

# Aboriginal people's perceptions of patient-reported outcome measures in the assessment of diabetes health-related quality of life<sup>†</sup>

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## ABSTRACT

**Background.** Patient-reported outcome measures (PROMs) provide clinicians and consumers a platform to inform and improve healthcare planning and management. Aboriginal people experience disproportionately high rates of chronic diseases, including type 2 diabetes. Treatment and management require holistic approaches that draw on culturally relevant resources and assessment tools. This study explored perceptions of Aboriginal people about two diabetes management-related PROMs (PROMIS-29, PAID Scale). **Methods.** Twenty-nine Aboriginal people living with diabetes in the Shoalhaven discussed two PROMs in one of four focus groups or at an individual interview. Preliminary data coding was conducted by clinician researchers, with thematic analysis overseen by Aboriginal co-researchers. Subsequent individual interviews with participants were undertaken to seek further feedback and articulate what is needed to improve methods of evaluating Aboriginal people's self-reported quality of life and diabetes management. **Results.** The PROMs did not capture information or knowledge that Aboriginal people considered relevant to their diabetes-related health care. Participants' recommendations included adapting survey materials to be more culturally sensitive; for example, by improving the alignment of measures with common day-to-day activities. This study also describes a genuine collaborative, Aboriginal community-guided approach to evaluate 'fit-for-purpose' diabetes management tools. **Conclusions.** Appropriate evaluation methods are paramount to address the disproportionate burden of diabetes experienced by Aboriginal peoples and overcome inverse diabetes care. Our learnings will contribute to development of tools, resources or methods that capture culturally tailored outcome measures. Study findings are relevant to clinicians and researchers using and/or developing Patient Reported Measures, particularly in relation to the practicality of tools for First Nations peoples.

**Keywords:** Aboriginal, delivery of health care: integrated, diabetes, disease management, healthcare disparities, indigenous health services, patient-centred care, Patient Reported Measures.

## Introduction

Illness rates, disease and disability are much higher in the Aboriginal population compared to the non-Aboriginal population. The largest contributor to illness in the Aboriginal population is chronic disease, including cardiovascular disease, mental health, injury, cancers and diabetes (NSW Ministry of Health 2012; Gardiner *et al.* 2021). Around 7.9% of the Aboriginal population have diabetes, and it is estimated that Aboriginal people are three-fold more likely to have diabetes than their non-Aboriginal counterparts (Australian Institute of Health and Welfare 2020).

<sup>†</sup>The term 'Aboriginal' will be respectfully used in this document to refer to both Aboriginal and Torres Strait Islander peoples. We acknowledge the diversity of Aboriginal and Torres Strait Islander peoples, cultures, and customs.

Early detection and education are key factors in reducing morbidity from chronic disease, and improving the quality of life (QOL) of Aboriginal people. Aboriginal health and QOL extends past physical health, encompassing social, emotional, and cultural wellbeing of not just the individual, but the whole community (NSW Ministry of Health 2012). QOL status must be based on Aboriginal people's definition of well-being and extend beyond biomedical and individual factors (Butler *et al.* 2019).

Monitoring QOL is an important component of equitable health service delivery for chronic diseases like diabetes because it informs where services could be better distributed or enhanced (Aspin *et al.* 2012; Kite and Davy 2015). QOL survey administration is a component of health management, which is usually 'expert' driven, shaped by western cultural perspectives. The data obtained from administration of QOL surveys assist in directing holistic, patient-centred care; however, the specific needs of Aboriginal people are often not addressed (Kite and Davy 2015).

The World Health Organization (WHO) has an established focus on QOL surveys. These surveys identify the impact of disease, the burden on day-to-day activities and health behaviours, and also encompass physical, mental, and social wellbeing of the individual (World Health Organization (WHO) 2012). The WHO defines QOL as an 'individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (World Health Organization (WHO) 2012). However, WHO have not identified specific QOL needs for Aboriginal people (World Health Organization (WHO) 2012). A 2016 review by Angell *et al.* (2016) reported that 38 out of 41 health-related QOL (HRQOL) instruments used with Indigenous populations were not specifically tailored to include relevant social, cultural and community domains. Thus, traditional HRQOL domains are unlikely to capture relevant data from Indigenous peoples' perceptions of their QOL.

Patient-reported outcome measures (PROMs) are HRQOL tools that are widely used in health internationally, and started to be used in Australia about 30 years ago (Williams *et al.* 2016). PROMs have been introduced into some NSW public healthcare settings since June 2019 as a tool to assess HRQOL in individuals from their own self-reported perceptions (Agency for Clinical Innovation 2022). Historically, PROMs have not commonly been used in Aboriginal Community Controlled Health Services (ACCHS) in the Shoalhaven. However, more recently (May 2021), the Agency of Clinical Innovation (ACI) have trialled PROMs in Aboriginal Health Aunty Jeans programs across three local health districts, including Illawarra Shoalhaven Local Health District (Agency for Clinical Innovation 2022).

When delivering diabetes management, the Patient-Reported Outcome Measurement Information System-29 (PROMIS-29, Supplementary Appendix S1) and the Problem Areas in Diabetes (PAID) Scale (Supplementary Appendix S2)

are two PROMs used in diabetes management in the public health sector in New South Wales (NSW). Despite these surveys being used in health services accessed by Aboriginal people, they have not yet been examined for cultural relevance and cultural sensitivity or whether their use is culturally responsive in terms of the specific needs of this population (Wilson *et al.* 2018; Brooks *et al.* 2019).

The availability of quality health care can vary inversely with the needs of a particular population; therefore, those individuals with greater disease burden, those with limited access to services, and those who have specific cultural needs may be subject to less proficient health care, and consequently further deterioration in health (Tudor Hart 1971). Given the desire to improve the health outcomes of Aboriginal people and the higher incidence of diabetes, a reliable and valid HRQOL tool is paramount to directing quality diabetes care.

## Study aim

The aim of this study was to investigate how the PROMIS-29 and PAID Scale surveys are perceived by the Aboriginal people living in Shoalhaven, in relation to their health-related quality of life with diabetes.

## Methods

This descriptive qualitative study involved Aboriginal community-based participatory research methods informed by Aboriginal philosophy and pedagogy (Yunkaporta 2009; McPhail-Bell *et al.* 2018). This was the first phase of a two-phase study conducted by health workers collaborating with five Shoalhaven Aboriginal communities on Dharawal and Yuin land (Nowra, Jerrinja, Wreck Bay, Sanctuary Point and Ulladulla) to explore a diabetes PROM set. The study methodology was informed by the Indigenous values of relationality and reciprocity, with Aboriginal ways of knowing, being and doing (National Health and Medical Research Council 2018; Riley 2021; Webster *et al.* 2021) respected and incorporated throughout research planning, implementation, and analysis.

The PROM set included the PROMIS-29 and PAID Scale. The PROMIS-29 is a general health-related QOL survey for adults and includes seven domains (physical function, anxiety, depression, fatigue, sleep disturbance, ability to participate in social roles and activities and pain interference). There are four questions for each domain measured on a five-point Likert scale, plus a single item pain intensity scale out of 10 (Huang *et al.* 2019).

The PAID Scale is a disease-specific survey that is intended for people with diabetes. There are 20 questions rated on a five-point Likert scale from 'not a problem' to 'a serious problem' and designed to measure the patient's perspective

of diabetes-related stress (Welch *et al.* 1997). A detailed description of the PROMIS-29 and PAID Scale and their use as PROMs within the NSW public health sector, and the consultative processes used to develop the protocol for this study, have been described previously (Burgess *et al.* 2022).

## Participants

Eligibility criteria included Aboriginal people living in the Shoalhaven, with type 1 or type 2 diabetes, aged  $\geq 18$  years. Purposive sampling was coupled with a snowballing technique by Aboriginal Health Workers to recruit Aboriginal people with lived experience of type 2 diabetes and interactions with health service providers. Aboriginal people recruited to the study had the choice to be personally identified or de-identified in reported findings. Consultation with the community deemed it important that participants be offered a choice about whether their contributions were identifiable.

## Recruitment

Participants were recruited to the study between August 2020 and March 2021. Aboriginal people had the choice to attend either a focus group or individual interview, with refreshments supplied. Participants received a AU\$20 supermarket shopping voucher, a specifically designed Aboriginal shirt, and bag with drink bottle, recipe book, pen, and dietary portion plate as a reimbursement for their time.

## Focus groups and individual interviews

Community consultation confirmed that participants wanted the choice to participate in either a focus group or individual interview, and were aware that these would be conducted by a Principal Aboriginal health worker (CK) and health professionals (AB, JH) who were known to the communities. At the beginning of each focus group or interview, the researchers introduced themselves and shared why they were interested in the research topic and hearing from the community. Focus groups were conducted, and home interviews were provided by AB and JH. The participants had an opportunity to read the PROM surveys and complete them if they wished. An audio option was also available.

Broad open-ended questions were asked about what the participants liked and disliked about the PROMIS-29 and PAID Scale surveys. Participant personal opinions were also sought on whether the surveys appropriately assessed the HRQOL of Aboriginal people living with diabetes in the Shoalhaven. Conversations around the surveys were directed by the participants and redirected if they were not on topic. All focus groups and individual interviews were conducted in person. Focus groups were held in community halls and centres, and interviews were held at the participants'

homes. At two of four focus groups, there were non-participants present for interpretative and cultural support.

## Data coding and analysis

Focus groups and interviews were audio recorded and professionally transcribed. All participants were asked whether they would like a copy of the transcript to keep. AB sent out a transcript and cover letter sheet to all requesting participants, and AB or JH made a follow-up phone call to ensure the transcript was received. Participants had the opportunity to discuss the focus group or interview transcript. No changes to transcripts were requested as a result of this process.

Transcripts were inductively coded prior to thematic analysis (Braun and Clarke 2006). Preliminary coding of transcripts was performed by two non-Aboriginal researchers (AB, JH), with data segments transferred out of the transcripts into a Microsoft Word document (Microsoft Corporation). AB and JH discussed coding with the associate Aboriginal Investigator (CK) to ensure the spirit and integrity of the views of the participants were reflected with an appropriate Indigenous lens. First-level analysis involved AB and JH grouping, arrangement and rearrangement of codes using a coding tree, then further discussion with CK. Thematic memoing was used to describe and refine preliminary themes. Throughout the preliminary coding and analysis, qualitative research methodological input was provided by KD and SP, and guidance by an Aboriginal academic with extensive qualitative research expertise (MK).

Member checking of data interpretation involved reflective discussions about the preliminary data analysis with participants and interested community members in two follow-up, face-to-face sessions. A short education session 'Diabetes and Your Feet' was presented at the end of these sessions by JH (Diabetes Educator and Dietitian) and AB (Podiatrist) as part of the reciprocal relationship between the researchers and community.

Coronavirus disease 2019 (COVID-19) restrictions prevented face-to-face member checking with all participants, so AB and JH contacted remaining participants via phone to finalise checking of data interpretation. All participants were offered a written summary of the research that had been created and reviewed by AB, JH and CK (Supplementary Fig. S1), and a copy of the education presentation slides. These documents were handed out at face-to-face sessions or posted or emailed to other participants who requested a copy. All participants were offered the option of receiving a copy of the final report. Two participants were unable to be recontacted due to unavailability of contact details. Member checking confirmed that data analysis was considered accurate by participants.

Following member checking, data analysis and interpretation were completed by the research team. This involved a combination of memoing, writing and graphical data representation (AB, JH) and circulation of written documents for consideration and discussion in meetings with CK, KD, SP

and MK. The final analyses documents were transformed into a manuscript format for reporting. Participant quotes in the manuscript were identified by data collection method, focus group (FG) or interview (IV) and participant identity (anonymised or named, as per participant preference).

## Reflexivity

The premise of this study is to retain the spirit and integrity of Aboriginal people in responding to government-initiated evaluation of health outcomes (National Health and Medical Research Council 2018). As a research team, we acknowledge the past history of disingenuous and misguided research performed in and on Aboriginal communities. Potential biases and power imbalance from having non-Aboriginal research team members involved in conducting focus groups and interviews, as well as analysing Aboriginal voices, is recognised. The PROMIS-29 and PAID Scale surveys are currently used with Aboriginal people in NSW health services, one of which employ AB and JH. Interest of the researchers in hearing and responding to the opinions about these surveys from Aboriginal people is genuine. We prioritised keeping the power, integrity, and voices of Aboriginal community members at the forefront, with continual community engagement and involvement throughout all stages of the research process, from study design to data collection and analysis (National Health and Medical Research Council 2018). Aboriginal and non-Aboriginal research team members also collaborated closely with each other to collect, collate, analyse and interpret findings. Consistent with Berger (2015), discussions and meetings between researchers and with community members contributed to reflexivity (Berger 2015). The identifications and positioning of all research team members are outlined in Table 1.

**Table 1.** Research team members identifications.

Team member	Identification
AB	A non-Aboriginal woman and Podiatrist born in Dharawal Country who has worked with the study communities for the past 10 years, providing education, foot assessments and organising Podiatry referrals
JH	A non-Aboriginal woman born on Dharawal Lands who has worked in health as a dietitian and diabetes nurse educator for 12 years. She has been involved with the Aboriginal community through dietetic and diabetes education with the Aunty Jeans program and study communities with AB and CK
CK	An Aboriginal woman and descendent from the Yuin Nation who holds a Bachelor of Public Health and post graduate certificate in Indigenous Trauma and Recovery Practice. She has worked in the health sector for 13 years and has extensive project managing experience working on various Statewide programs and strategies. More recently, project leading an initiative to improve access to care and outcomes for Aboriginal people living with diabetic-related foot disease in the Illawarra Shoalhaven area
KD	A non-Aboriginal woman born in Yuin Country on the South Coast of NSW who works as a research education manager in the public health sector. She has 25 years' experience in Aboriginal health research and Aboriginal health researcher development
MK	A Wiradjuri woman raised on Worimi country, she holds an NHMRC early career fellowship and is the Assistant Dean Indigenous Strategy and Leadership for the College of Health Medicine and Wellbeing at the University of Newcastle. She has over 16 years' experience working with Aboriginal communities across community development, social work and health research
SP	A non-Aboriginal woman, podiatrist and academic. She has facilitated professional student placements with Aboriginal communities and set up the first ongoing student podiatry clinic at a local Aboriginal Medical service to address culturally sensitive health service provision and early career workforce education

## Ethics and reporting

Ethics were obtained as follows: the study was designed in collaboration with five Shoalhaven Aboriginal communities and this process was previously reported (Burgess et al. 2022). This study was overseen by a Community consultative group consisting of Aboriginal Elders, healthcare professionals and community members to ensure all voices were included in the project design and delivery.

The study was approved by the Joint University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical Human Research Ethics Committee (HREC) (2019/ETH13468), Australian Capital Territory Health HREC (2020.STE.00005, 2019/ETH13468) and the Aboriginal Health and Medical Research Council (AHMRC 1602/19). This manuscript has been written in accordance with Consolidated criteria for reporting qualitative research (COREQ) Checklist (Tong et al. 2007).

## Results

### Participant characteristics

Four focus groups, each involving between 4 and 10 participants, and five individual interviews, were held in eight different locations across the five Shoalhaven communities between October 2020 and March 2021. In total, there was 29 Aboriginal participants aged 30–87 years, with type 2 diabetes (100%) and who were predominately women (65.5%). There was a larger age range for people participating in focus groups (Table 2). An additional three participants consented to participate, but they were unwell at the time of focus groups and interviews and they declined to participate via

**Table 2.** Participant characteristics.

	Interviews (n = 5)	Focus groups (n = 24)
Age mean (s.d.)	71.0 (5.6)	63.7 (14.1)
Type 2 diabetes n (%)	5 (17.2)	24 (82.8)
Gender n (%)		
Female	4 (13.8)	15 (51.7)
Male	1 (3.5)	9 (31.0)

phone. The focus groups went for 2–3 h and interviews for 1–2 h, with the duration determined by the participants.

### Aboriginal perspectives of current PROMs used in diabetes

A majority of participants strongly and consistently expressed the opinion that the PROMIS-29 and PAID Scale surveys were not meaningful to them. The participants felt that the surveys contained many irrelevant questions and excluded important components relating to day-to-day life, including family, culture, and support. Our analysis of perceptions about the surveys uncovered five thematic areas: relevance, specificity, terminology, stigmatisation and mistrust, and accessibility, which we describe and discuss individually.

### Perceptions of the PROMIS-29 and PAID Scale surveys

#### Relevance

The participants identified that the PROMIS-29 and PAID Scale surveys were not relevant to their circumstances and concerns about living with diabetes. A common observation by participants was that the surveys lacked relevant questions about medications used in diabetes management, and did not address medication access issues or concerns about adverse reactions to medications: For example, a participant shared:

Where was the questions like, ‘Have you ever had, is there difficulties with you keeping your medications up? The cost of your medication?’ I’ve come across many people in my experiences who can’t afford to get their medications ... (Denise, 60 years, FG2)

Participants also felt that a higher focus on medications in the surveys would be useful in assessing holistic, person-centred care, rather than treating diabetes in isolation from the whole person, in their own circumstances:

... [A] medication one should be added into questions. The thing is, I was on a medication for my sugar, but I’ve only got one kidney, so when I gone to the chemist to get a script and they show me to about it, and they said, you really need to talk to your doctor, you’ve only got one kidney, this medication they’ve got you on there is going to damage that one kidney ... (Jackie, 65 years, FG3)

Participants expressed the importance of including questions that resonated with the day-to-day priorities of community members. Another commonly reported concern about the surveys was the overwhelming number of questions, many of which seemed redundant or repetitive. Participants commented:

Well, what’s the point of having a questionnaire (that’s) not relevant to your daily lifestyle...with diabetes, so why waste your time looking at that? (Female, 55 years, FG2)

... How do you feel from day-to-day? What’s your daily (life) like ...? (Dawn, 71 years, IV2)

I felt there was way too many questions, and they were off-track to what we really need to find out and know about. I just thought the questions weren’t relevant, and way too many questions. (Denise, 60 years, FG2)

Participants acknowledged that the PROMIS-29 and PAID Scale survey questions were often not relevant to concerns Aboriginal people may have about their diabetes management and what they would like their health professionals to know about how they are managing their diabetes. There were suggestions for more specific questions, about regularity, and how and where health care was sort.

There’s another question. For somebody to do a survey, do you get those sort of regular check-ups? How do you get those regular check-ups? Who are the doctors that you see? (Female, 46 years, FG1)

Many participants completed the PROMIS-29 and PAID Scale surveys in their focus groups interview session, which helped to prompt their feedback. Others chose not to complete the survey, or commenced the survey, without finishing due to the length or difficulty of completing. Of the participants who did not have difficulty completing the surveys, most did not understand how it would relate to their diabetes care.

What I did was went through and marked what I thought I should, just to see if I could do the survey and it’s quite okay. There’s a lot of things that I don’t understand why they are asking the questions, that’s all, but as you went through, I tried to mark them to see what I could do and it was quite okay, but again, I don’t know what the survey is for, actually. (Male, 69 years, FG1).

### Specificity

Participants were concerned that the PROMIS-29 and PAID Scale surveys did not address their specific needs. Factors that related to specificity included lack of cultural consideration, low access to services and inadequate individualisation of care. Participants reported that this

lack of specificity meant the surveys could not accurately depict their HRQOL concerns of living with diabetes. The written format of the surveys was a barrier to articulating diabetes management for some participants, who felt that written mediums are less appropriate than verbal and visual mediums:

... we come from the culture where we're visual, we talk more... (Female, 55 years, FG2)

Completing the HRQOL surveys raised questions for participants about diabetes, which were then not addressed in the management or health care. For example:

You wonder if you're eating right, or if you're eating enough (Margaret, 73 years, FG4)

The need for surveys to allow for more specific responses in relation to locality was also raised by participants, who thought that their geographic location influenced access to services. Participants reported that having the ability to add specific details about where they live would help contextualise their responses:

And that should probably be in the question too, especially like if you're regional or rural or do you have access to a diabetic educator? Do you have access to a podiatrist? Do you have access...? They're more the dietitian because they're more relevant to what that person is doing than whether they can walk 15 minutes, do you know what I mean? (Female, 46 years, FG1)

## Terminology

Most participants reported that the technical language used in the PROMIS-29 and PAID Scale surveys was overwhelming. The 'medical jargon' was difficult for participants to understand, making it less desirable to complete. One participant commented:

I didn't like it much. I didn't understand it...it wasn't relevant to me as an individual with diabetes. (Female, 55 years, FG2)

This individual-level response was echoed at the community-level, with participants reporting that Aboriginal people prefer more direct and pragmatic wording, more consistent with their community conversational language. For example:

Indigenous people don't understand big words and that. Just bring it down in little brackets, and a bit more common sense, be more direct to our Indigenous people... myself, I don't understand hardly any of it because the wording's wrong, not in our culture. (Bim, 67 years, FG2)

Like they're not in our language, we don't say chores, people don't say chores, such as vacuuming or yard work, we more or less say...working in the yard, or doing a bit of vacuuming, stuff like that. Errands, do we normally say that? I'm just running to the shops, that's all we say...change it to how we speak, every day speak. (Anne Marie, 63 years, FG4)

Another concern of participants was their perceived inadequate knowledge about the basics of diabetes pathophysiology. Participants wanted an accurate, working knowledge of diabetes that made them feel empowered to manage their diabetes:

I don't know what diabetes is, you know, in plain English I don't. All the doctor just give me a little tablet and I just took it, and I still don't know what it means. (Anna, 79 years, FG2)

## Stigmatisation and mistrust

Some participants commented that questions in the PROMIS-29 raised concerns about being judged or stigmatised by health professionals, or that their responses to survey questions may be misrepresented:

Well, I always want to know why you're asking the question, you know, am I going to be labelled here or something. It's that worrying about what... why they're asking those questions. (Graham, 43 years, FG3)

You're asking someone's personal relation to how you feeling actually. And then they're diagnosed that you, yeah, you got a mental problem. I mean I haven't got a mental problem; you know what I mean? I just some days, well that's a fact of life, some people you feel up, and then you feel down...So, the questions need to be looked out from us, like from a cultural way. We start off with kidney problem and now we're mental and we're depressed!! (Female, 59 years, FG3)

Mistrust in the healthcare system and how information would be used was also raised, with potential links to a history with a lack of shared decision-making.

There's a lot of people out there in an area that won't see a doctor because of their... because they're too scared to have information going to be put out there, or you know, they're going to be passed in categories. (Graham, 43 years, FG3)

We come from a history where there wasn't good medical care; no one cared. It was all about taking things from us, taking everything. (Female, 55 years, FG2)

It's really important that people could relate to that [living under the Aboriginal Protection Board], and we were terrified of anyone that come to, because we were used to be given medicines...they didn't have to get permission off our parents to give us medicines. (Dawn, 71 years, IV2)

Furthermore, participants wanted more holistic care, rather than being categorised into one treatment option; that is, medications.

Respect, you've got to look at better solutions for that (doctor management) without just chucking them on tablets or using Western stuff. (Graham, 43 years, FG3)

### Accessibility

The focus group and individual interview conversations provided opportunity for participants to reflect and provide feedback about diabetes management beyond the PROMIS-29 and PAID Scale surveys. Participants expressed concerns about poor access to diabetes services and perceived discoordination of services in the Shoalhaven. Participants reported that their primary diabetes service provider was their general practitioner, and raised concern about access to diabetes-specific services:

We don't really have a lot of access to diabetes [health care] unless we go to our doctor. We don't really have that... (Female, 46 years, FG1)

The importance and need for coordinated, multidisciplinary care was reported by participants, who acknowledged that this continuum of care was improving:

... [Services] don't work together ... , it doesn't really sort of work out too well. I think we're sort of moving towards that now...because it's not going to work unless the services have all got together... (Dawn, 71 years, IV2)

Participants also mentioned the need for person-centred rather than medical-centric models of care that have flexibility in terms of scheduling appointments:

... they give you follow ups and they're making appointment times for you, but it doesn't suit me because I was working at the time, and you can't get the time off at work to go into town into Nowra and spend a couple of hours in there with the nurses at the diabetic place. (Female, 62 years, IV4)

The need for genuine, extensive Aboriginal community involvement to inform development of culturally sensitive and responsive diabetes management-related PROMs is highlighted by the following quote:

If you want to have some cultural respect and ethics and that, get more of our people involved with stuff like this... look at yourself [research team] you've got the scholarships and training... get an Aboriginal and Torres Strait Islander person that can break down the barriers of communication, involved with more work and more surveys and that, so there is another process of breaking the gaps. (Female, 55 years, FG2)

### Discussion

This study identified that the PROMIS-29 and PAID Scale surveys do not appropriately assess the HRQOL of Aboriginal people with diabetes living in the Shoalhaven region. The participants identified that the PROMIS-29 and PAID Scale surveys do not identify the relevant or specific needs of the Aboriginal community, and are unnecessarily challenging to complete. Beyond the themes of relevance and specificity, concerns were also raised around terminology, stigmatisation and mistrust and accessibility. These findings were expected because the QOL tools used have been shaped by western perspectives. They are unlikely to identify the true needs of Aboriginal people, whose values and beliefs, family, culture and support, and lived experiences have not been incorporated. Not accurately identifying, or misrepresenting, the HRQOL of the Aboriginal community could negatively impact their diabetes management and inhibit trusting and meaningful relationships between Aboriginal community members and the health professionals involved in managing their care.

Two related studies about the appropriateness of QOL tools for Aboriginal populations in Australia further consolidate the need for Aboriginal-specific QOL and disease-specific surveys. A study by [Smith et al. \(2019\)](#) sought to develop a QOL tool for older Aboriginal Australians. Research was conducted in Perth (Nyoongar people) and Melbourne (Kulin nations) via social yarning groups and semi-structured interviews to identify important factors required in a QOL tool. Twelve good spirit factors were identified, including basic needs, family and friends, Country, community, culture, health, respect, elder role, support and services, safety and security, spirituality and future planning ([Smith et al. 2019](#)). Similarly, a study performed by [Howard et al. \(2020\)](#) investigating wellbeing measures in Aboriginal and Torres Strait Islander adults concluded that culture, values and spirituality were key contributors to wellbeing for Indigenous people. They acknowledged that the QOL and wellbeing of Aboriginal Australians is poorly understood and that current measurements are insufficient to meet the needs of Aboriginal communities ([Howard et al. 2020](#)).

[Smith et al. \(2019\)](#) and [Howard et al. \(2020\)](#) both reported similar QOL determinants for Aboriginal Australians, as we reported in relation to diabetes. Each also cautioned

existing QOL tools may not be suitable for all Aboriginal populations nationally. To achieve the goal of evaluating and improving HRQOL, PROMs need to address the specific culture, values systems, and ways of knowing and being that shape each particular community (Angell *et al.* 2016).

The current study reinforces the need for tailored HRQOL assessment, addressing the specific needs of each community that health services are engaging with. Concerns expressed by participants about how survey responses would be used, highlighted the need to ensure that HRQOL tools and the assessment process itself, do not contribute to stigmatisation or perpetuate inverse care. Themes around cultural relevance, and stigmatisation were similarly identified in a study investigating QOL in Aboriginal children with chronic illness (Butten *et al.* 2021). Poor communication and understanding of traditional and cultural aspects of the Aboriginal people, were reported to leave those accessing healthcare systems feeling disrespected and disenfranchised, and less likely to engage with these services (Butten *et al.* 2021).

Given the health disparity in Aboriginal populations (Australian Institute of Health and Welfare 2020; Lowitja Institute 2022), the current study further supports the need for culturally sensitive HRQOL survey content that is tailored to Aboriginal people's broader understanding of wellbeing, and health knowledge beyond current biomedical and individual models (NSW Ministry of Health 2012; Brooks *et al.* 2019). Cultural responsiveness has been a key enabler in this study and will be vital in the future translation of the research findings (Wilson *et al.* 2018; Webster *et al.* 2022). HRQOL survey content revision, dissemination and survey administration approaches used by health professionals and services should be inclusive of genuine co-design and consultation with Aboriginal communities and Aboriginal subject matter experts (Sherwood *et al.* 2015; Wilson *et al.* 2018; Aboriginal Health and Medical Research Council Ethics Committee 2020). Culturally sensitive diabetes-specific HRQOL surveys that are developed and disseminated using culturally responsive approaches will improve connections between health service providers and Aboriginal people, and result in improved understanding of Aboriginal people's diabetes management status and needs.

Success of research in the Aboriginal population relies on placing Aboriginal people at the centre of the research and allowing ownership of the stories told, ensuring Indigenous perspectives are at the forefront of the research process (Lovett *et al.* 2020). In this research, discussions about the PROMIS-29 and PAID Scale surveys in relation to diabetes management and QOL, led to Shoalhaven Aboriginal community members sharing valuable stories and insights about their desire for improved diabetes-specific health literacy and knowledge (i.e. diabetes understanding, how and when to access services for diabetes, understanding their medications, and managing their diet for diabetes). Consistent with the need for impactful research that benefits the Aboriginal community (Bainbridge *et al.* 2015), the research team and

Aboriginal community members will progress a diabetes education component of this study. Responsiveness to the culturally specific needs of Aboriginal communities will be prioritised in the process of determining how to improve diabetes education with Aboriginal people in the Shoalhaven region (Sherwood *et al.* 2015; Wilson *et al.* 2018; Brooks *et al.* 2019).

Limitations in diabetes applied knowledge and lack of patient-centric shared decisions, are consistent with findings reported by Webster *et al.* (2017), who report that participants described significant historical and colonial influences on their understanding of diabetes, its management and how they experienced a diabetes model of care. However, as diabetes education and service provision were not the primary focus of this particular study, these factors will be further explored in future research with the community to identify ways to address potential gaps in the diabetes service provision and improve access to diabetes education in the Shoalhaven for the Aboriginal community members.

Although rich and important data were obtained by the generous stories shared by the Shoalhaven Aboriginal community about the current diabetes PROM set, the stories shared may not reflect the opinions of Aboriginal people elsewhere in NSW, or more broadly in Australia. However, the methods utilised to engage with community may be adapted to other Aboriginal population groups. There was also an under representative sample of males in the current survey (33% vs 77%), which is inconsistent with similar rates of diabetes in Australia (Australian Bureau of Statistics 2019, 2022), and needs consideration in future work. A more diverse demographic of Aboriginal people in the Shoalhaven may have provided additional insight into the diabetes PROM set, such as people living with type 1 diabetes, younger Aboriginal people and carers of Aboriginal people.

## Implications

This study is one of the first looking at the appropriateness of PROM surveys in the Aboriginal population. The findings indicate that the PROMIS-29 and PAID Scale diabetes PROM set do not meet the needs of the Aboriginal community living in the Shoalhaven. Further research is needed to co-design a HRQOL tool for diabetes that will meet the holistic needs of this community, and to inform HRQOL survey development elsewhere. A co-designed Aboriginal-specific diabetes PROM set will increase engagement with health services and ultimately improve the overall diabetes management of Aboriginal people.

## Supplementary material

Supplementary material is available [online](#).

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