

Report Summary

Not a postcode lottery: What Queensland First Nations and non-Indigenous rural, remote & regional consumers want from their health care in 2023





The Board and staff of Health Consumers Queensland and CheckUP acknowledge Aboriginal people and Torres Strait Islander people of this nation. We acknowledge the Traditional Custodians of the lands on which our organisations are located and where we conduct our business. We pay our respects to ancestors and Elders, past, present and emerging for they hold the memories, traditions, culture and hopes of Aboriginal people and Torres Strait Islander people.

We acknowledge that sovereignty was never ceded.

Report written by Cas Nest of Nangu First Peoples Health Consulting for Health Consumers Queensland in 2023.

These consumer engagement activities were supported by funding from the Australian Government Department of Health.

Use of term First Nations.

The author has chosen to use the term First Nations to refer to Aboriginal people and Torres Strait Islander people throughout this document. The author recognises and respects the differing opinions held by Aboriginal people and Torres Strait Islander people about the terminology used to describe their culture and has chosen the term First Nations for inclusivity. The author recognises the differences between Aboriginal people and Torres Strait Islander people and the diversity within language groups, clans and tribes within Australia.

Warning to First Nations readers:

This report contains the personal stories of First Nations health consumers and as such may cause triggering due to vicarious trauma.

Photography: Biren Cultural Group Dancers by SJ Campbell Photography.

Indigenous artwork: "A connected community" by Leah Cummins.



Background

Through the Outreach programs CheckUP undertakes an annual health service planning process to identify consumer priority health needs across Queensland. To understand both First Nations and non-Indigenous rural, remote, and regional consumers' healthcare experiences, CheckUP enlisted Health Consumers Queensland (HCQ).

Queensland's First Nations and non-Indigenous rural, remote and regional health consumers suffer disproportionate health outcomes to their metropolitan counterparts. Health care services across rural, remote and regional Queensland are limited, are provided by either fly-in-fly-out services, or consumers are required to travel to their closest urban area for treatment.

In peer-led consultations facilitated by Health Consumers Queensland, health consumers said these factors negatively impacted their health care experience causing undue stress. This impacts on their quality of care, continuity of care and increases wait times. The complex nature of fly-in-fly-out services and the lack of communication between health care

services and the local community was reported to cause mistrust and frustration as consumers do not know what services are available and when they are available in their community.

Consumers believe that their health and wellbeing and health care experiences could be improved by addressing the social and cultural determinants of health that have a potent and underlying causal effect on their health and wellbeing. Factors such as socioeconomic position, food stability, social support for carers, education and health literacy, system access, transport and travel considerations were raised as concerns that undermine the health and wellbeing of people within their communities.

Yarns from First Nations consumers revealed instances of mistreatment, disrespect and negligence which were not discussed by their non-Indigenous counterparts. This infers individual and institutional racism and implicit bias impacted their experiences of health care. The adverse impact of unaddressed needs on First Nations people's health and wellbeing in rural, remote and regional areas is exacerbated by culturally unsafe care.

Key Themes

This summary report is broken down into key themes.

First Nations First - Key themes identified by First Nations consumers

Overall themes - Key themes identified by all rural, remote and regional consumers (including First Nations consumers).

About CheckUP

CheckUP is a not-for-profit organisation dedicated to better health for people and communities who need it most. CheckUP is proud to administer Outreach Programs on behalf of the Australian Government Department of Health as the jurisdictional fundholder in Queensland. With the support of over 140 contracted health providers, we lead a strong, effective consortium that is committed to improving access to a wide range of healthcare services for people living in urban, rural, and remote locations and Aboriginal and Torres Strait Islander communities.

About Health Consumers Queensland (HCQ)

HCQ is the peak organisation representing the interests of health consumers and carers in the state. HCQ's priority focus is on consumer engagement that influences and leads improvements, and delivers better health outcomes for all Queenslanders by amplifying consumers' voices and advocating for consumer representation at all levels of the health system.



Methodology

HCQ used an evidence-based consumer engagement methodology called kitchen table discussions, and yarning circles (for First Nations hosts and participants), to hear rural, remote and regional consumers' voices. The methodology is led by consumer hosts within their own communities and enables health consumers who do not ordinarily participate in healthcare consultations to have their say in a safe, informal, and supportive environment.

HCQ equipped hosts with the tools and training necessary to facilitate these sessions and remunerated them, and their participants for their time. Hosts gathered up to 10 consumers to hear their experiences of accessing

health care in rural, regional and remote communities, de-identified this feedback and provided it back to HCQ. HCQ's First Nations engagement and partnership consultant then collated and themed the feedback to ensure participants stories were correctly and appropriately reported back to CheckUP, to inform best practice for health and wellbeing services across Queensland.

Due to the nature of CheckUP's outreach work, consumers were not aware what services were supported by CheckUP specifically and therefore participants shared experiences from a variety of different services.

Yarning circles and kitchen table discussions demographics

Number of consumers consulted (including hosts): 62

Kitchen Table Discussions

Seven consumers/carers with strong community connections were recruited to host either a kitchen table discussion or yarning circle with members of their local community in May 2023.

Kitchen Table Discussion Locations:

Ravenshoe, Toll (near Charters Towers), Boulia, Kingaroy (represented on the map with a blue dot)

Yarning Circle Locations:

Palm Island, Home Hill, Cherbourg (represented on the map with an orange dot)

Participant Demographics:

- Rural and remote
- Regional
- First Nations
- LGBTQI+
- Caring for someone with a disability
- From a non-English speaking background
- Living in a residential aged care facility





What First Nations consumers want

I. We want culturally safe care and culturally safe health care systems.

Cultural safety was considered by all yarning circle participants as an important factor that impacts on their health care experience and encompasses many factors dependent on the individual and their unique community.

"You can tell when doctor, nurses and health staff are culturally aware or don't have experience in living and working in Aboriginal communities. There should be cultural awareness training for staff coming to [our community] — to help them understand the history of [our community] and why our mob are the way some of them are."

2. We want to be treated with respect.

Respectful communication and respect for personal boundaries was discussed by First Nations consumers as important in making them feel heard and valued. Non-Indigenous consumers did not mention respect when discussing their health care experiences.

One yarning circle yarn focused strongly on the respect of children and infants. It is important to note that within First Nations culture children are the future Elders and power is distributed equally among the community and includes the rights and responsibilities of children and infants.

3. We want sovereignty, self-determination, and stewardship in health.

First Nations sovereignty is the acknowledgment of First Nations people's custodianship of land since time immemorial and includes First Nations people being in control of their holistic view of health which encompasses not only themselves but their whole community.

The recommendations from yarning circles move towards First Nations stewardship where decisions about First Nations people's health are no longer at the remit of non-Indigenous health care practitioners but the responsibility of the individual. They want education and treatment that considers their holistic view of health to make informed decisions.

"Doctors shouldn't just prescribe drugs — more needs to be done to investigate and educate our mob on what it is and why we need to take it. Even more should be done to try and show our people how to naturally heal ourselves."

"More education so that the patient understands the diagnosis, they have all the information about the disease, medication and pros and cons. So we can make informed decisions."

4. We want a well-resourced First Nations workforce.

First Nations people want to be treated by more First Nations staff who are upskilled to provide care that is specific to their community's health concerns. First Nations consumers shared that identified staff improved communication between them and non-Indigenous health professionals while assisting with navigating health care systems.

5. We need culturally safe ways to make complaints.

A conversation limited to First Nations consumers in one yarning circle was the unclear process for raising complaints. First Nations consumers noticed that there was a difference in the promotion of complaints procedures between their rural and remote community and metropolitan services. This lack of visibility leaves First Nations people feeling unheard and that the cycle of mistreatment is perpetuated. It was evident from yarns between First Nations people that a culturally safe way to raise complaints should be considered for each individual community.

"Knowing how to give feedback or access the complaints service. I don't feel like we have knowledge on how to go through the complaints process. It doesn't seem to be advertised or placed around the health buildings so that we know what to do or who to go to and where do we start when we leave the hospital or primary health centre with a bad experience."

"When we don't know how to complain, we feel unheard. And things aren't made better for the next person."



What all rural, regional and remote consumers want

I. We want better communication between health care services and community.

This communication impacted people's awareness of available services, leading to adverse outcomes and health issues. Consumers expressed that they became aware of preventive programs only when they were already in a state of crisis, resulting in a loss of trust in the healthcare system.

2. We want care in our community.

Consumers discussed feeling helpless and that they had no other options for care when care did not meet quality standards.

"I am afraid of leaving home. A lot more services could be utilised at [closest town] to come here occasionally. We all (murri people) don't like to leave our Country because we might never come back."

"We have no options or anywhere else to go but take what we are given, and if we don't like it then miss out." "It takes guts to ask for help and that's all we have heard about, "its ok to ask for help..." but it's like a kick in the guts when you get the guts to do it, and there's just nothing."

3. We want more services to reduce wait times.

The lack of services within communities caused long wait times which prevents people from accessing services in a timely manner and has a negative impact on their health and wellbeing.

"Waiting times for doctors are also a little thing that causes big ripples. People find it hard to get into a doctor so they just don't go so their chronic diseases get worse."

4. We want easily accessible transport systems.

The availability of transportation had a positive impact on consumers' experiences; however, the challenges and burdens associated with travel were raised as significant concerns. Consumers expressed frustration about missing appointments due to inadequate consideration of travel times and the lack of flexibility from healthcare providers when transport services were delayed. Navigating transport services and travel subsidies was deemed difficult and caused unnecessary stress and fatigue.

"Having to travel for chemo and radiation is a sadistic torture for daring to get sick. Why can't we get that help here? There is no good side to the health care service here in our rural town."

5. We want health care professionals who care.

Consumers want person-centered care from health care workers who are skilled in their profession and provide quality care. They want health care workers who ask their name, they want to feel heard and they do not want to feel rushed through appointments. A number of consumers voiced that not feeling heard made them feel like an inconvenience and prevented them from accessing care.

"You need to be able to assess the person and look at how they are talking, their body language. Not just go off a sheet of paper, which is what I have seen and experienced."

6. We want continuity of care.

Frequent staff turnover and reliance on fly-in-fly-out workers hindered consumers' ability to establish meaningful connections with healthcare providers which had a detrimental effect on their overall healthcare experience.

"It just feels like everyone wants to leave. Even doctors. We get a good doctor and they leave as well."

7. We want meaningful co-design.

Consumers want co-design that makes them feel comfortable to share without fear, judgement or shame. They want actions to be taken from the feedback provided and for this to be relayed to the participants (close the feedback loop). Consumers valued small groups as everyone has an opportunity to share, and thought that using a mixed methods approach of both survey and small yarning circle or kitchen table discussions would facilitate the best collaboration.

"We heard, you said, we did"

The HCQ CheckUP kitchen table discussions and yarning circles report gathers stories, feedback and yarns on consumers experiences of accessing health services across rural, remote and regional Queensland. This report highlights that the health and wellbeing of Queensland rural, remote and regional residents is directly and indirectly impacted by the social determinants of health, and that their experiences of health care moves beyond direct patient-provider and into the broader health care system functions.

By incorporating patients' experiences, needs, and preferences into the design process for outreach services, meaningful co-design can foster more personalised, effective, and satisfying health services. Involving consumers as co-designers can bring fresh insights into health care delivery, challenge traditional assumptions, and lead to innovative solutions. This collaborative process can improve consumer engagement, health outcomes, and overall system efficiency by creating outreach services that better meet patients' needs and expectations.





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