

# BMJ Open “Should be a dynamic tool”: Aboriginal and Torres Strait Islander primary health care service staff perspectives on an effective patient reported experience measure (PREM) in Australia – a qualitative study

Amal Chakraborty ,<sup>1</sup> Emma Walke ,<sup>1</sup> Alison Frances Laycock ,<sup>1</sup> Tracey Piccoli ,<sup>1</sup> Veronica Matthews ,<sup>1</sup> Rachel Walpole,<sup>2</sup> Ross Bailie ,<sup>1</sup> Paul Burgess,<sup>3</sup> Erika Langham,<sup>4,5</sup> Sarah Larkins ,<sup>6</sup> Roxanne Bainbridge ,<sup>5</sup> Bena Brown ,<sup>7</sup> Bronwyn Silver ,<sup>2</sup> Girish Swaminathan ,<sup>8</sup> Samantha Smorgon ,<sup>9</sup> Nalita Turner,<sup>1</sup> Megan Passey ,<sup>1,10</sup>

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For numbered affiliations see end of article.

## Correspondence to

Dr Amal Chakraborty;  
amal.chakraborty@sydney.edu.au

## ABSTRACT

**Objectives** The Validating Outcomes by Including Consumer Experience (VOICE) project is developing patient reported experience measure (PREM) tools to collect consumer feedback for Indigenous primary healthcare (IPHC) services’ accreditation and quality improvement processes. This study aimed to explore the views of health service staff about: (1) optimising the feasibility of collection, analysis and interpretation of findings; and (2) resourcing requirements for implementation of the PREM.

**Design** A participatory action research qualitative study design, guided by an Indigenous advisory group. Our team of Indigenous and non-Indigenous researchers conducted semistructured focus groups and individual interviews with IPHC staff. Focus groups and interviews were recorded, transcribed and thematically analysed. Multiple sense-making meetings were conducted with the Indigenous advisory group.

**Setting** Eight partner IPHC services across four Australian states and territories.

**Participants** All staff were eligible and invited to participate in the study via purposive and snowball sampling. Administrative staff (eg, receptionist, programme facilitator), clinicians/practitioners (eg, general practitioner, nurse, Aboriginal and Torres Strait Islander health workers and practitioners) and service managers (eg, CEO, practice manager) from partner health services participated.

**Results** 63 staff participated; 44 attended across 13 focus groups, with the remainder participating in individual interviews. The majority of participants were between 35 years and 55 years old (52%), female (66%) and working in frontline IPHC service delivery roles (56%). Equal numbers identified as Indigenous (50%) and non-Indigenous (50%). Many had worked in the Indigenous health and well-being sector for over 10 years (40%). ‘Culturally safe care’ and ‘accountability’ were identified as primary themes and key reasons for gathering consumer feedback. Subthemes identified were ‘Relationships’, ‘trust

## STRENGTHS AND LIMITATIONS OF THE STUDY

- ⇒ This study was conceived through discussions with Indigenous primary healthcare (IPHC) services and policy partners and initiated at their request to design and implement a PREM to appropriately capture Indigenous consumer perceptions of their healthcare.
- ⇒ The study embodied the principles of co-design and Indigenous data sovereignty. All data collection, analysis and feedback processes were led by Indigenous research team members in collaboration with the Indigenous advisory group.
- ⇒ The inclusion of participants from diverse geographical settings with extensive experience working in the IPHC sector added richness to the findings and may be generalisable to wider health service delivery contexts.
- ⇒ There may be some selection bias, as purposive sampling and snowballing were used in an existing network to recruit participants from IPHC services partnering in the VOICE Project.
- ⇒ Social desirability bias cannot be ruled out, as participants were asked to share their perspectives from their experience of working with the partner health services.

and respect’, ‘communication about consumer feedback’, ‘timing and frequency of requesting consumer feedback’, ‘health service systems’, ‘health service and staff capacity’, ‘staff skills’ and ‘structure and administration of the PREM’. All themes and subthemes need to be considered for the successful design and implementation of PREMs in IPHC settings.

**Conclusion** Many of the issues identified are not currently considered in the process of collecting PREM data for accreditation yet, if addressed, would likely improve the

quality and relevance of data collected. The findings from this study will inform the co-design and validation of Indigenous-specific PREM tools to collect consumer feedback. Critically, service and community input will ensure the PREM tools meet service needs for continuous quality improvement and accreditation and reflect the priorities and values of Indigenous peoples.

## INTRODUCTION

Australia is home to the oldest continuing cultures on Earth,<sup>1</sup> where Indigenous knowledge systems have survived for more than 60 000 years. As Indigenous knowledge, including that of health and well-being, is holistic and relational, the environment (land, sea and sky) and people's place within where they live are intertwined.<sup>2</sup> Consequently, the experiences of healthcare for Indigenous peoples are shaped by historical, social, environmental and cultural factors.<sup>3,4</sup> The ongoing inter-generational trauma resulting from the legacies of colonisation, disruption of family and kinship, loss of language and culture, dispossession of lands and social marginalisation continues to impact the experiences and well-being of Indigenous peoples globally, including Aboriginal and Torres Strait Islander peoples in Australia (*hereafter respectfully referred to as Indigenous Australians*).<sup>5</sup> For Indigenous Australians, good health is not just a matter of having access to biomedical services or the absence of a disease, but also the holistic well-being of the community and the environment, essential for strong kinship and culture.<sup>6</sup>

Increasing engagement of Indigenous communities with comprehensive primary healthcare (PHC) is critical in addressing health disparities between Indigenous and non-Indigenous Australians.<sup>7–9</sup> Better patient experiences of care are associated with improved engagement and health outcomes, efficient use of healthcare resources and fewer adverse events.<sup>10–12</sup> Continuous quality improvement (CQI) processes, informed by patient reported experience measures (PREMs), enable services to identify and act on areas in need of improvement and to monitor changes over time.

A PREM is often questionnaire-based and defined as a 'measure of a patient's perception of their personal experience of the healthcare they receive'.<sup>13</sup> Patient-reported indicators are increasingly valued by policymakers for decision-making, benchmarking and value-based purchasing and are also used by healthcare organisations to measure health systems' performance and service delivery.<sup>14,15</sup> Therefore, healthcare experiences of Indigenous Australians are critical to understanding and redressing existing healthcare inequities.<sup>16</sup> The benefits are also optimised when the experience data collected reflect the gaps in what care is delivered by health services and how patients/clients (*hereafter 'consumers'*) experience care and provide 'actionable' information to support CQI.

Routine collection and use of PREMs is a policy goal and a mandatory accreditation requirement within the Royal Australian College of General Practitioners' (RACGP) Standards for general practices.<sup>17</sup> Hence, Australian PHC

services, including Indigenous PHC (IPHC) services that choose to be accredited against the RACGP Standards, are required to collect consumer experience data to comply with national health quality and safety standards. However, the currently mandated PREM used by IPHCs contains no questions that address cultural security or experiences of racism or discrimination. It is known that culturally unsafe practices and racism are commonly experienced by Indigenous Australians in healthcare settings<sup>18</sup> and are associated with disengagement from health services, poor chronic disease management and poorer mental and physical health.<sup>3,19</sup> Various PREM tools are available to measure consumer experiences in different healthcare settings, including Australia.<sup>13,20,21</sup> They are generally underpinned by Western healthcare service models and do not capture the complexity and diversity of IPHC settings.<sup>22</sup> Consequently, the tools do not adequately capture important holistic experiences of care of Indigenous Australians, nor return information that is meaningful for improving IPHC service delivery.<sup>23,24</sup> Recently, frameworks have been developed for Indigenous-specific PREMs that privilege Indigenous voices, practices and values.<sup>25–29</sup> Some of these frameworks identify the foundations of Indigenous health and well-being. Others offer protocols and guidelines for framing survey questions. None of these frameworks has yet been tested in Australian IPHC settings.

The 'Validating Outcomes by Including Consumer Experience (VOICE)' Project was conceived through discussions with IPHC services and policy partners in Australia and initiated at their request to address this vital gap and develop new PREM resources.<sup>30</sup> The VOICE Project recognises that self-determination and community control of health services, including input to service design and delivery, are important for individual and community well-being.<sup>3,29,31,32</sup> Indigenous consumer and health service participation in the VOICE Project will lead to the development of a community-led PREM tool that can inform practice and enhance the quality of healthcare delivery locally.<sup>26</sup>

This article addresses one of the aims of the VOICE research project, to engage with IPHC service staff in Australia to determine their views on the new PREM that is being developed, including how to: (1) optimise the feasibility of data collection, analysis and interpretation of findings in this unique setting; and (2) resource requirements for the PREM's implementation.<sup>30</sup> Findings about consumer views on the PREM will be published separately. The Standards for Reporting Qualitative Research<sup>33</sup> have been followed to report on the results of our engagement with staff members from partner health services across Australia.

## METHODS

### Overview of research approach and design

This study is one of the foundational studies within the larger VOICE Project, which uses a participatory action

research design and draws on research approaches from both Indigenous and Western knowledge systems.<sup>6 34</sup> Recognising the need for mechanisms for community-led healthcare improvement, the VOICE Project was conceived through discussions with IPHC services and policy partners and initiated at their request. We undertook cyclical data collection, analysis and dissemination of the findings in several phases for this study. Each participating service was initially visited by the research team prior to any data collection to optimise community and staff engagement. Meetings were held with key service staff, the service board (or other relevant advisory group) and with other community leaders and groups consistent with local protocols and cultural norms. To maximise benefit to communities and services, local site feedback mechanisms were established to share and consider findings at several points throughout data collection and dissemination. The learnings from this process will be further enhanced through a combined 'service learning' workshop in early 2026, where services will consider and respond to commonalities and differences across the sites.

An Indigenous advisory group, comprising Indigenous staff members from partner IPHC services and their peak bodies, and community members from each project site,

provided cultural governance and contributed to data analysis and interpretation. The advisory group met quarterly online and in person once a year to discuss the study progress and advise on community engagement and participant recruitment, determine research questions and methodologies to be applied and disseminate findings. The advisory group was also engaged in data analysis and interpretation of the findings. Members welcomed and appreciated the opportunity to bring their lived experience, practical knowledge and community-first approach, and contributed meaningfully to the ongoing success of the study. A project management group provided operational oversight. The detailed study protocol of the VOICE Project has been published elsewhere.<sup>30</sup>

### Context and settings

The VOICE research project builds on over 20 years of applied quality improvement research involving IPHC providers, policymakers and researchers in Australia.<sup>35</sup> Figure 1 below shows the locations of project sites depicted by circles on the Australia map. The eight sites are in New South Wales (NSW), Queensland (QLD), South Australia (SA) and the Northern Territory (NT). Sites include



**Figure 1** Location of VOICE Project sites across Australia. VOICE, Validating Outcomes by Including Consumer Experience.

**Table 1** Types of partner health services involved in the VOICE Project.

| Service | Service type                    | Location                          | State/territory |
|---------|---------------------------------|-----------------------------------|-----------------|
| 1.      | Indigenous community controlled | Remote town with outreach clinics | NT              |
| 2.      | Indigenous community controlled | Remote town with outreach clinics | QLD             |
| 3.      | Government managed              | Remote isolated community         | NT              |
| 4.      | Indigenous community controlled | Remote isolated community         | NT              |
| 5.      | Indigenous community controlled | Metropolitan                      | SA              |
| 6.      | Government managed              | Metropolitan                      | QLD             |
| 7.      | Indigenous community controlled | Regional town                     | NSW             |
| 8.      | Indigenous community controlled | Regional town                     | NSW             |

NSW, New South Wales; NT, Northern Territory; QLD, Queensland; SA, South Australia; VOICE, Validating Outcomes by Including Consumer Experience.

community-controlled and government-managed IPHC services in remote, regional and metropolitan settings.

Additionally, refer to [table 1](#) for the types of partner health services involved in the VOICE Project.

### Population and sampling strategy

Purposive and snowball sampling techniques were applied to recruit participants. All staff members involved in consumer interaction, health service accreditation, management and research and evaluation were eligible to participate. Administrative staff, clinicians/practitioners, research and evaluation officers and service managers from partner health services were invited to engage in focus groups or individual interviews, according to their preference. Potential participants were sent an open invitation by local study champions at our partner health services, emphasising that participation was entirely voluntary. Different approaches to recruitment were used in different settings, consistent with local organisational norms.

### Data collection methods and timing

All eight partner IPHC services were engaged in two rounds of data collection between August 2022 and November 2024. In *Round 1*, primary data were collected through focus groups and/or individual interviews with health services staff to ensure a comprehensive understanding of issues and that all participating services were engaged. Data saturation was deemed to have been reached after no new information emerged at the sixth site. However, data saturation was re-assessed across the sites to ensure that the data captured represented the diversity of settings and contexts of participating services. Following preliminary analysis, we returned to each service in *Round 2* between May and November 2024 to share the results and check our interpretation of findings (eg, are findings correct?, have we missed anything?). This provided an opportunity for clarification, further sampling and identification of additional issues, although none emerged. The extended data collection and feedback period was necessary for meaningful engagement between the research team, communities and health

services involved. The duration of site visits ranged from 2 days to 5 days.

*Obtaining participant consent:* during the participant recruitment campaign, service staff expressing interest in participation were given a participant information sheet (PIS), explaining the project and emphasising that participation was voluntary and they could withdraw from the study at any time during data collection. The study purpose, participant involvement and confidentiality agreement were also explained, and questions were invited. At the beginning of data collection, those interested were again given a copy of the PIS with a verbal explanation by the lead Indigenous research team members. They were encouraged to ask questions to ensure clarity and understanding of the purpose, the process and expectations. Written consent was sought from each participant using a plain language consent form.

### Data collection tools

Before commencing each focus group/interview, participants completed a brief questionnaire about their age, gender, cultural identity, length of time working in IPHC and position in the organisation. A semistructured focus group/interview guide was used to explore a PREM's meaningfulness and feasibility for the service's CQI and accreditation needs, and how to effectively implement the proposed PREM. The questions in the guide were brainstormed within the research team and trialled with Indigenous and non-Indigenous research team members, including those with experience in the IPHC sector. The questions were slightly adjusted after the first data collection site visit based on the facilitation experience. All focus groups and interviews were audio recorded and transcribed verbatim using a cloud-based voice transcription software, Otter AI (<https://otter.ai/>). The research team de-briefed after each day of data collection, with notes taken and used in data analysis.

### Data processing

Focus group/interview transcripts were de-identified. Research team members (AC, EW, MP, TP, VM and NT) who were present during respective data collection

sessions listened to one or more of the audio recordings and cross-checked/corrected transcripts to ensure accuracy.

### Data analysis

The data were analysed following Braun and Clarke's reflexive thematic analysis guidelines.<sup>36 37</sup> Reflexive thematic analysis aided critical self-reflection while engaging with the data to ensure true reflection of what participants had said. All transcripts were read repeatedly by research team members (AC, EW, MP, TP, VM and AFL) to familiarise themselves with the data. Then, a hierarchical coding structure (*see* online supplemental file Box S1) was developed, based on the research questions, after reading through all the transcripts. A deductive-inductive technique<sup>38</sup> was applied to code the data line by line using NVivo qualitative data analysis software (Q.S.R. international, NVIVO V.11). In this process, the parent codes and subcodes were generated by capturing segments of raw data and organising them into meaningful groups as per the preconceived coding structure, which was reviewed iteratively throughout the analysis. This process continued until no new codes were identified. Any discrepancies were resolved through the verification of transcript data and discussions among research team members. Recurring data patterns and themes were identified using the constant comparison method.<sup>38</sup> Workshops were held to analyse the facilitator team's de-briefing notes, review the coded data, identify and refine themes, identify illustrative 'anchor' quotes and generate a visualisation of the interrelationships between the themes. These interrelationships were analysed and interpreted together with the Indigenous advisory group.

### Patient and public involvement

Members of our Indigenous advisory group included both staff and community people, all of whom are sometimes patients at participating services.

### Researcher characteristics and reflexivity

Guided by the Indigenous advisory group, the research team comprises Indigenous and non-Indigenous members with extensive experience in mixed-methods Indigenous health research. The Indigenous team members have extensive lived community experience with deep cultural knowledge, ensuring that the data collection, analysis and dissemination are conducted in a culturally safe way that reflects Indigenous worldviews. One of the authors (EW) was formerly the practice manager and is currently on the governing board of one of the participating services. She was not involved in data collection or transcription for this service, but, together with other team members, was involved in the analysis of de-identified data. Collaborative data analysis workshops provided an opportunity to examine/address assumptions and experiences research team members brought to the interpretation process.

**Table 2** Round 1 participant characteristics.

| Characteristics                                   | Variables                                     | Count | Percentage (%) |
|---|---|-------|----------------|
| Role/position (n=61; two missing data)            | Clinical services manager                     | 5     | 8              |
|   | Director/chief executive                      | 3     | 5              |
|   | Frontline health worker*                      | 34    | 55             |
|   | Other managerial/policy position              | 15    | 25             |
|   | Programme manager                             | 4     | 7              |
| Years of work experience (n=61; two missing data) | <1 year                                       | 7     | 12             |
|   | 1–3 years                                     | 8     | 13             |
|   | 4–6 years                                     | 12    | 20             |
|   | 7–9 years                                     | 10    | 16             |
|   | ≥10 years                                     | 24    | 39             |
| Age (n=61; two missing data) in years             | 18–24   | 4     | 6              |
|   | 25–34   | 10    | 17             |
|   | 35–44   | 17    | 28             |
|   | 45–54   | 15    | 25             |
|   | >55   | 15    | 24             |
| Gender (n=62; one missing data)                   | Male  | 19    | 30             |
|   | Female  | 41    | 66             |
|   | Non-binary                                    | 1     | 2              |
|   | I use a different term                        | 1     | 2              |
| Cultural identity (n=62; one missing data)        | Aboriginal                                    | 29    | 48             |
|   | Torres Strait Islander                        | 1     | 1              |
|   | Both Aboriginal and Torres Strait Islander    | 1     | 1              |
|   | Neither Aboriginal nor Torres Strait Islander | 31    | 50             |

\*Frontline workers include Aboriginal health workers/practitioners, nurses, general practitioners/medical doctors, social and emotional well-being workers, outreach workers, receptionists, quality improvement facilitators, etc.

## RESULTS

**Table 2** shows participant characteristics. In Round 1, 63 staff members participated in data collection. The majority were women (67%), aged 35–64 years (74%) and in frontline roles (56%). There were equal numbers of Indigenous and non-Indigenous participants. Almost 40% of participants had worked in IPHC for over 10 years.

**Box 1 Primary and subthemes****Primary themes:**

1. Culturally safe care
2. Accountability

**Subthemes:**

1. Relationships
2. Trust and respect
3. Communication about consumer feedback
4. Timing and frequency of requesting consumer feedback
5. Health service systems
6. Health service and staff capacity
7. Staff skills
8. Structure and administration of the PREM

On average, 8 staff per site (range: 3–18) participated in Round 1 focus groups/interviews.

In Round 2, a total of 95 staff members from partner health services were engaged in the feedback sessions of preliminary findings; two of these sessions comprised approximately 30 staff members each.

**Themes**

We identified two primary themes, supported by eight underlying subthemes (see [Box 1](#)). *The definitions of the themes* (online supplemental Table S1), *with illustrative ‘anchor quotes’* (online supplemental Table S2), *are presented in the Supplementary File*. Brief illustrative quotes are also included in the main body of text in this article. All identified themes were relevant to ensuring the feasibility of collecting and interpreting consumer feedback; seven also related to resourcing requirements. Where data are related to more than one theme, they have been presented within their dominant theme.

**Primary themes****Culturally safe care**

Culturally safe care was the ultimate goal of services. Staff perceived PREM tools as a mechanism to improve the delivery of culturally safe care and that it was important to capture consumer experiences in a culturally safe way. Languages spoken by consumers and English literacy were considered important, along with the availability of Indigenous interpreters and survey facilitators. Staff commonly suggested that questions about culturally safe care should consider different aspects of the service environment, including a welcoming physical environment/safe space, and the interpersonal or relational skills of staff members.

The need for a PREM to capture all aspects of Indigenous holistic comprehensive healthcare (not solely medical care) was also identified, with a need for questions relating to access, belongingness and inclusivity. Examples included asking whether consumers are aware of the services available to them; whether they feel the service is part of the community and whether they were asked about preferred types of services to meet their cultural needs.

*I think after that it would be like, how we can make our services celebrate Aboriginal culture, rather than just making bare minimum safety, you know? How can we make our services ... like, people want to engage, and they feel respected and celebrated in them.* – Staff focus group, remote.

**Accountability**

Accountability to consumers and the wider community was identified as important across staff focus groups/interviews. Participants reiterated that as service providers they need to know what they are doing well or not doing well, and what changes need to be made. Participants talked about consumer feedback being used to strengthen organisational systems and processes supporting CQI and to assess the ongoing impact of the care provided. In addition to CQI, identified uses of a PREM included health services' goal setting, meeting accreditation and reporting requirements, informing work reviews and programme and services evaluation.

Some staff felt that acting on the results of a PREM could help to develop and uphold community confidence and trust in the health service and support consumer empowerment. Participants also talked about a PREM acting as a mechanism for clients to understand their rights and choices, and for services to understand why clients do/do not attend services and how to improve access. Several participants highlighted the importance of timely feedback to consumers and communities and of managing expectations about outcomes following a survey. Showing that the service is accountable to family and community means people can associate improved clinical outcomes with their experience as consumers.

*[...] you always want them to have the power to give the voice, you know? So if we're not doing something right, tell us. And tell us how you think we can do it better too.* – Staff focus group, regional.

**Subthemes****Relationships**

Participants commonly expressed the importance of positive relationships between services/staff and community members for the successful implementation of a PREM. Relationship-building was identified as necessary for engaging under-served groups (eg, men, LGBTQIASGBB+people, people with disabilities), those who have disengaged from services and particular groups (eg, Elders, mums and bubs, youth). Conversely, the use of a PREM was perceived to facilitate consumer engagement and strengthen community-health service relationships. Knowledge of the community was considered crucial when seeking consumer feedback.

For local Indigenous staff, relationships and accountability to family and community were associated both with their cultural obligations and their day-to-day roles within the health service. Importantly, the hierarchy in services and the power imbalances between consumers and

service staff were seen to strongly impact what consumers feel comfortable expressing in their feedback to services.

*I think building, having that relationship with patients first, because if you go to them and say, 'Oh, look, do you want to do a survey?', they just back off straightaway. – Staff interview, regional.*

### Trust and respect

Many staff reported that consumers did not currently trust the process for providing feedback, including having concerns about confidentiality—how the data would be used and who would see the data. Some staff thought that knowing who is analysing and interpreting data, and feeling confident that feedback is understood, would help people trust the process. Some believed consumers would be concerned that their data might be used by government agencies (eg, children's services), with negative repercussions, or would impact the services and benefits they receive, including being treated differently by service staff. Understanding how history affects Indigenous people's responses was perceived to be important for those who facilitate consumer feedback processes.

Considerations relevant to trust and respect for developing and conducting feedback processes included: (1) anonymity versus needing help to complete written surveys, (2) one-on-one yarn versus community group session, (3) written feedback versus verbal feedback and (4) a local Indigenous person facilitating and explaining questions versus needing to retain anonymity in the community. Adherence to local protocols and clear explanations about the purpose of the survey and how the data will be used were considered to enhance consumers' trust that their data and feedback will be used for service improvement.

*I think it would be important who's delivering it, like who's asking, because it couldn't be just another white person. It has to be someone they trust, someone they feel comfortable with. – Staff focus group, remote.*

### Communication about consumer feedback

Communication was commonly identified as either an enabler or a barrier to collecting consumer experience feedback, as well as reporting back to the community. Staff frequently discussed the need for clear communication at the outset with stakeholders such as consumers, the governing board and health service staff about the PREM's purpose, the process for collecting feedback, the analysis of data and how data will be used. Similarly, clear and timely sharing of the results with stakeholders was considered paramount for engendering trust and empowering clients in effecting service change.

Many participants also thought that results from the PREM survey should be communicated to the community and individual consumers in appealing ways, and be tailored to the local context using multiple modalities. Some spoke about the role of the feedback process

in affirming consumers' rights, demonstrating respect for their experiences through messages that are direct, concise and without jargon (eg, "80% of our clients said...").

*"So, little things like they've been waiting too long in the clinic, and then you straightaway address that, and the next time they come in, then it's just a flow. 'Oh, my God, they heard me.' So just a little thing, to them is a big thing. – Staff focus group, metropolitan.*

### Timing and frequency of requesting consumer feedback

Staff highlighted that consumers need to be respected and asked for feedback at appropriate times, as they are often busy with other priorities (eg, caring for family). Moreover, some may not understand the purpose or see the benefit of the survey, while others may want time to think about the answers and give considered responses. Many staff held the view that convenience for consumers should be a priority—for example, surveys completed while waiting for an appointment, received as an SMS with a link to the survey after an appointment or undertaken at the point of care. Some participants thought that consumer feedback captured immediately after service provision is likely to be accurate, notwithstanding that high-quality feedback sometimes requires considerable thought.

Staff stated that larger services might have the capacity to administer surveys at their different clinics at different times, with the collection of feedback spread over several days. Some reflected on the merit of frequent short surveys compared with in-depth feedback at longer intervals. Most staff suggested that consumer feedback be collected more frequently than is currently done in response to the 3-yearly accreditation cycle, somewhere between monthly to every 6 months. Overall, most staff indicated a need for ongoing consumer feedback that can be used for CQI purposes. A mechanism to track who has completed a survey was suggested so that regular service users do not get asked to provide feedback at each appointment.

*I'd probably aim for no more than quarterly. So people aren't seeing this link and just go, 'it's another one of these, I'm ignoring it.' Because ... lots of places are looking for feedback all the time, you might not see it as meaningful. – Staff interview, regional.*

### Health service systems

Organisational systems and processes that can enable or hinder the smooth implementation of a consumer experience survey were identified. Enablers were ease of access and administration and fitting with existing CQI and risk management systems. A dedicated position to manage the process was suggested for larger services. An automated system that can 'flag' in the client chart when consumer feedback is due and a modular approach incorporating options to capture feedback across the range of services were recommended.

A key barrier identified was inadequate database management systems to collect and process survey data, including automated information technology (IT) programmes that can bring together and analyse data and run reports. Voice recognition or artificial intelligence (AI) tools were recommended for managing verbal data. It was suggested that the cost of automated data management systems may be offset by increased efficiency in data processing.

*I like the programmes like Qualtrics, where it just collates all the information for you, and it comes back to you. So, I guess we want some paper-based face-to-face stuff that can easily translate into some sort of database. There's always going to have to be data entry to make that work. – Staff interview, regional.*

### Health service and staff capacity

Many staff highlighted the lack of service capacity to manage consumer feedback survey data. The issue was identified because services experience critical staff shortages and high workloads, particularly in remotely based health services. Most services have administrative staff who can enter data, but not designated staff who can process, analyse, interpret and report the data in different ways. Few services have the capacity to record and analyse verbal data. Larger services, regardless of remoteness, may have the capacity to fund external consultants to do this work. It was clear from the conversations that services need a dedicated position or team employed to specifically assist with the survey implementation, including collection, processing and analysis of data.

Some suggested employing Indigenous people external to their clinic to facilitate or interpret the survey because staff were already overburdened. Staff spoke about the greater reporting demands in IPHC settings compared with other services while acknowledging the potential for feedback to be used for common reporting purposes and building evidence for funding applications and advocacy. Organisational capacity also influences services' ability to connect with their full catchment area and target people who miss appointments.

*... we're large enough to have a team, you know, quality safety reporting team, that they can support the organisation with this sort of activity and what they do with that feedback and facilitating some of those conversations. – Staff focus group, metropolitan.*

### Staff skills

Further to capacity, it was highlighted that many health services lack the staff skill set to collect, process, analyse and interpret survey data. For example, staff seeking verbal feedback need skills and confidence to motivate individuals to participate, to ask questions in a culturally appropriate way, to engage clients who are shy or lack confidence to speak up and to manage dynamics when

seeking feedback in group settings. Many believed local community members to be skilled in these areas.

*So, [pseudonym] and [pseudonym] are our local community people who work here as the receptionist or receptionist [cum] driver. I think if we could give them the skill set and the ability to have conversations with [consumers], I think we'd get a better response that way, because they probably feel more comfortable being honest with them. – Staff focus group, remote.*

### Structure and administration of the PREM

Participants were asked for suggestions about PREM constructs (eg, questions and format) that would aid implementation. Most called for a survey that is practical, flexible, useful (to both service and consumers) and adaptable to the local context, with a limited number of precise, non-repetitive questions that use plain language with no jargon. A 'free text' option would allow people to explain why they answered in a particular way, thereby supporting interpretation and CQI. Some participants discussed how a feedback survey should not merely record consumer experiences during an episode of care but capture the care journey and changes to health outcomes over time. Asking the right questions in the right way would enable people to tell their care stories.

Many staff talked about needing a range of mechanisms for collecting feedback from a cross-section of consumers. For example, older people might prefer paper-based surveys, and younger people might prefer online surveys. Suggested options for meeting consumer preferences were the use of an iPad, an app or QR code access, phone calls, paper-based (scannable), a survey link sent electronically via email or short text messages and a suggestion box in the reception area. It was felt that a face-to-face approach using an informal 'yarning' style<sup>39 40</sup> could encourage some consumers to share their experiences.

Participants advised the need to consider client health literacy and languages when designing and implementing the survey, especially in remote communities where English may be the third or fourth language spoken. Translation of the tool into local languages and facilitation by local language speakers or interpreters may be necessary for fully understanding the survey questions.

Some suggested including generic questions in the PREM that apply to all services and programmes, with the flexibility to accommodate changing service environments and circumstances (eg, COVID-19, flood recovery). General questions could include whether: the care provided was kind, compassionate and thorough; the consumer was happy with the consult; they felt respected and listened to; they felt empowered, with some control of the conversation; the clinician communicated in a way that was understood; whether the person felt supported on their care journey; and whether the family was appropriately involved in care. The use of visual scales (eg, expressive faces) was suggested for adapting the survey for children and youth.

Having a mechanism for follow-up if the respondent chooses to give their contact details was suggested. Several participants identified strategies for collecting feedback from underserved groups (eg, men), for example, attending community events or offering incentives such as morning tea, shirts and gifts. Participants also expressed concern that mechanisms used for collecting feedback should ensure confidentiality and anonymity. For example, consumers might not feel comfortable dropping a feedback form into a 'suggestion box' in a waiting room. Phone surveys could create confidentiality and anonymity concerns where phones are shared among family members, and some consumers feel uncomfortable being audio/video recorded.

*It's got to be short, sharp and sweet. To get an accurate response, it needs to be a very precise question. It needs to be very simple, as in yes, no. Not maybe, could be, should have been, might have been, it could have. The more choice, the less you're going to get a response. – Staff focus group, regional.*

## DISCUSSION

This paper reports IPHC service staff views on the design and implementation of a PREM to appropriately capture Indigenous consumer perceptions of their healthcare. Conversations with staff members from eight diverse IPHC services identified two primary themes: culturally safe care and accountability, and eight subthemes: relationships; trust and respect; communication about consumer feedback; timing and frequency of requesting consumer feedback; health service systems; health service and staff capacity; staff skills and structure and administration of the PREM. Staff discussed the importance of ensuring the value and relevance of the PREM feedback within the local health service and community contexts.

We believe the 'culturally safe care' theme is an essential consideration for the PREM design and implementation across Australian IPHC services. Without Indigenous-specific PREMs, health services operate in an information vacuum, unable to know whether they are building or eroding trust, healing or harming, aligning with community priorities or missing the mark. Our findings are supported by a recent Canadian study which concluded that the administration of a PREM with Indigenous consumers should prioritise community preferences, as well as cultural ways of connecting and communicating.<sup>26</sup> Indigenous consumers often feel unwelcomed and experience negative attitudes and judgments from PHC providers, stemming from a lack of understanding or disregard for colonial history, and the ongoing impact on socioeconomic and political circumstances of Indigenous peoples.<sup>41</sup> We acknowledge that cultural safety frameworks have been promoted for years in health settings, but the integration of cultural safety into PREMs is still developing. Therefore, tool developers must reflect on cultural, historical and power differentials and

ensure that PREMs are designed and administered using culturally appropriate methods.<sup>25 26 42</sup> This approach can include meaningful processes of informed consent, engaging an Indigenous interviewer if the survey is being done verbally, and in the spirit of respect and reciprocity, ensuring patients are acknowledged for the time spent in sharing their experience.<sup>26</sup>

In terms of 'accountability', staff in our study emphasised that consumers appreciate the 'feeling of being heard' when they are informed about actions taken in response to their feedback. The findings from a PREM survey can also be used for improved funding, advocacy for more services and keeping the health service accountable to its client base. These findings are supported by other research suggesting that PREM findings should be shared and used to inform changes to care delivery that are communicated to consumers.<sup>26</sup>

Our findings show that 'relationships' and 'trust and respect' should be central to any PREM survey development and implementation with Indigenous communities. In the health services sector, consumers may not see the same service providers on every visit.<sup>43</sup> These fragmented relationships appear more prevalent in rural and remote contexts where PHC providers are often transient, and their recruitment and retention are challenging.<sup>44</sup> In addition to the impacts on continuity in clinical care, the lack of sustained relationships between consumers and service providers can adversely affect consumer engagement in surveys, especially in light of power differences. Also, intergenerational trauma and distrust of government and bureaucracy stemming from historical and ongoing colonial processes result in Indigenous consumers being reluctant to trust organisations in relation to confidentiality, use and sharing of data.<sup>45</sup>

Staff highlighted the importance of establishing relationships, trust and respect between consumers, community, health services and other stakeholders (eg, funding agencies, policymakers) before implementing the PREM survey. Such an approach would likely enable greater consumer participation and opportunities for reporting survey outcomes. Other studies acknowledge that PREM administrators should invest adequate time and resources to build, sustain and nurture mutually trusting relationships.<sup>26 46</sup> Developing trust in the health system is fundamental to creating healthcare experiences that encourage Indigenous consumers to actively seek care and share their experiences and concerns with staff.<sup>16 41</sup>

Our findings confirm effective 'communication' as an essential prerequisite for the implementation of any PREM survey. This is consistent with a study that highlighted the need to define and communicate the purpose of surveys and the value of using consumer experience feedback to inform reflective team-based learning in general practice settings.<sup>20</sup> Culturally appropriate care and clarity of communication by healthcare professionals are key contributors to positive consumer experiences and engagement that minimises the power differentials between Indigenous clients and the healthcare system.<sup>21 42</sup>



'Yarning' style conversations in a relaxing informal environment allow Indigenous consumers to feel more comfortable by fostering cultural dynamics.<sup>16</sup>

Our findings recommend the use of interpreters, especially in remote settings. Engaging local Indigenous people and translating PREM questions from English to local languages enable the capture of accurate and thorough client feedback. In line with these findings, a recent evidence synthesis assessing approaches for enhancing PREM collection with ethnically diverse communities consolidated several methods: engaging bicultural workers, translation and community outreach to access and support communities at one or more stages of PREM design or administration.<sup>21</sup> Other scholars recommended hiring and training local Indigenous community members to translate or facilitate the administration of the PREM survey to support collaboration, exchange of knowledge and strengthening of capacity.<sup>26</sup> However, challenges in achieving equivalence of meaning when adapting a survey for different language groups have been well documented.<sup>22</sup> Therefore, a collaborative approach engaging local cultural and language experts working with IPHC service staff and researchers has been strongly advocated for all stages of planning, development, implementation and evaluation of a PREM feedback tool.<sup>22</sup>

'Organisational capacity' and 'staff skills' for providing support to consumers when experience questions are asked should also be considered while implementing PREM surveys.<sup>26</sup> Employing local Indigenous community members can help to reduce the power differential between the community and service providers, leading to gathering more accurate data for the community.<sup>47</sup> Consistent with our findings, a lack of resources, IT infrastructure, capacity building and sustained funding have been identified as barriers to implementing consumer feedback surveys in mainstream general practice.<sup>20</sup>

Our findings relating to the 'structure and administration of the PREM' identified the need for a range of tool features. Relevant research reports similar findings. The most commonly researched approaches for measuring consumer experience include surveys, interviews and consumer stories, with tools adapted to local contexts and consumer characteristics.<sup>48</sup> Studies with Indigenous consumers report a preference for a face-to-face conversational approach, using the Indigenous language that enables the sharing of detailed and nuanced accounts of care experiences and what needs to change.<sup>22 49</sup> The mode of data collection and location also appeared to influence the completion rates of PREM surveys. For example, surveys with higher response rates (>70%) were completed verbally and face-to-face, a survey with the highest response rate of 95% included only three items, and the lowest response rates (<30%) were for paper-based or postal surveys.<sup>21</sup> However, in a hospital-based development and validation of a parent-proxy health-related quality of life survey for Indigenous Australian children, participants indicated that shortening the survey instrument was not

a priority for them, as all the content in the survey was relevant and appropriate.<sup>50</sup>

The difference between a complaints system and a PREM, and between CQI and accreditation processes, should also be understood by staff. It was clear from our conversations that some staff do not understand these distinctions and processes and may have difficulty informing consumers and communities about a PREM survey. Additionally, a PREM can act as a conversation starter that may lead to more detailed comments or complaints that would also be very valuable to action in real-time with health service management. Concerns about existing PREM tools available in Australia include the focus on care delivered by individual clinicians (eg, General Practitioner and nursing staff) rather than multidisciplinary teams, failure to return 'actionable' information and inability to support benchmarking or tracking of improvement in comprehensive healthcare delivery over time. Flexibility and modular aspects built into the PREM would enhance feasibility and usability for effectively capturing holistic consumer experience feedback.

The findings presented demonstrate an inherent tension between the desire of services and their staff to collect regular, meaningful feedback in culturally safe and appropriate ways, and the capacity of the services to achieve this. The demands of collecting PREM data for accreditation may override the preference for attending to the cultural appropriateness of the process. Where there is capacity to do this well and integrate with CQI processes, PREM data can enable services to identify and act on areas in need of improvement and monitor changes over time, enhancing patient-centred care.<sup>51</sup> Consideration should be given to which of the issues identified by this study should be prioritised in PREM development and administration, as it might be difficult to develop a tool that addresses all the issues raised while being acceptable, practicable/feasible to implement and report on. The core themes of 'culturally safe care' and 'accountability' should be the starting point for ensuring the integrity and value of the process. In order to keep the tool short and acceptable to consumers, the proposed PREM should consider a core set of questions that reflect consumer priorities, with additional optional questions that reflect either the maturation of the service or the diversity of the health service model. A parallel VOICE study with consumers is identifying their concerns and will confirm the content of the tool.<sup>30</sup>

Our findings suggest that, if done well, there is potential for an Indigenous-specific PREM to have a profound impact, where services will gain real-time insights into what matters to their patients and identify areas for culturally responsive improvements from the patient point of view. Furthermore, patients will become active participants in their care, not passive recipients, thus fostering trust, improving communication and even leading to better health outcomes through improved engagement. Communities will be empowered to lead quality improvement in partnership with services and feel heard and safe

when accessing the care they need. When combined with data from patient reported outcome measures, services and policymakers will have additional patient-level data collected through PREM tools to inform service performance evaluations and drive funding and accountability decisions.

### Strengths and limitations

The key findings of this study must be interpreted in the context of a number of strengths and limitations.

The VOICE project responds to a sector-driven need and was initiated at the request of PHC services and policy partners.<sup>30</sup> PHC staff in various roles in rural, remote and urban-based services contributed to understanding the diverse contexts and issues that affect Indigenous consumers' experiences of care and how best to capture those experiences. These staff perspectives have been instrumental in the design of culturally safe PREM, currently being co-designed by the VOICE Project. Most participants had been working in the Indigenous healthcare sector for over 10 years, with 50% bringing an Indigenous staff perspective. The inclusion of participants from diverse geographical settings adds another layer of richness to the findings, as it allows for a more nuanced understanding of how location may impact healthcare experiences. A 20-member Indigenous advisory group is supporting the VOICE Project with ongoing cultural and expert oversight in all stages of the PREM survey development, providing a strong base for the acceptability of the tool.

A limitation of this study is that many of the participants had not previously been involved in collecting consumer feedback and were not familiar with the accreditation process. Therefore, their views could be considered hypothetical and not based on experience. Another limitation is that health services face many competing demands, and the majority are not resourced to participate in research activities. Consequently, the services' capacity to effectively coordinate, engage or 'make available' staff to participate in this study may have been limited by competing demands, that is, potentially some staff who could have contributed well did not get the chance to, for various reasons. Additionally, primary data were collected through in-person and virtual focus groups/individual interviews; however, data were not analysed and synthesised comparing these data collection modes. This may have omitted some distinct findings and depth of data collected, which could be assessed in future studies. Although the invitation to participate in the study was open to all staff involved in interaction with consumers, health service accreditation and management and research and evaluation, it may be that we have missed a sample who would have dissenting views. Furthermore, social desirability bias cannot be ruled out, as participants were asked to share their perspectives from their experience of working within the partner health services.

### CONCLUSIONS

The primary themes of 'culturally safe care' and 'accountability' identified through this study emphasise the need for a PREM tool that meaningfully captures the care experiences of Indigenous peoples accessing IPHC services in Australia, while the subthemes provide guidance for tool development. Many of the issues identified are not currently considered in the process of collecting PREM data for accreditation yet, if addressed, would likely improve the quality and relevance of data collected. The findings from this study will inform the co-design and validation of Indigenous-specific PREM tools to collect consumer feedback. Critically, service and community input will ensure the PREM tools meet service needs for CQI and accreditation and reflect the priorities and values of Indigenous peoples.

Additionally, our findings suggest a PREM needs to be relevant to the community-controlled context, supporting the PHC service delivery for the Indigenous communities they are designed to serve. Capturing consumer experience in Indigenous community contexts requires careful planning and execution with an appropriate facilitator and/or data analyst collecting the data and processing it. How the data are used and how results are fed back to consumers and the community will also require adequate attention in PREM implementation. Clear communication needs to be in place regarding the purposes of the PREM—not just to capture complaints or meet the requirements of health services' accreditation standards, but also for supporting CQI processes, and ultimately improving the health and well-being of Indigenous communities. For this process to be meaningful and impactful, services will need appropriate skills and resourcing, including funding.

### Author affiliations

<sup>1</sup>University Centre for Rural Health, Faculty of Medicine and Health, The University of Sydney, Lismore, New South Wales, Australia

<sup>2</sup>Central Australian Aboriginal Congress Aboriginal Corporation, Alice Springs, Northern Territory, Australia

<sup>3</sup>Public Health Division, Northern Territory Department of Health, Darwin, Northern Territory, Australia

<sup>4</sup>School of Public Health, Faculty of Health, Medicine and Behavioural Science, The University of Queensland, Herston, Queensland, Australia

<sup>5</sup>ARC Centre of Excellence for Indigenous Futures, The University of Queensland, St Lucia, Queensland, Australia

<sup>6</sup>College of Medicine and Dentistry, James Cook University, Townsville, Queensland, Australia

<sup>7</sup>Inala Indigenous Health Service, Southern Queensland Centre for Excellence in Aboriginal and Torres Strait Islander Primary Healthcare, Inala, Queensland, Australia

<sup>8</sup>Australian Commission on Safety and Quality in Healthcare, Sydney, New South Wales, Australia

<sup>9</sup>The Royal Australian College of General Practitioners, East Melbourne, Victoria, Australia

<sup>10</sup>Daffodil Centre, The University of Sydney Faculty of Medicine and Health, Sydney, New South Wales, Australia

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#### ORCID iDs

Amal Chakraborty <http://orcid.org/0000-0003-1837-1224>

Emma Walke <http://orcid.org/0000-0001-6962-4231>  
 Alison Frances Laycock <http://orcid.org/0000-0001-7756-4398>  
 Tracey Piccoli <http://orcid.org/0009-0001-5845-1715>  
 Veronica Matthews <http://orcid.org/0000-0002-1319-257X>  
 Ross Bailie <http://orcid.org/0000-0001-5966-3368>  
 Sarah Larkins <http://orcid.org/0000-0002-7561-3202>  
 Roxanne Bainbridge <http://orcid.org/0000-0003-1206-8072>  
 Bena Brown <http://orcid.org/0000-0002-7537-2402>  
 Bronwyn Silver <http://orcid.org/0009-0007-7932-4807>  
 Girish Swaminathan <http://orcid.org/0009-0007-8191-6254>  
 Samantha Smorgon <http://orcid.org/0009-0009-6943-5989>  
 Megan Passey <http://orcid.org/0000-0001-5766-0235>

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