for hospitals of the future.

The catchment area of the new facility consists of 49 suburbs, comprising a land area of almost 500 square kilometres and an estimated population in 2019 of approximately 300,000 residents.(9, 10) The 2016 Census reported 0.9% of the Rouse Hill catchment area population identified as Aboriginal and/ or Torres Strait Islander, compared with 1.5% in Western Sydney Local Health District (WSLHD) and 2.9% of the NSW population.(11) While Aboriginal peoples make up a small portion of the population in the Rouse Hill area within the sacred lands of Darug territory, Aboriginal peoples experience a significant burden of ill health and issues accessing health services.(5) Critical to the success and effectiveness of health service delivery is the inclusion of Aboriginal peoples who live and will use the services in the research, design, development and ongoing operations of health services. Including Aboriginal experiences and perspectives will inform the culturally appropriate development of innovative acute and chronic care and support service delivery that addresses the delivery preferences and concerns of the community.

REPORT STRUCTURE

Commissioned by Health Infrastructure (HI) and the WSLHD, this report details the results of the Aboriginal community consultations, a collaboration between the Aboriginal community and the Australian Institute of Health Innovation (AIHI) to inform the design of the new Rouse Hill Hospital, situated on the sacred land of the Darug nation.

To best tailor the evidence from the literature to the Rouse Hill population, a demographic analysis was conducted to identify conditions prevalent in the Rouse Hill catchment. For Aboriginal peoples living in the Rouse Hill hospital catchment during 2018-2019, WSLHD reports the top nine principal diagnoses for hospital

presentations as single spontaneous delivery (i.e., childbirth) (4.6%), chest and throat pain (4.2%), abdominal and pelvic pain (3.5%), liveborn infants according to the place of birth (3.1%), ulcerative colitis (2.7%), cutaneous abscess furuncle and carbuncle (2.3%), other urinary system disorders (1.9%), hand and wrist fracture (1.9%), and foreign body in alimentary tract (1.9%). Recent Aboriginal population data indicates that 766 Aboriginal peoples (50.6% Male) live in the Rouse Hill area, constituting 354 households with a median weekly household income of $2,830).(12)

INNOVATIVE MODELS OF CARE

Before eliciting Aboriginal community members and providers needs and expectations, AIHI researchers undertook a grey and academic literature review of the evidence on innovative models of care.(2) Models of care describe alternative methods of healthcare delivery that differ in setting, type of care, provider, population, or patient experience.(13) The review identified six innovative models of care(2):

- Ambulatory care: Non-admitted services, diagnosis and treatment on the same day
- Digital Hospitals: New technologies to improve care
- Hospital in the home: Care is delivered in the patient's home
- Integrated care: Care delivered by interdisciplinary teams including primary care providers
- Virtual care: Consultation or care delivered over the telephone or video
- Specialist hospital: Selective care, targeted to specific conditions

AIM

This report aims to elicit the Aboriginal community healthcare needs (consumer and provider), expectations, understanding, perception and experiences concerning the new Rouse Hill hospital and the six identified innovative models of care.

Methods

This study employed a mixed-methods design. The study involved the synthesis of data derived from consumer and provider responses to a questionnaire and a culturally responsive methodology, yarning circles. The project was co-designed with AIHI researchers and led by two Aboriginal women employed by WSLHD. Early research team meetings identified potential barriers that might impact the ability of Aboriginal peoples to be meaningfully engaged. Before data collection, Aboriginal team members reached out to Elders groups for discussions to ensure they were appropriately consulted and an active part of the collaborative process. In addition, Aboriginal team members reported there are factions within the individual communities and all factions need to be individually involved. Therefore, this research involved visiting and speaking to Elders, community groups and providers meaningfully to facilitate engagement.

ETHICS

The Aboriginal Health and Medical Research Council of NSW Human Research Ethics Committee (HREC) approved the study (1870/21). The Western Sydney Local Health District HREC approved the study (2021/ETH00812).

RECRUITMENT

Communication with the Aboriginal community via networks (Figure 1). The project team, led by Aboriginal team members, reached out to the Elders within the community to explore if they and their community would be happy to be contacted to take part in a yarning circle. The project team also shared the project within their networks, colleagues and workplaces to invite the Aboriginal community to participate in the project.

Communication with the community via media and services. Aboriginal media organisations such as the Koori Mail Newspaper and Koori Radio were approached, as well as Aboriginal services in the Rouse Hill community to disseminate the project. The newspaper posting and radio collaborations included a phone number to ring to register interest.

Written communications such as emails and newspaper advertisements underwent a readability test before publication. The researchers also sought advice and support from the District Director for Aboriginal Health Strategy and Aboriginal service providers in the area to support engagement across the LHD of both consumers and providers.

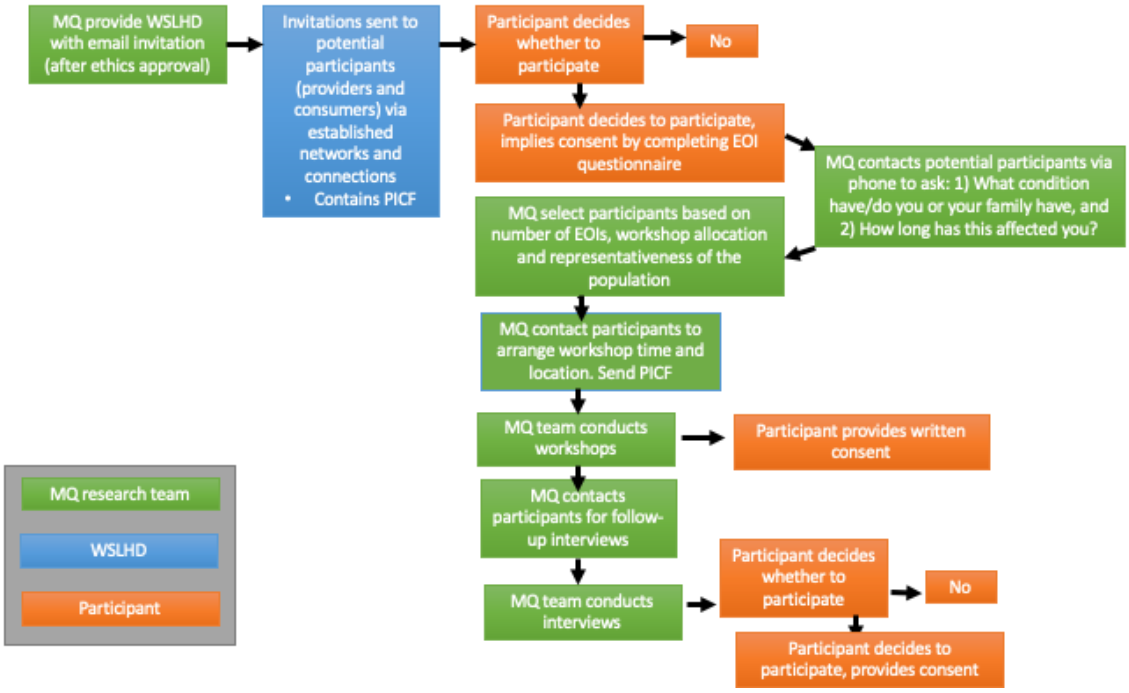

Figure 1. The recruitment process for Birang Daruganora

MQ: Macquarie University

CONSENT

For all participants who agreed to attend a yarning circle, we obtained written and verbal informed consent before the commencement. Disability was identified as a potential barrier that might affect the ability of Aboriginal peoples to be meaningfully engaged. We believe all people have a story to share and recognise that different strategies to support participation needed to be implemented depending on disability. The team took steps to include everyone who could provide informed consent whether their disability was physical, mental, hearing impairment, or vision impairment. For example, participants were provided with the information sheet beforehand accompanied by an explanation of the content. Any questions were answered on the day before informed consent was sought. Flexible participation options were also made available (regarding timing and place or telephone) to individuals living with disability.

YARNING CIRCLES

Yarning circles are a culturally appropriate method for data collection and involve a conversational process of telling stories, focusing on strengths and not criticisms or problem-solving.(14) Yarning circles are a collaborative way to communicate and provide a respectful place to be heard and to respond.(1) Figure 2 presents the Yarning Circle process as adapted from the Queensland Curriculum and Assessment Authority.(14)

Two streams of yarning circles were conducted, one each for healthcare providers and community members. Yarning circles were held in community centres, facilitated by two project team members and lasted up to two hours. Yarning circles started with a brief explanation of the study and the participant information and consent form, and the opportunity to ask questions about participation before completing the consent form. Following

consent, participants were asked to provide demographic and health information via the completion of a paper form. Where participants needed support, demographic and health form questions were read to participants and the supplied answers were marked on the forms by researchers. Cultural needs, experiences and models of care were explored and data was collected by AIHI researchers in the form of handwritten notes.

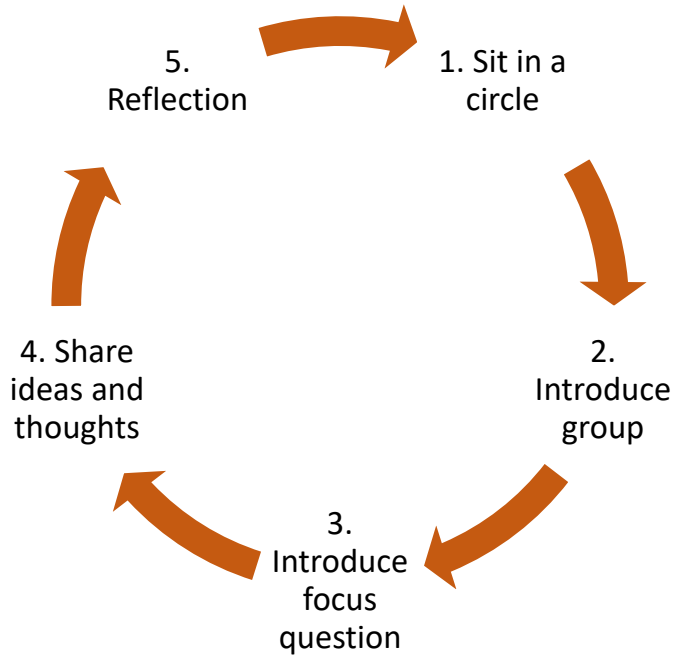

Figure 2. The Yarning Circle process (adapted from qcaa.qld.edu.au)

ANALYSIS

The demographic data were analysed using descriptive statistics and conducted in the Microsoft Excel package. Qualitative data were analysed using high-level inductive analysis to synthesise the expectations and needs of the health providers and community members of the Rouse Hill Hospital catchment. Yarning circle notes were independently coded by the research team. Through an iterative approach themes and subthemes that arose from independent coding were discussed, synthesised and incorporated into a framework.

Findings will ultimately be triangulated to inform the planning options and feasibility of implementation of the options for the development of the Rouse Hill hospital. This means checking, comparing and integrating the findings from the community and provider consultation with the literature, experts and relevant stakeholders (HI and WSLHD). Bringing together these data sources will enable us to identify the key elements for a service to simultaneously meet consumers' cultural and healthcare expectations whilst incorporating contemporary innovative and evidence-based models of care delivery.

Results

Two providers and 18 community members (14 female, 6 male) participated in the yarning circles. Figure 3 presents the age distribution of our participants. Yarning circle participants reported experiencing a range of health conditions and services including cardiac, pulmonary, orthopaedic, gastroenterology, trauma, metabolic, gynaecology and obstetrics, and mental health. Four participants reported being carers for individuals with cognitive, mental health, pulmonary and orthopaedic needs.

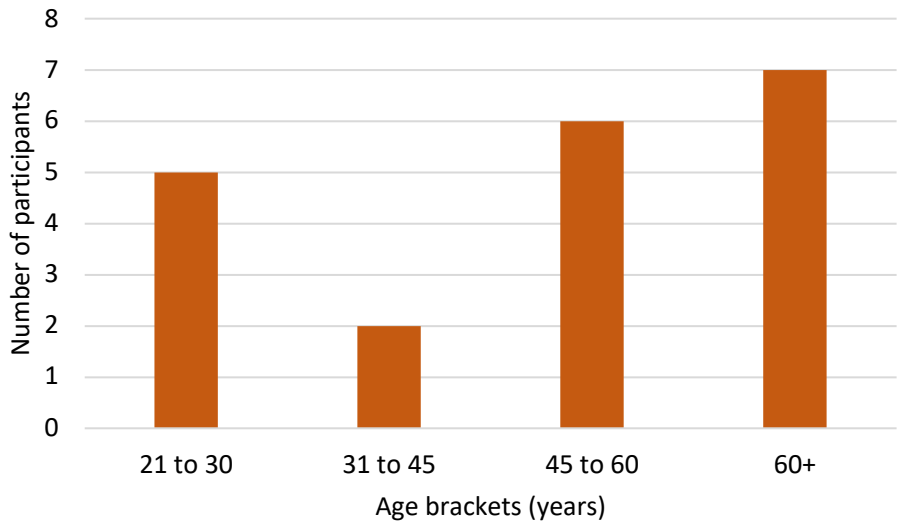

Figure 3. Age distribution of yarning circle participants.

Yarning circle participants identified as Aboriginal, Australian, or both (Figure 4). As two of the models require a level of consumer digital literacy (e.g., digital hospital and virtual care), community members were asked about their level of comfort using a smartphone, a smartwatch and a computer. Most of the community members were somewhat or extremely uncomfortable using smartphones, smartwatches, and computers (Figure 5).

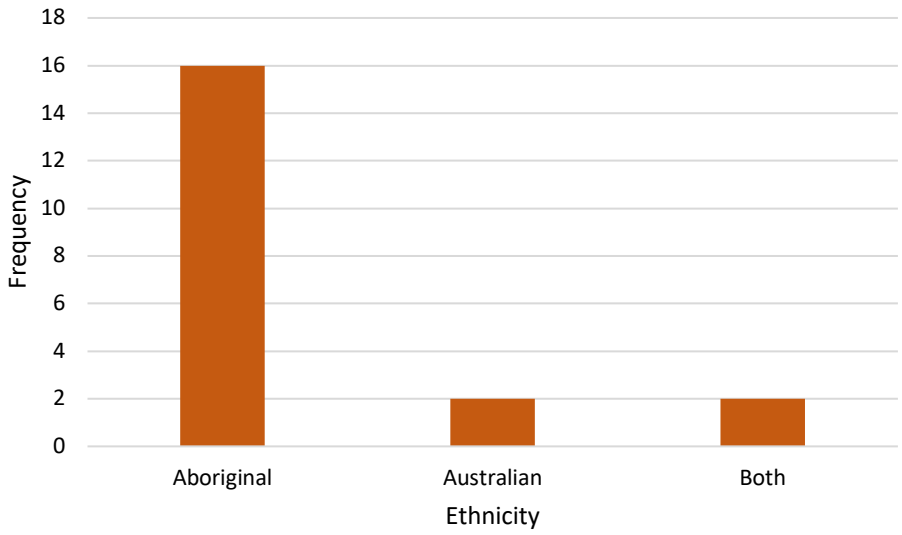

Figure 4. The ethnic identity of yarning circle participants.

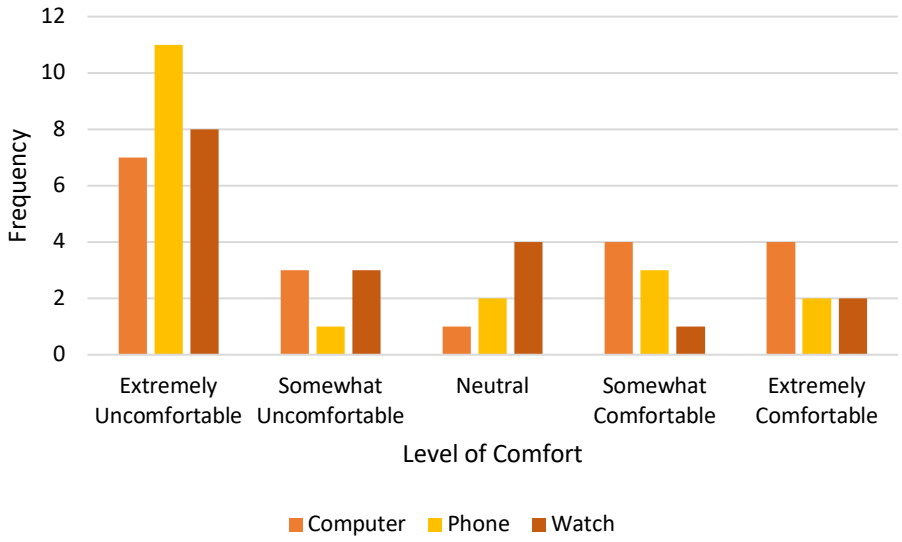

Figure 5. Yarning circle participants' level of comfort using digital devices.

Three primary themes emerged from the yarning circles – 'culturally responsive spaces', 'systems', and 'models of care'.

CULTURALLY RESPONSIVE SPACES

Yarning circle participants expressed the importance of the physical environment and the impact that the design of spaces has on their wellbeing. For example, spaces to walk and reflect including a garden with bush medicine plants, families to gather, and smoking ceremonies to be conducted. Hospital environments that use colour, shape and materials to create the perception of flow and demonstrate respect for culture provide a welcoming, happy and healing environments. It was important for the Aboriginal community to be a part of the design process. Other suggestions for creating culturally responsive spaces include the naming of units or spaces with

Aboriginal names, and including the Aboriginal flag onsite.

For Aboriginal peoples, the times immediately before and following death are subject to customary practices that are sacred. The provision of a space that allows them to practice their cultural and spiritual traditions and customs without the presence of other religions or churches is important to enabling culturally and clinically responsive care for Aboriginal patients and their families. Aboriginal families gather to support their loved ones when they are in hospitals or engaging with care services. Therefore, clinical spaces that have enough space for family to be present during care, as well as culturally appropriate and accessible accommodation, offsite or outreach service options and accessibility services (e.g., shuttle transport services) would ensure services meet the needs of the community.

CULTURALLY RESPONSIVE SYSTEMS

Aboriginal peoples are diverse people and must be recognised as comprising a range of distinct cultures with customary practices varying between and within tribal groups. Yarning circle participants expressed that, wherever possible, care services should be co-designed with their local community to ensure appropriate, accessible, culturally responsive care. Participants specifically reported the need for systems to support accessibility, identifying logistical issues including transportation and technology as constituting barriers to timely care. Transport logistics were often discussed as a barrier for patients who rely on public transport or family members to get them to and from medical appointments, or the cost of (and availability of) parking at the hospital. Participants identified possible solutions that could include a community shuttle service for patients in order to support them attending medical appointments at the hospital. Many expressed that current appointment/clinic systems required access to technology that they did not have or could not access (because they could not afford them) including smartphones and the internet.

Some suggested solutions include Aboriginal patient navigator roles to support patient's navigation of their healthcare journey, greater than currently in place staff-to-patient ratios, greater numbers of Aboriginal healthcare providers (where the workforce is predominantly female, more males) and easier access to services that are specifically geared to address Aboriginal peoples' health and cultural needs. These include diabetes, ear nose and throat, dental and acute care, as well as innovations in appointment systems that include non-tech options as well as enabling access to those who can't afford technology or moving towards drop-in clinics, and or access to free internet. Yarning circle participants discussed the idea of an Aboriginal health unit, open 24/7 that specialises in care that is culturally specific and staffed by Aboriginal clinical and professional staff. Patients would have the choice of whether to receive their care there or not. Related to choice is control, specifically over care, with participants expressing concerns about loss of control. Participants reported experiences of care being altered without consultation and not being heard when reporting that something went (or is going) wrong. While participants did not specifically mention racism, reflecting that their experiences could be just bad care experiences, these experiences of discrimination may stem from racism.

Representation is critical for engagement with care services. For example, the inclusion of Elders in hospital

management structures, pathways for Aboriginal and Torres Strait Islander peoples to enter care professions (e.g., internships), staff retention programs, and training and recognition of qualifications and skills to allow Aboriginal health providers to work (and be remunerated) to the full scope of their abilities. Participants highlighted the need for visibility of health service providers, in particular managerial personnel, to be visible to and connected with the community. For example, management team members visit community groups and organisations to connect with Elders. Participants also highlighted the need for the care they receive in hospitals to be linked with other service providers such as aged care, National Disability Insurance Scheme (NDIS) and offsite clinics to reduce the administrative burden on patients and their families. Finally, yarning circle participants identified an opportunity to improve the current method for providing WSLHD staff with cultural awareness training. It was felt that online training was not sufficient for non-Indigenous staff to develop an understanding of Aboriginal culture. They suggested that cultural awareness training should include face-to-face conversations with the local community and that they would be supportive of such a training model.

CULTURALLY RESPONSIVE MODELS OF CARE

The overarching preference was for care to be holistic, considering individual and cultural needs. Participants' perspectives on six evidence-based innovative models of care were explored.

Ambulatory Care

Ambulatory care involves non-admitted services, where patient care does not include an overnight stay and typically involves diagnosis and treatment on the same day. Examples of ambulatory care include same-day joint replacement and iron infusions.

Ambulatory Care Enablers

- Capable and caring providers
- Community transport
- Patient navigator
- Systems and processes streamlined

Source: Yarning circle participants

Yarning circle participants identified positive aspects of this care model might be that it is more comfortable than inpatient care as it reduces the time spent as an inpatient in the hospital. Some negative aspects of this model include barriers for Aboriginal community members including ease of access (e.g., insufficient parking, high cost of parking, lack of personal vehicle, poor public transport options), organising transport to and from if the family are unavailable, the need for repeat visits and the coordination of care delivery and delays (extensive waiting to see providers) both in time till appointment and on the day of the appointment.

Hospital in the Home

The hospital in the home model is where patient care and consultation which would normally be delivered in the hospital setting is delivered to patients in their own home. Examples of hospital in the home include early discharge hospital care at home for chronic obstructive airway disease managed by a community service.

Hospital in the Home Enablers

- Safety and security procedures are put in place
- Clear communication and communication pathways for patients and providers
- Required equipment is setup safely with 24/7 support available
- Adequate resources
- Aboriginal cultural training for healthcare providers

Source: Yarning circle participants

Yarning circle participants reported that this model of care would be more convenient and comfortable than inpatient care delivery models. Participants reported they would feel safer at home than in the hospital and could be cared for by some family members while continuing to provide care for others. Privacy was also felt to be better preserved with this model of care. Negative aspects and barriers related to this model of care included a lack of trust in the visiting healthcare providers and the patient's housing situation. For example, participants expressed discomfort with the idea of letting a provider into their home when it wasn't clean and tidy, when living in a share home, showed signs of poverty, or when there was not sufficient space for care delivery.

Integrated Care

The multidimensional needs of the patient are delivered in a coordinated manner by an interdisciplinary team or network of healthcare professionals. An example of integrated care is an orthogeriatric fracture service.

Integrated care Enablers

- Patient navigator or Aboriginal liaison officer to help patients successfully move through the system
- Access to information
- Communication systems
- Patient/family involved in decisions
- Inclusion of GPs as part of the team
- Handover planning for doctors
- Succession planning for when doctors retire or go on leave

Source: Yarning circle participants

Participants reported that this model of care would provide targeted, holistic care that addressed multiple needs and reduced the amount of waiting time they experience. With this model of care, participants felt they would have confidence in their care and that any concerns they expressed would be heard and acted upon. Participants were enthusiastic about the opportunity for effective communication between providers that this model might create. However, negative aspects of this model were discussed, such as the experience of paternalism, a sense of exclusion from care decisions and a lack of control or choice in the care itself and the way it is delivered. Participants worried that inaccuracies in health information (e.g., conditions, symptom type and severity, current medications, preferences) would exacerbate and create issues with accessing appropriate care. In addition, fears were expressed that wait times would increase and patients would find it difficult to access their doctor promptly. Participants reflected that because a lot of the work within this model is done between providers, this model requires a large amount of trust and that some community

members might find it difficult to communicate their personal experiences due to previous personal and family experiences of trauma during care delivery.

Virtual Care

Virtual care is patient care and consultation delivered through telephone or video communication media, for example, telehealth management in patients with heart failure.

Virtual Care Enablers

- Support person
- Pathways to enable equity
- Access to computer/ internet/ smartphone

Source: Yarning circle participants

Participants reported that the virtual care model would provide them with the benefit of being able to receive care remotely, in the comfort of their own space. Participants also reported that this model might be easier, faster and more convenient by eliminating the need to travel. However, participants also identified several negative aspects that represent significant barriers to accessing this model including, connectivity issues related to not owning or having access to a computer and experiencing stress when using technology. Stress could be increased due to consumers' limited digital literacy, especially if trying to troubleshoot under time pressure, such as when technology is not working before an imminent appointment. Participants also highlighted the concern that with this model, there is no physical examination. A physical exam provides time and space to 'open up' and reduces the patient's ability to be dismissive or negate issues. Therefore, without a physical exam, there is a real concern that things might be missed. Participants reported that community members with cognitive issues or Elders living alone might have trouble accessing this model without extra support.

Specialist hospitals and population-specific care units

Specialist hospitals provide selective care services for targeted patient groups. Population-specific care units are pathways within general hospitals dedicated to the treatment of specific conditions, for example, comprehensive cancer centres that provide cancer treatment.

Specialist hospital enablers

- Information (accessible)
- Accurate diagnosis
- Access to resources to support care
  - Patient navigator/ support person for patient and for family

Source: Yarning circle participants

Yarning circle participants reported feeling safe with this model of care. The reasons identified for this sense of safety were that things (i.e., clinical issues, signs and symptoms – known and unknown) might not get missed and that care in this model would be holistic care customised to the individual needs backed up by expert knowledge. In this model of care, it was felt that a higher level of care would be delivered than that currently provided in a hospital. Participants identified barriers related to choice and control; that is, they were concerned about whether adequate communication pathways would be available. Participants reported that transport to and from specialist hospitals was also a concern including public transport limitations, accessibility and affordability of parking, and constraints around a family's ability to support them to get to appointments. Participants expressed concern about the availability of options (i.e., choice or opportunity

to access the model or not) and what the alternative was if the service was not a good fit for them, as well as the potential for the focus of the care to be narrow rather than holistic.

Digital hospitals

Digital hospitals make extensive use of new technologies to provide streamlined care, improve patient safety and care quality, and improve overall care cost-effectiveness. For example, a digital hospital might provide a machine learning algorithm for the prediction of the early warning signs of cardiac arrest.

Digital hospital enablers

- Technology support
- Orientation to technology
- Shared tools for communication and health monitoring
    - Back-up systems, in case technology fails

Source: Yarning circle participants

When reflecting on this model of care, participants agreed that technology provided a means to help monitor health status and that this monitoring would be convenient, removing from the provider the manual load of collecting health information. Consistent with their concerns with the virtual care model, the digital hospital model raised worries about what happens when the technology fails, and the potential inflexibility of the system, as well as the safety of the data from hacking, including data privacy and ownership. Participants were concerned that some community members might not feel comfortable accessing this model due to a lack of understanding of the model. Participants also suggested that this model might not be suitable for all conditions and healthcare needs, with some conditions benefiting from less (or less visible) technology.

Discussion

For hospitals of the future to meet the needs of the Aboriginal community, they must be able to deliver care that is responsive to the needs of the individual's culture. Understanding that culture is central to how communities access care and that cultural knowledge and skills impact how care is delivered. To establish innovative ways of delivering hospital care for the new Rouse Hill hospital that is culturally responsive, we sought to ascertain the Aboriginal community's views about cultural needs and experiences for hospitals of the future. We identified three significant factors that shape how Aboriginal peoples access care. Across the physical spaces, systems and the six evidence-based innovative models of care, cultural respect and recognition, relationships and partnering, and capacity building were identified as necessary for hospitals of the future. The relationship between these factors can be understood with culture centrally placed and it is through relationships and partnering that capacity and engagement are built (see Figure 6).

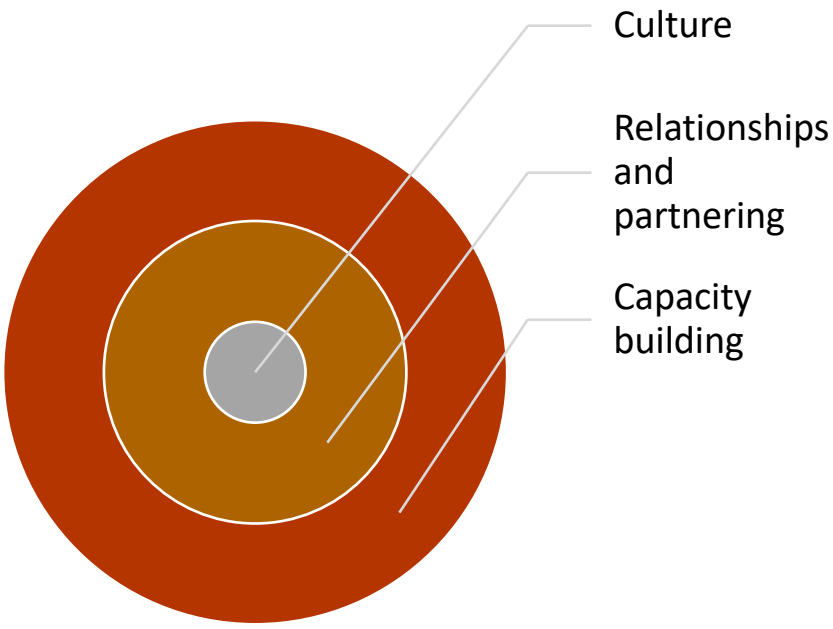

Figure 6. A framework for understanding the interaction between culture, relationships, and capacity building.

CULTURAL RESPECT AND RECOGNITION

There are differences between Aboriginal and non-Aboriginal perspectives on health, wellbeing, death and dying, as well as experiences with healthcare services. For example, for non-indigenous people, the hospital represents a place to treat health problems and heal. For Aboriginal people, hospitals can represent a place of trauma and exclusion. For example, one yarning circle participant reported "I remember my mother telling me about how they weren't allowed in the hospital, they were treated on the [hospital] veranda". Another participant reported not being provided with the full consent process for a procedure – he was in a bed next to

a non-Aboriginal person being consented and when the doctor came to his bedside the doctor said, “you heard that, didn’t you?”, meaning the patient was not consented appropriately. Recognising the impact of historical trauma and current experiences on how Aboriginal peoples access care is critical in developing strategies to address inequalities in health care.

For Aboriginal peoples, the desire to return to country is more important than staying in a hospital and receiving treatment for their disease. Recognition of the importance of connection to country and land is critical for hospitals of the future to meet the needs of Aboriginal peoples. For example, physical spaces such as gardens for reflection that include bush medicine, families to gather, and cultural ceremonies, as well as structures and systems that allow for families to provide support such as access to accommodation (at short notice) and transport. Flexible models of care, such as hospital in the home, virtual care and integrated care that link in with the community (i.e., Elders) and existing community services (e.g., pharmacy, community groups) that allow consumers to remain at home will be vital in meeting the needs of the community by a future hospital. It should be noted that technology-based models may create significant barriers to community members accessing services due to their inability to afford technology and internet access or their low digital literacy. Recognising that providing care is stressful, systems and structures that support (e.g., provide time and space) Aboriginal healthcare providers connect with an Elder to debrief and heal as part of their role would ensure staff feel their culture is recognised, respected and valued.

RELATIONSHIPS AND PARTNERING

Aboriginal peoples have not always experienced the same level of access to healthcare as non-Aboriginal Australians.(5) A key aspect of addressing this inequality in future hospitals is through forming meaningful relationships and partnering, not just with patients and their families at the time of care delivery, but with Elders and community groups to ensure the delivery of care is culturally responsive and linked with community. Yarning circle participants reported the importance of hospitals establishing relationships with Elders and community groups and partnering with them on the design and delivery of care to ensure services and care delivery processes reflect their cultural values, roles and responsibilities. For example, embedding a community Elder into hospital management structures where their role is not to be ‘management’ but function as an Elder, would better connect the community with health services and ensure culturally appropriate services are established (e.g., models of care that meet community needs) and accessed by the community. Similarly, yarning circle participants suggested the development of an Aboriginal Health Unit. Community members could choose to access care through the unit which would be staffed by Aboriginal providers.

Respect and rapport are critical for partnering with patients, their family and the community in service delivery. Existing support roles such as Aboriginal Liaison Officers (ALOs) are critical in providing emotional, social and cultural support and assistance to Aboriginal inpatients and their families. Similar roles to support the access the evidence-based innovative models of care were identified by participants including technology support and a

patient navigation support role. Connecting with community-based services, such as hospital management visiting the community, was also identified as a critical pathway for bridging the gaps between hospitals and the community and collaborating on improving the health and well-being of the community.

CAPACITY BUILDING

Aboriginal peoples' trust in health services has been impacted by colonisation, religion, and past government policies where their cultures were systematically suppressed as western systems and religions were imposed including dislocation, assimilation, segregation and removal of children.(15) These factors make representation in healthcare professions critical for addressing the resulting inequalities and ensuring hospitals of the future meet the needs of Aboriginal peoples. Care that is led by Aboriginal peoples for Aboriginal peoples builds trust and capacity. This involves creating pathways that foster Aboriginal peoples entering health professions after they finish school (e.g., internships), staff retention programs and pathways for growth, recognition of qualifications and expertise through remuneration and integration into multiple healthcare units. Current cultural awareness training was identified as a potential opportunity for growth and connection. Providers and consumers reported a need for cultural awareness training to move beyond online training to include conversations with the community to enrich non-Indigenous Australians understanding of Aboriginal experiences and needs as well as the role culture plays in health.

Access to technology, now and in the future, is a critical factor when considering implementing innovative models of care. Participants reported difficulties in affording technology such as computers, smartphones, and tablets, as well as internet and telephone services. For example, some participants reported not owning smartphones or having access to a computer and the internet. Coupled with this lack of access to technology is participants' reported discomfort with technology. Participants reported concerns about their inability to troubleshoot if something goes wrong with technology or knowing who will help. Participant age and literacy level may contribute to their discomfort with technology. Models where technology is integrated into care delivery, such as Hospital in the Home, virtual care, and the digital hospital will not be accessible for those without technology.

PLACING THE FINDINGS OF BIRANG DARUGANORA IN THE CONTEXT OF THE ROUSE HILL HOSPITAL DEVELOPMENT

This mixed methods study has considered the needs and experiences of the Aboriginal community in Western Sydney for hospitals of the future. The community have identified a variety of needs, barriers, and preferences for the community in the Rouse Hill catchment. For the development of Rouse Hill, it is imperative to note that collaboration (i.e., consultation, co-design, inclusion) with the Aboriginal community in the design,

development, and ongoing operation of the Rouse Hill Hospital is critical for care if it is to be culturally responsive and accessible, and the subsequent health outcomes of the Aboriginal community to improve.

CONCLUSION

To deliver care that is responsive to Aboriginal needs, the physical spaces, systems and models of care should be developed with Aboriginal peoples. Collaborating with the Aboriginal community on the design and development of hospitals of the future will help ensure culture is respected and recognised in the delivery of care, care is holistic and connected with the community, and the capacity of future Aboriginal healthcare providers is fostered. Common characteristics of consumer needs for evidence-based innovative models of care include technology support and orientation, service navigation support, caring people, access to technology (i.e., computer, phone, internet) and transport, and space for family and Elders to be included in care.

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