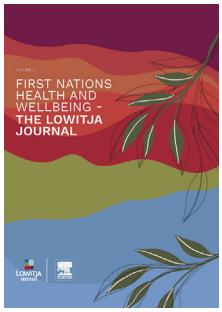

Original Research

These mob here have integrity; they genuinely care about the people: Service users' and care providers' perspectives on enablers of good chronic disease care for Aboriginal and Torres Strait Islander peoples

Sarah Catherine Bourke (Gamilaroi, Jaru, Gidja)[a,*], *Deborah Wong*[a], *Uday Narayan Yadav*[a,b], *Andrea Timothy*[c], *Chelsea Liu*[a], *Abby-Rose Cox (Kija, Nimanburru)*[d], *Rosemary Wyber*[a,e]

[a]Yardhura Walani, National Centre for Aboriginal and Torres Strait Islander Wellbeing Research, Australian National University, Canberra, Australian Capital Territory, Australia
[b]International Centre for Future Health Systems, University of New South Wales, Sydney, New South Wales, Australia
[c]Australian Institute of Health Innovation, Macquarie University, Sydney, New South Wales, Australia
[d]Kimberley Aboriginal Health Research Alliance, Djugun, Western Australia, Australia
[e]The Kids Research Institute Australia, Western Australia, Australia

Abstract

Research about Aboriginal and Torres Strait Islander chronic disease management in primary healthcare services rarely considers the perspectives of service users in identifying what works. This research aimed to elevate the voices of clients and providers from high performing primary healthcare services (termed Lighthouse Services) around Australia about the successes and opportunities for improvement in chronic disease management for Aboriginal and Torres Strait Islander peoples. Seventy-five individuals, representing clients (n = 29), their carers (n = 7) and health providers (n = 39), from four Lighthouse Services participated in in-depth focus groups and interviews conducted by the researchers and local partners. The transcripts of these discussions were reviewed in NVivo 14 (https://lumivero.com/products/nvivo/) using reflexive thematic analysis to identify key themes representing their lived experiences.

Access, Communication, Systems, Hub and spokes, Relationships and Workforce were the six themes chosen to represent the range of personal experiences about what works for managing chronic disease at

*Corresponding author.
E-mail address: sarah.bourke@anu.edu.au (S.C. Bourke).

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the primary healthcare level. Services that effectively employed a holistic patient-centred model of care, provided culturally safe spaces and were connected to and involved in the community were viewed as providing good care for their clients. The findings of this study support existing literature and make an important new contribution by focusing on the insights of clients, carers and service providers about what and why different aspects of chronic disease care work. It is suggested that this research approach would be beneficial across a range of other settings (e.g. non-Aboriginal community-controlled health organisations and urban services) and conditions (e.g. acute care, social and emotional wellbeing) to enhance Aboriginal and Torres Strait Islander health outcomes.

Keywords: Aboriginal and Torres Strait Islander; Chronic disease; Holistic approaches; Primary care

Highlights

- The success of chronic disease care for Aboriginal and Torres Strait Islander peoples is intrinsically tied to how well a service applies a holistic approach that is culturally respectful and inclusive.
- Incorporating Aboriginal and Torres Strait Islander language use into standard healthcare facilitates trusting relationships and effective knowledge translation between clinic staff and clients.
- Sufficient financial resourcing and flexible systems lead to better staff and client outcomes.

Introduction

Ensuring person-centred and culturally safe and responsive chronic disease care is a strong priority of the Australian Government, peak bodies and other stakeholders (Department of Health 2022; NACCHO 2021a). Prevention and management of chronic disease requires a complex multidimensional approach from both patients and health service providers. Considerable research efforts have explored the myriad of factors that act as enablers or barriers for the prevention and management of chronic disease for Aboriginal and Torres Strait Islander peoples (Parmenter et al. 2020; Sushames et al. 2017; Yadav et al. 2023a) and how primary healthcare may be optimised (McBride et al. 2022; Yadav et al. 2023b). However, the perspectives of service users and providers themselves have rarely been detailed in this research. Given the disproportionate burden of chronic disease for Aboriginal and Torres Strait Islander peoples because of colonisation, in combination with a lack of services framed around Aboriginal and Torres Strait Islander models of health and wellbeing, it is crucial that local service users' and providers' perspectives be incorporated into research seeking to identify what works and what requires improvement for chronic disease management.

In 2019, the Commonwealth Department of Health and Aged Care commissioned a team at the Australian National University (ANU) to explore policy and practice options for improving chronic disease care for Aboriginal and Torres Strait Islander peoples. The lived experience experts in this area are Aboriginal and Torres Strait Islander people receiving high-quality care and their service providers. In line with the principles of a strengths-based approach, the team sought to identify high-performing health services. Identifying such services allowed for exploration of the perspectives of service providers and clients about key aspects of high-quality chronic disease care in primary

care settings. This paper describes the qualitative findings from a series of focus groups and interviews held between October 2022 and April 2023 with four of these high-performing service providers and their clients about how chronic disease care works for them. This contribution to the literature moves beyond identifying *what* matters most to focus on the lived experience about *why* it matters.

Methods

Lighthouse Services: Selection and invitation to participate

Primary care services that receive funding through the Indigenous Australians Health Program are required to report on National Key Performance Indicators (nKPI) twice a year (Australian Institute of Health and Welfare 2023). Twenty-five nKPI, administered by the Australian Institute of Health and Welfare (AIHW), are used to provide information to primary care services about their care delivery. The ANU team worked with the AIHW to develop a protocol for identifying high-performing primary care services (Figure 1). Input was received from the Aboriginal and Torres Strait Islander reference group, Thiitu Tharrmay, suggesting that these services be called Lighthouse Services.

Organisations in the top 20% of services for six relevant nKPI results (PI18, PI20, PI23, PI24, PI06 and PI05 – pertaining to cardiovascular disease, chronic kidney disease and type 2 diabetes mellitus management) were placed in the candidate pool, based upon the latest single result (December 2020 reporting period) and the trend for improvement over time (across the 2017–20 reporting periods). Candidate services were also grouped according to the size of their Aboriginal and Torres Strait Islander consumer population (<2,000 or ≥2,000 regular Aboriginal and/or Torres Strait Islander service users). This strategy ensured that the Lighthouse Services that were invited to participate were sampled from a range of service sizes.

The AIHW team utilised this protocol to identify a pool of 47 services representing 40 organisations. These were grouped according to size and whether they were currently high-performing or demonstrating a trend of improvement over time. A selection from each of these groups was chosen by the AIHW to be approached to seek consent for the ANU team to contact the service Chief Executive Officer.

Ethics approval was provided by the Australian Institute of Aboriginal and Torres Strait Islander Studies (HREC reference number: EO234-20210223) and the Western Australian Aboriginal Health Ethics Committee (HREC reference number: HREC1191). This research was also guided by the National Health and Medical Research Council's (NHMRC) values and principles of conducting research with and for Aboriginal and Torres Strait Islander peoples and communities (NHMRC 2018).

Four Lighthouse Services consented to participate in this study: two based in northern Australia and two in Western Australia, servicing communities of various sizes (Table 1).

Focus group and interview question guide development

Semi-structured question guides were iteratively developed throughout the project (Supplementary material). These were adapted from a framework (Timothy et al. 2021) incorporating elements from the One21seventy systems assessment tool (National Centre for Quality Improvement in Indigenous Primary Health Care 2012), the World Health Organization building blocks of health systems (WHO 2010) and supplemented with the domains included in the Kanyini Health Systems Assessment tool (Peiris et al.

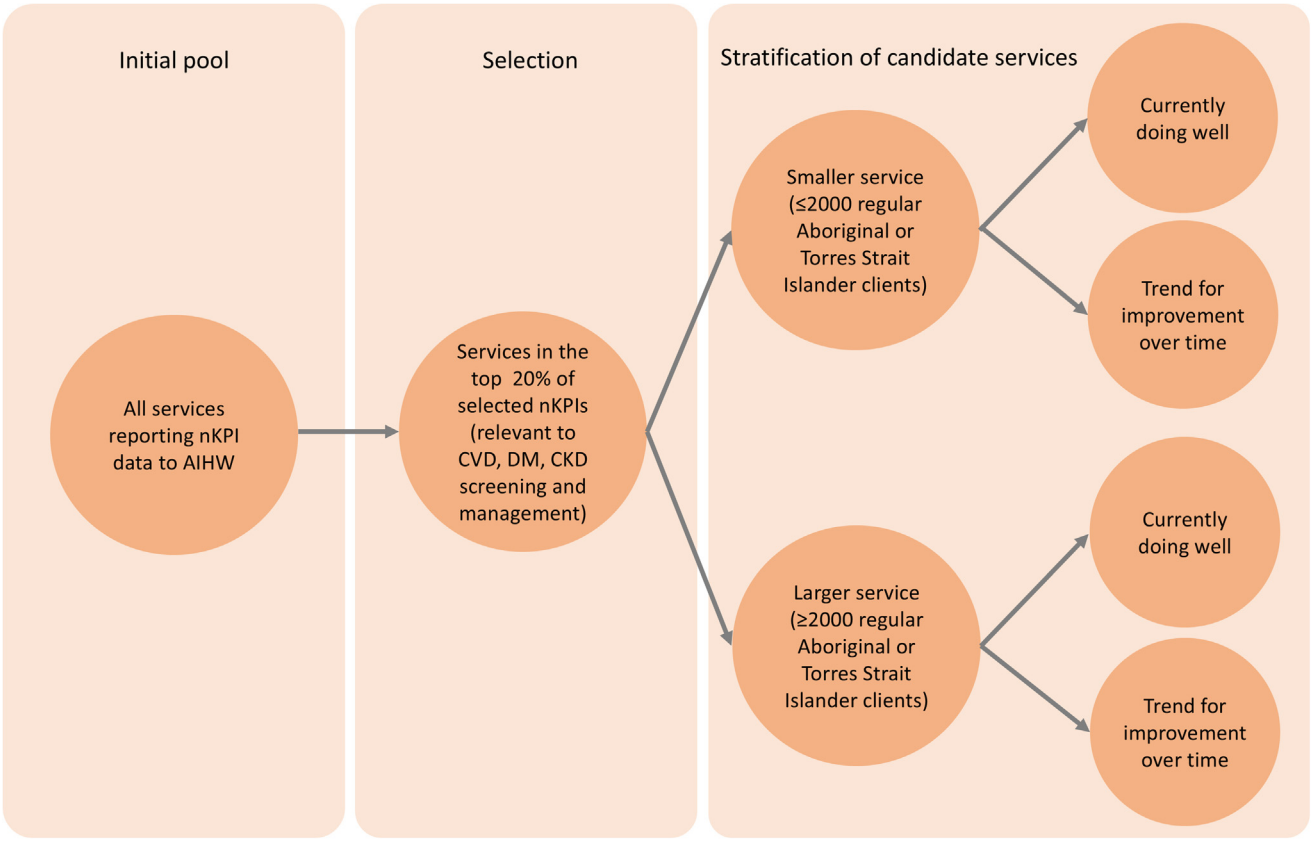


Figure 1: Protocol for using National Key Performance Indicators to develop candidate pool of Lighthouse Services. Abbreviations: nKPI, National Key Performance Indicators; AIHW, Australian Institute of Health and Welfare; CVD, cardiovascular disease; CKD, chronic kidney disease; DM, diabetes mellitus.

2012). These domains included accessibility, quality of care, cultural safety, models of care and communication, with the addition of shared decision-making. Questions were designed to be purposefully open-ended to allow free-flowing discussion, with prompts provided for interviewers to ensure that all

Service	Location, context and key service descriptors
1	Lighthouse Service 1 (LS1) is an Aboriginal community-controlled health organisation (ACCHO) service in northern Australia (MM5) servicing >15,000 consumers. There is nearby access to a tertiary hospital with emergency services and specialist services.
2	Lighthouse Service 2 (LS2) is an ACCHO service in northern Australia (MM7) servicing a community of <500 people. There is a nearby hospital providing 24-hour emergency services and visiting specialists.
3	Lighthouse Service 3 (LS3) is an ACCHO service in Western Australia (MM7) that provides primary and emergency healthcare services to a community of approximately 500 people. The service is nurse-led and run with support from general practitioners by phone, video conference and scheduled visits. In most months there are visiting specialist and allied health outreach team services from tertiary urban services.
4	Lighthouse Service 4 (LS4) is an ACCHO service in Northern Australia (MM7) servicing a community of <500 people for emergency services and primary care. Service is provided by Aboriginal health workers and practitioners, nurses and visiting general practitioners.

Table 1: Overview of the participating Lighthouse Services setting and context, including their remoteness identification (MMx) using the Modified Monash Model (Department of Health and Aged Care 2023)

areas were covered. As the focus was on eliciting responses around good chronic disease care at a systems level, the questions were aimed at discussion of chronic disease screening and management care. Substantive feedback from local research partners was received and actioned, as outlined in the Supplementary material.

Participant selection and eligibility criteria

Service providers, clients and their carers were invited by the Lighthouse Services to participate in interviews or focus groups, which were facilitated by local researchers or the ANU team. All participants were aged ≥18 years. Providers included any allied health staff or employees involved in the delivery of any chronic disease care, including those predominately working outside the clinic, such as drivers transporting clients to the service. Clients and carers were invited if they attended the service, cared for or provided support in some capacity for someone who attended the service. As the focus of questions was on general chronic disease care, there was no exclusion based on the type of chronic disease that clients experienced.

Data collection

Two-day or three-day site visits were conducted between October 2022 and April 2023 by local research partners of participating sites or research team members from the ANU, who conducted interviews or facilitated focus groups. Conversations were audio-recorded with consent and later transcribed and anonymised by a professional transcription company. A total of 75 participants provided 54 person-hours of qualitative data through in-depth interviews and focus group discussions across the four Lighthouse Services, including providers (n = 39), clients (n = 29) and carers (n = 7). Participant details and numbers are presented in Table 2.

Data processing and analysis

Transcripts were entered into the NVivo 14 qualitative data analysis software (https://lumivero.com/products/nvivo/). An initial reflexive thematic analysis (Braun and Clarke 2019) was conducted (DW, UNY, SCB, RW, CL) to specifically inform formation of policy and practice recommendations and align with domains developed during an associated literature review (Yadav et al. 2023b). A final review of these codes was led by SCB to further explore individual perspectives on what works in chronic disease care and elevate their voices in this research paper. This process involved a full assessment of the initial 121 NVivo 14 codes created by the original research team, and their re-organisation into a story about what works, what is not working and the pathways for improvement within the participants' lived experience of chronic disease care. Informed by these perspectives, the research team identified six key themes to highlight different facets of the lived experience story: Access, Communication, Systems, Hub and spokes, Relationships and Workforce.

Results

Access

Different forms of access were identified by clients and providers as key enablers for attending and engaging with primary care services for chronic disease management. The most common example was physical access, mainly the provision of transport to attend primary care. In most Lighthouse Services, this was facilitated by drivers employed by the clinic and using clinic vehicles. The importance of these drivers was repeatedly identified, both in physically transporting people to attend clinic and serving as an extended interface between clinic and community. Clients volunteered that they liked the clinic drivers or felt encouraged by them to attend the clinic. Service providers noted that clinic drivers delivering messages from the clinic or looking for people due for follow-up

	Providers	Clients	Carers	Total participants	Total person-hours
Service 1	7	9	6	22	22
Service 2	9	6	0	15	8
Service 3	15	10	0	25	20
Service 4	8	4	1	13	4
Total	39	29	7	75	54

Data are shown as *n*

Table 2: Number of participants and data collected per Lighthouse Service

was a critical component of outreach. This perspective was encompassed by one clinic driver who was interviewed:

> *I deal with the patients all day. I pick them up and they tell me a lot of stuff that they never share with other people. And have a cry with the people in vehicle with me. But I always give them that advice and say, 'Have a yarn to your doctor, and they can put you into the next step where you need to go' – Provider*

Providers also reflected in more detail about their role in arranging transport to secondary and tertiary care services. The responsibility for managing transport arrangements for critical hospital appointments was keenly felt and difficult to manage. Clinical information systems did not generally support the recording of transport arrangements, and some staff described maintaining large spreadsheets of clients who needed transport. One staff member reflected that they would 'go to sleep dreaming about it'.

Facilitating physical access to specific medical equipment or services was also identified by clients as being important. Examples included provision of blood sugar testing machines and local dialysis services. On-Country specialist services were considered critical to culturally safe care and highly valued by clients:

> *And one of the things the community has been wanting is more dialysis chairs and we're just getting two more in the new building... which will mean more people can be treated in their own community – Provider*

Incentives offered to clients were identified as generally beneficial for supporting access to and engagement in chronic disease care. These were most discussed in the context of Aboriginal and Torres Strait Islander people's health assessments (Medicare Benefit Scheme Item 715) and took the form of a T-shirt, grocery vouchers or 'pamper packs' once people had attended their health assessment. Some providers also said that people attended the clinic for a health check to access grocery vouchers when they ran out of food (see Discussion).

Communication

Providers at all sites identified that health education was most enabling when it best met the needs of clients. This included the use of Aboriginal language interpretation services, visual word poster aids, avoidance of medical jargon, use of relatable metaphors as examples, and using Aboriginal language/terms/names during clinical interactions. Of these strategies, the most notable was the use of Aboriginal language/terms/names by clinic staff to help engage clients in the care delivery process. Some providers said that asking knowledgeable community members to teach their staff local language was an effective strategy at building rapport, respect and engagement:

> *We try and encourage the staff to use language. And, actually, a lot of us are starting to incorporate into our*

normal business of the day and try to use some of their language as we introduce ourselves, and we talk through. Even simple things. The Elders are very, very good at teaching us a word – Provider

Barriers to knowledge translation were created when medical advice or information was not effectively communicated by the staff to their clients. Clients from two sites expressed that a lack of information or misunderstanding existed within the community regarding the progression of chronic disease, biomedical test results and chronic disease treatment. Clients said that if providers were able to communicate relevant medical information in their Aboriginal language, they would not feel frustrated or misunderstood. However, only a few clinical staff checked whether their clients fully understood what was being said during appointments.

Barriers to communication were partially overcome when trusted family members with a better understanding of English accompanied clients during their visits to the clinic. Additionally, one provider highlighted the role of Aboriginal health workers/practitioners in bridging the communication gap between service providers and clients. Aboriginal health workers/practitioners were recognised as knowledge brokers, key in translating knowledge, fostering community relationships and enhancing primary healthcare delivery:

I try to explain to them, break things down to the T, pretty much. We have patients coming in, and a lot of the time, they don't know why they're just... getting bloods. But I try to explain to them that it's not just that they're getting bloods. 'You're having medication, and the doctor is checking if these medications are working for you, and if they're actually helping you'. I try to encourage them to speak up, and say, 'How are you feeling? How's that medication making you feel? Are you experiencing any... feeling sick, or diarrhoea, or anything like that?'. But then I try to go on and explain further why we want to know those things. I think that's what's missing, a lot of times. They don't know exactly why we're asking these questions – Provider

Opportunities for feedback were identified as being important. Some clients and carers appreciated the service providers supporting them and their families, and were interested in holding regular, ongoing discussion groups with clients, carers and staff together to share their experiences and provide feedback. Providers from multiple sites mentioned that the suggestions of administrative and clinic staff, including doctors, nurses and drivers, were taken on board via regular staff meetings to improve the services.

Many participants identified the cultural competency of non-Indigenous staff as an essential element in driving respectful communication between providers and clients. Clinicians also reported that spending time outside the clinic building relationships with communities was crucial for fostering healthy communication with clients in a clinical setting. Patient-led care, two-way active listening and indirect questioning also helped clients feel supported:

The patients are actually being heard. Knowing that their feelings matter, and stuff like that. They're going to want to come back here... the patients that do come in regularly, they're quite active in their management and stuff. They know when there are changes in their medications, and they know when they're not feeling good, or they know when something is off with their body, type of thing, and they'll sort of bring themselves in. We have a few diabetic ladies that tend to get some wounds, and they'll come in, and they'll know that when

they get one little scratch or something, they come straight away – Provider

Systems

Providers across sites described similar systems being used for follow-up and case management of chronic diseases. These approaches were supported by use of clinical information software and by undertaking follow-up and recalls in a team-based manner. Participants, especially clinic staff, spoke of the importance of developing bespoke processes on-site to support their follow-up with clients, which worked well when they were flexible yet systematic. In remote areas, linking recalls to the provision of transport and outreach activities was crucial. Clinical meetings at one site were combined with transport coordination to support recalls in a coordinated but patient-centred manner:

Yeah, every morning. So, the reason for the clinical meeting is that we do recalls. How we get the recalls, they're based off pretty much the health check, one of them, when people come and get their blood test, and stuff. So, if they have any abnormal results, the doctor will put them on recall. A driver will be sent out to go to their houses to assist them with transport then. Sometimes, if they don't come at their normal recall, two or three occasions after, and then if follow-up isn't done by then, the health workers will go to their houses individually – Provider

Many clients also expressed a sense of safety or appreciation for systematic approaches to follow-up, including receiving reminders via a phone call, letter or SMS for follow-up appointments initiated by service providers. This removed the burden of clients needing to remember to book in for their reviews, and helped make clients feel taken care of through familiarity and continuity of care:

Continued support that always comes. I don't have to remind reception that I have to have my three-monthly review. They ring me up and tell me. It's all that sort of stuff. I don't have to tell the doctor to write out my blood testing and urine testing that I need done. They tell me. So, it's that kind of thing that keeps us going – Client

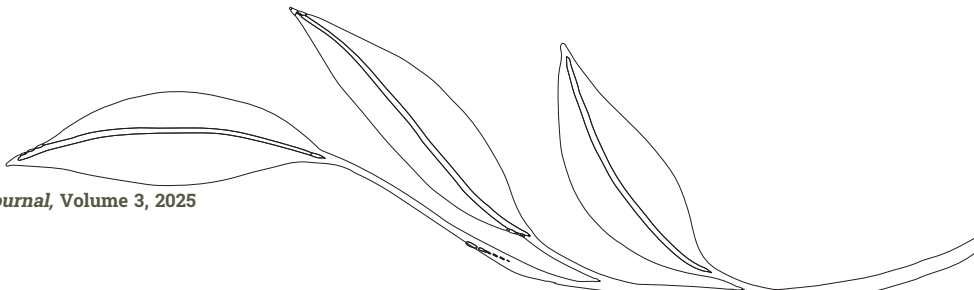
Staff and clients said that their team approach, combined with chronic disease-specific plans, supported case management:

A checklist thing [was developed by another staff member] which I find handy… I photocopy it and I have a look, and as I'm sitting there talking to them I scribble a lot of it out and then after they've left I enter the info, because they do not want to sit there while you're entering info [into the computer] while you're talking… the folk out here don't respond to that, they want you to pay them attention and get them what they want, which is fair enough – Provider

Service staff described clinical information systems software as 'taking the guesswork out of it' by facilitating standardised care delivery during consultations and supporting recall processes. However, the software was not always fit for purpose, so providers had to develop their own workarounds to suit the priorities and needs of their clients and clinic teams; this included creating spreadsheets and paper copies for people requiring specialist review or referrals. They also reported that clinical information systems were not intuitive and required training and time to learn to use effectively in the course of chronic disease consultations like health checks.

Hub and spokes

Clients and carers frequently described their care services as hubs: 'it's not just a medical centre… it's a hub of support' (Carer). The research team employed the hub and spokes concept to emphasise that chronic disease care for Aboriginal and Torres Strait



Islander peoples is most effective when integrated into a one-stop access model. In this model, the 'hub' symbolises the priority of consolidating various services, while 'spokes' represent outreach services that enable clients to have comprehensive access to these services. Service integration was identified by both providers and clients as coming to the forefront of the hub and spokes model. This integration should include specialist services, allied health, amenities and other related services:

> *…we've got a specialist email group that we have, where it's just the specialist, me, our managers, and our head admin lady here… Say a nephrologist is coming here to [place], they'll organise a room, make sure they've got [specialist name], make sure they get picked up from the airport… We've got a whole team that sort of work together when specialists come… and they'll leave notes for our doctors… and that's where we come in, and we're in that middle. It makes follow-up happen faster, as well, when we actually get to sit in with the patients, with their specialist visits – Provider*

Clients and carers underscored the importance of access to allied health services, including but not limited to physiotherapy, dietetics, speech pathology and podiatry, as well as associated amenities such as gym, pool and hairdressing services. These services were considered to be key facilitators of community engagement and should be integral components of the overall service offering. Medication dispensing was used as a prime example of how effective service integration can enhance care quality and clients' overall experience:

> *When I go interstate, and something happens to my medication, it's just a phone call away. That's all it is. Just a phone call away and they'll have it there in Victoria the next day – Client*

> *I love the fact that the chemists here are connected to the doctors. So, I don't even have to now get my prescription. They just ring up and renew the prescription, so that's another stress gone. And I get all my tablets delivered to home. So, it's the best service I've ever been to – Client*

One person in particular emphasised the importance of the hub and spokes model of healthcare for their chronic disease management:

> *I have three chronic illnesses. And I see all the specialists and everything that come. What I love about this place is everything condensed into it. My bloods, I can just go downstairs. All my x-rays, scans, everything, I can just go round the corner. Chemist right at the door. And again, makes my tablets up, delivers them. If there's anything else, and I can't get in to see a doctor, you can go and talk to the chemist. And they're just right on the ball with everything. There's even a hairdresser here. But I absolutely love the fact that the specialists come here, and as I said, I've got three different ones that I have to go see, so for the most part I can see them here, and I've only got to go to [capital city] a couple of times a year. So, I love that – Client*

However, providers noted that limited and/or rigid funding and resources significantly hindered integrated service delivery and increased the cost burden on clients. This situation highlights the necessity for adaptable, local needs-driven funding and resource allocation to build a connected community and effectively address clients' holistic needs.

> *For example, for kids I can refer from 0 to 5 years olds to XYZ nutrition but after they hit over 5 [years of age] there's no resources available to them – Provider*

I think with the renal it's the fear that they do have to leave the land because when they go off lands they're off for a long time. You go to [capital city] initially that could be six to nine months, then it's a wait for a chair in [regional town], that can be another six to nine months, and then they come and they have to sit and wait for a chair and there's only one way you get in the chair because there's not too many people have a renal transplant – Provider

Relationships

Clients and carers often spoke about the importance of healthcare providers actively building relationships with their patients and the wider community. Fostering these connections was said to be representative of the cultural practice of respect and demonstrated that the providers were invested in the holistic health and wellbeing of their clients and their families. Several clients and carers emphasised the importance of the clinic environment and staff being welcoming for them to feel culturally safe and for supporting people when they are feeling vulnerable to talk about their worries or have a laugh together. Privacy and confidentiality were key aspects of building trusting and respectful relationships between the health service and their clients:

It's that quality of care, and confidentiality is a big one here. I feel like you can go into anywhere in this area and have a chat that you need to have a chat with. I can go have a chat with this gentleman here and know that's between us. And the confidentiality thing is huge, because you want to – as an Indigenous person you want to be able to feel that any information that you're talking about in regards to the person you're caring for, is between you, the health worker or doctor, and the patient. You want them to be able to feel that, otherwise you're not going to be bringing that patient back here – Carer

Clinic staff commented that developing care plans with clients was a key opportunity to be proactive in asking more questions about their holistic health and wellbeing beyond what is included in standard clinic forms. Being flexible by conducting these sessions over several visits also helped to ensure that clients were engaged in the process and provided with the opportunity to reflect, ask questions and build a relationship with their healthcare provider. Tailoring sessions to the clients' individual context, being encouraging and recognising clients for progress in managing their health conditions made a significant difference to one person's experience:

Can I just say that when you are being treated, the encouragement that's given, and the support that's given makes a difference. Oh, goodness. When you feel like you just want to give up, they're there to pick you up. Yes. And they don't push you, they pick you up, literally, and go with that. And it just makes such a difference. I look forward to coming in. The very first thing I do when I walk in is I go down the nurse's station and jump on the scales. It's the very first thing I do. And I get so much encouragement, and because of that encouragement I can tell you I've lost over 50 kilos – Client

Running health-related events for community members to attend, with food provided, was viewed by many as a way for the service to become better integrated within the community. For the service staff, being out in the community enabled them to connect with potential clients or re-engage with old ones outside of a clinical environment. Organising one type of event, such as hearing screenings for children at schools, enabled providers to engage in a wider spectrum of health education and support, such as teaching hand hygiene practices. These informal engagements also gave community members the

opportunity to discuss what they needed from the health service. For example, health services providing financial and logistical support to hold women's and men's sessions was seen as generating greater social wellbeing alongside physical health benefits for community members.

> *It's really good because what goes on in the room stays in the room. And there's just so much support in amongst us, and strength... Empowering one another... And with our men's group... it's not just the actual physical benefits for us... it's the wellbeing of our mental health. Getting around one another. Getting outdoors... So, all these different things they just network together and become a strong chain. It makes you feel like you're worth something. Because everyone is all in the same boat. We all care about one another – Client*

Workforce

Staffing and workforce considerations permeated conversations in all four Lighthouse Services. This inevitably included discussions about staff shortages, unfilled positions, turnover and new clinic workers. Service providers and clients had a shared sense of frustration about workforce issues and reflected on the direct implications for their own experiences, such as increased waiting times when services were understaffed. Frequent staffing changes also constituted a barrier to culturally safe care, partly because they made it difficult for people to form trusting relationships. Staff remaining for a longer period of time and actively seeking to spend more time in the community helped to build trust with clients and their families:

> *I've been blessed enough to have the one doctor here, and she's been amazing... I've got chronic diabetes or had chronic diabetes. They say it's a hereditary thing... And I've had it for 25 years, and it was always something that I was just taking medicine, just treating it. It was never improving. I'd come here and then my doctor decided to go about more – I love the way that she goes about a holistic approach about medicine. Not just putting you on medicine, and that's the end of it... And I decided one day to actually take her advice... And then, I'll never forget the time after three months, we'd do our tests for three months for your diabetes and that. And my health workers beside me, he's telling me saying... 'Well [name], I've got to let you know that you've just reversed Type 2 diabetes.' ...it was taking the advice from my doctor here. And I went and actually put it into practice... I've got eight kids, and I thought no, I want to be around a lot longer than this. I want to get a hold of it. And to see the snowball effect of me sharing my testimony to all mob back home, and mob around here, was an amazing thing. Because they all realised, no, this diabetes is not just treatable, it can be, you can reverse it. And I actually reversed it, so I'm very thankful for my doctor and the way she goes about that holistic approach of treating chronic diseases – Client*

Providers frequently said that understaffing was a barrier to delivering the kind of quality and relational care that they would like to deliver. Workforce shortages were a barrier to accessing their own professional training and development. This also contributed to reduced Medicare benefits schedule income for services when specific items could not be claimed unless a doctor was physically present to see clients. Providers described experiencing a professional tension between acute service needs and the value of preventative healthcare. The idea that preventative care was valuable and valued – but almost impossible to have time to do well – was mirrored by clients.

Strategies to manage or mitigate workforce issues were widely discussed. Employing clinic staff from the local community was identified as a way of reducing both staff turnover and barriers to culturally safe care. Having the service staffed by community members was mostly seen in a positive light because it facilitated a deeper connection to the wider community. However, some individuals found it difficult to manage this dual role, as family members contacted them on their personal phones or outside work hours to organise access to services:

> *Like, from my own family, but I tend to put my foot down with my own family. Because they know I work here, they tend to ask me, myself, on my private number, 'Can you get my medication?', or 'Bring my medication home.' I'll forget, and they'll tell me off, later. But then I tend to tell them, 'No, I'm not the clinic. You guys need to call the clinic and put your name down' – Provider*

Other strategies to mitigate workforce shortages included establishing chronic disease-focused clinical roles or portfolios. These positions were felt to provide some protective effect from the competing demands of acute care and engendered a sense of responsibility for specific chronic disease care delivery among named staff.

Discussion

The most important finding of this paper was that, from the various perspectives of health service providers, clients and their carers, the success of chronic disease care for Aboriginal and Torres Strait Islander peoples is intrinsically tied to how well a service applies a holistic approach that is culturally respectful and inclusive. The participants described a range of instances when they had, or had not, experienced this approach at their health service and each of the six themes above elaborated on these different aspects. These themes intrinsically connect to one another through the healthcare services that are provided. For example, the important role that clinic drivers play in transporting clients to a service, which was highlighted under the theme Access, is also dependent on Workforce provisioning, and facilitates building Relationships through caring and effective Communication, and so forth. This connected approach reflects the National Aboriginal and Community Controlled Health Organisations' (NACCHO) Core Services and Outcomes Framework and the acknowledged strength of ACCHO services in addressing structural determinants of health and wellbeing (NACCHO 2021b; Pearson et al. 2020). An enabling policy and funding environment for this kind of comprehensive care includes flexible needs-based funding and community-led priority setting.

The context of life in remote communities was implicit throughout many of the interviews and group discussions. Participants discussed family responsibilities, food security, geographical isolation, perceptions of clinical staff safety and poverty as factors influencing engagement with healthcare. The experiences of living in very remote settings were indivisible from the experiences of seeking care in those settings. Many participants volunteered observations about these social determinants of health contributing to chronic disease burden or barriers to care.

An important limitation of the research was that despite attempts to recruit Lighthouse Services from different jurisdictions and governance structures, only services from two jurisdictions, and only ACCHO services, were ultimately able to participate. This was notably due to the COVID-19 pandemic that coincided with the recruitment period. The number of services

included in this research may limit generalisability of the results in other settings, although it is reassuring that these findings are closely aligned with existing literature and among the participating Lighthouse Services.

Further research could explore the relevance and resonance of these findings in different settings (including non-ACCHO and urban contexts) and for other conditions (including acute care and social and emotional wellbeing services). However, the themes in this study are largely congruent with existing literature and what is known to be important to Aboriginal and Torres Strait Islander people seeking healthcare (e.g. Davy et al. 2016; Nolan-Isles et al. 2021; Pinero de Plaza et al. 2023). The value of this work is less in identifying what matters most and more about elevating the voices of lived experience experts about why it matters. Given that the details of these perspectives have largely been omitted from previous research, as highlighted in the Introduction, this paper offers an important person-centred contribution. Specific examples and shared stories bring meaning to concepts that may otherwise be abstract or reductionist, such as 'provide welcoming waiting areas' or 'offer outreach services'. Research should provide a foundation for evidence-informed decision-making by communities, health services, governments and funding agencies. This work adds weight to the volume of evidence about factors that support primary care delivery and offers important contextual knowledge of why it matters.

Conclusions

This paper has demonstrated that focusing on the personal perspectives of service clients, their carers and healthcare providers helps to elucidate the deeper meaning and impact of key aspects of good chronic disease care and management for Aboriginal and Torres Strait Islander peoples. While these aspects inevitably reflect the broader social environment of this healthcare delivery, knowledge holders also emphasised the importance of cultural safety and inclusion for improving health communication, building trust and growing a sense of community that incorporates health service provision.

Author contributions

S. Bourke: Conceptualisation, methodology, software, validation, data curation, formal analysis, writing – original draft, writing – review and editing; D. Wong: Conceptualisation, investigation, methodology, data curation, formal analysis, writing – original draft, writing – review and editing, project administration; U. Yadav: Conceptualisation, investigation, methodology, data curation, formal analysis, writing – original draft, writing – review and editing; A. Timothy: Conceptualisation, investigation, writing – review and editing, formal analysis; C. Liu: Investigation, formal analysis, writing – original draft, writing – review and editing; A-R. Cox: Investigation, formal analysis, writing – review and editing; R. Wyber: Conceptualisation, methodology, investigation, data curation, formal analysis, visualisation, writing – original draft, writing – review and editing, supervision.

Declaration of interest

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Author biographies

Dr Sarah Catherine Bourke (she/her) is a medical anthropologist and Research Fellow at Yardhura Walani, the National Centre for Aboriginal and Torres Strait Islander Wellbeing Research at the Australian National University. She is a Gamilaroi, Jaru and Gidja woman born and raised on Ngunnawal and Ngambri Country in Canberra. Her research focuses on Indigenous knowledges and philosophies of what it means to be well and live a good life. She was awarded a 2024 Australian Research Council Discovery Indigenous grant to explore belonging and wellbeing for Indigenous peoples living in cities.

Dr Deborah Wong is of south-east Asian heritage, was born in Singapore and raised on Gadigal land of the Eora Nation (Sydney). She currently lives and works on Ngunnawal and Ngambri Country (Canberra). She has qualifications in medicine and science and was Research Coordinator for programs on cervical cancer screening and chronic disease prevention for Aboriginal and Torres Strait Islander people at Yardhura Walani. Dr Wong has contributed to several academic outputs and reports to government with a focus on cardiovascular disease prevention and screening in primary care.

Dr Uday Narayan Yadav (Madhesi/Tharu, Nepal) is a chronic disease implementation scientist at Yardhura Walani. His research interests include non-communicable diseases, Indigenous health, primary healthcare and evidence-based policy. In 2024, he was awarded the NHMRC Investigator grant to address social and cultural determinants among Aboriginal and Torres Strait Islander peoples with chronic conditions. His research has two major strands: one is on assessing the strengths/power of the communities and their unmet needs using a co-design approach, and another is on implementing and evaluating co-designed solutions to address those identified needs.

Dr Andrea Timothy is a Research Fellow at the Australian Institute of Health Innovation, Macquarie University. She was born in South Africa, and raised in Aotearoa New Zealand, Wurundjeri Country in Melbourne, the Philippines, Singapore and Malaysia. She has a background in science and public health, with a specific focus on health systems strengthening and implementation science. Her work has included investigating new approaches to develop strategies to strengthen immunisation service delivery in Western Cape province, South Africa, ensuring Australian cardiovascular disease guidelines are appropriate for Aboriginal and Torres Strait Islander peoples, and community-based strategies to improve the health and wellbeing of Aboriginal and Torres Strait Islander peoples. Andrea currently works across multiple projects focusing on developing and implementing approaches to improve aged care medication challenges in collaboration with aged care providers, clinicians and policymakers.

Dr Chelsea Liu is originally from mainland China and is of Han ethnicity. She has lived and worked on Ngunnawal and Ngambri Country in Canberra for over a decade. She is currently a Postdoctoral Fellow at Yardhura Walani. Her research focuses on enhancing primary healthcare for Aboriginal and Torres Strait

Islander peoples and addressing implementation challenges in the digital transformation of healthcare.

Dr Abby-Rose Cox is a member of the Nimunburr community with connections to Kija in the East Kimberley. Her experiences of teaching, primarily with Aboriginal youth, has been a driving force in pursuing a career in research. She works as the Evaluation and Research manager at the Kimberley Aboriginal Health Research Alliance in Broome, which aims to flip research in the Kimberley to ensure that First Nations peoples are involved in every stage of the research journey. Her PhD work centred culturally strong social and emotional wellbeing programs as a priority for health and education.

Dr Rosemary Wyber is a non-Indigenous/Balanda/Pakeha general practitioner and researcher from Aotearoa New Zealand. She currently lives and works on Ngunnawal and Ngambri Country. Her research focuses on health considerations with Aboriginal and Torres Strait Islander people and effective primary care systems.

Supplementary material

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