RESEARCH ARTICLE

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Delivering health programs for Aboriginal and Torres Strait Islander children: Carer and staff views on what's important

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Abstract

Background: The lack of evidence on the priorities of carers and their Aboriginal and Torres Strait Islander children undermines decisions to improve participant experiences and engagement.

Aims: This study describes carer and staff perspectives on the aspects of health services delivery that are important to carers and children.

Methods: Nineteen carers of Aboriginal and Torres Strait Islander children and 17 staff who work at child health programs across two urban Aboriginal Community Controlled Health Services (ACCHSs) and affiliate organisations in New South Wales, Australia participated in semi-structured interviews. We used thematic analysis to analyse the data.

Results: We identified five themes: valuing relational communication (building trust by keeping relationships at the centre, empowered to optimise child's development, feeling heard and known); confidence in provider's clinical and interpersonal skills (certain that the health issue will be resolved, engaging with the child to allay fears, facilitating timely health care); finding comfort and security in community embedded services (safety and acceptance in the familiar, strengthening child's connection to culture); support to access and navigate health services (accessible information appropriately presented, easy and flexible scheduling, easing the shame of financial hardship); sustaining service use (fulfilling expectations for service standards, demonstrating commitment through ongoing programs, clarity of benefits).

Conclusions: Carers and staff reported that approaches to communication, the content of that communication, how access is facilitated and the service environment managed influences their decisions to interact with health services. With these data decision-makers can better focus resources to improve experiences with their services.

KEYWORDS
Aboriginal and Torres Strait Islander peoples, children, program evaluation, primary care

1 | INTRODUCTION

In Australia, Aboriginal and Torres Strait Islander people seeking health care often have to consider their own or their community's experiences with health services before deciding where and when to interact with the health care system.[1–3] This additional step in decision-making is attributed to the discrimination and judgement that many Aboriginal and Torres Strait Islander people continue to face when receiving health care.[4] While there is greater awareness of these challenges among health care providers, there remains a lack of data connecting health service processes to participant experiences.[5] Knowing what Aboriginal and Torres Strait Islander communities prioritise when receiving health care could help to improve patient experiences and engagement.[6,7]

Most Australian states and territories collect data on Aboriginal and Torres Strait Islander patients' experiences with health care to determine whether services are meeting patient needs, however, data gaps remain.[8] Specifically, there is a lack of data on the process characteristics of the health services designed for Aboriginal and Torres Strait Islander people – what is done to and for the people who use those services and when and how those activities occur throughout the delivery of health care.[9] Further, data on health service processes that are valued by Aboriginal and Torres Strait Islander people varies across jurisdictions, with age, gender and health conditions and is rarely based on lived experiences.[7,10–12]

There are insufficient data on children's health service use in Australia, particularly for primary care.[6,13] Data on the experiences of Aboriginal and Torres Strait Islander people when accessing health services in general are also limited[6] and the available data on Aboriginal and Torres Strait Islander children are often state or region specific.[14,15] Typically, data to inform policy and decision making in Indigenous health have focussed on bio-medical measures[16,17] and less on participant and community reported experiences.

Information from Aboriginal and Torres Strait Islander carers and children about the health processes that are important to them can inform how decision-makers allocate resources and guide the design of service blueprints and health promotion that is responsive to the changing needs of communities. The purpose of this study was to describe the aspects of delivering child health programs that are important to carers and staff from two urban Aboriginal Community Controlled Health Services (ACCHSs) who are partners in the Study of Environment on Aboriginal Resilience and Child Health (SEARCH).

2 | METHODS

2.1 | Study design

This study was guided by the principles for conducting research in Aboriginal and Torres Strait Islander communities.[18] We conducted semi-structured interviews and used the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) to report this study. Ethical approval was obtained from the Aboriginal Health and Medical Research Council (1345/1) and the The University of Sydney human research and ethics committee (2018/103). Community consent was sought and obtained from two ACCHSs in New South Wales, Tharawal Aboriginal Corporation and Riverina Medical and Dental Aboriginal Corporation, who are partners in the Study of Environment on Aboriginal Resilience and Child Health. SEARCH is a longitudinal cohort study of urban Aboriginal and Torres Strait Islander children involving a partnership with ACCHSs to describe and investigate health indicators for Aboriginal and Torres Strait Islander children based on the priorities of the ACCHSs.[19]

2.2 | Participants and setting

Purposive sampling was used to recruit staff and carers of Aboriginal and Torres Strait Islander children attending child health programs offered through the ACCHSs and affiliate community organisations to ensure we included participants from a diverse range of demographic characteristics across the programs. Child health programs were defined as all services specifically designed to improve, maintain or promote the health of Aboriginal and Torres Strait Islander children. All participants were identified and recruited by SEARCH Aboriginal Research Officers employed at two urban ACCHSs. Carers were approached face to face by the research officers in the waiting room before or after their health appointments or programs at the ACCHs. Participates where invited to participate at a time that was convenient for them which was usually when they brought their child to a health service. Interviews were held at the ACCHSs and written informed consent was provided by all participants. A supermarket gift voucher worth AUD $25 was offered to participants to reimburse participants for their time and as a show of goodwill.

2.3 | Data collection

One author (SC) and a SEARCH research assistant conducted all the face-to-face semi-structured interviews using the interview guides provided in Appendix A. Both interviewers were non-Aboriginal or Torres Strait Islander and not known to the interview participants. To ensure cultural safety, an Aboriginal research officer was available to observe interviews with the staff or carers and one participant accepted the offer to have an observer present. Carers were asked about their expectations of child health programs based on their experiences with a health program their child had participated in. Staff were asked about their views on what was important to carers and children who participate in their programs. All interviews were conducted in May 2018, each lasting an average of 20 minutes.

2.4 | Data analysis

Using thematic analysis SC read the transcripts line and by line and using principles of grounded theory, inductively identified concepts to

capture the processes and approaches to care that participants valued and the impact on carer experiences and expectations of the child health programs. Similar concepts were grouped into themes and sub-themes. MD reviewed the preliminary themes and concepts were revised based on discussions with SC. The final themes and sub-themes were developed with the rest of the author group to ensure that the full range of data was reflected in the findings. To check for appropriateness, the themes were presented to a group of Aboriginal and Torres Strait Islander and non-Aboriginal or Torres Strait Islander research officers who either work at or work closely with the ACCHSs and revised until they were acceptable. SC coded the data using NVIVO version 12 for analysis.[20]

3 | RESULTS

We conducted 36 interviews, 19 (53%) carers and 17 (47%) staff. The characteristics of participants are provided in Table 1. Most of the respondents were female (30 or 83%) and 40 years or younger. The majority of participants were Aboriginal and Torres Strait Islander in both the carer (84%) and staff (71%) groups. Two participants interviewed were both carers of children using the health care services and staff members at the ACCHS providing the service. When discussing their experiences, participants referred to programs offering services in childhood development (15 or 42%

TABLE 1 Characteristics of participants (n = 36)

Characteristic	N (%)
Age group (years)	
<20	1 (3)
20-30	8 (22)
31-40	11 (30)
41-50	12 (33)
51-60	2 (6)
>60	2 (6)
Sex	
Female	30 (83)
Male	6 (17)
Participant group	
Carer	19 (53)
Aboriginal	16 (84)
Non-Aboriginal	3 (16)
Staff	17 (47)
Aboriginal	12 (71)
Non-Aboriginal	5 (29)
Child health program	
Childhood development	15 (42)
Medical	10 (28)
Mental health	10 (38)
Other nonclinical	1 (3)

respondents), medical services (10 or 28%) and mental health (10 or 28%). We identified five themes: valuing relational communication, confidence in provider's clinical and interpersonal skills, finding comfort and security in community embedded services, support to access and navigate health services, sustaining service use. Each theme and sub-theme are described below with selected quotations from carers and staff provided in Table 2. A schema to show the conceptual links among the themes is provided in Figure 1.

3.1 | Valuing relational communication

3.1.1 | Building trust by keeping relationships at the centre

Carers felt that when staff understood and valued Aboriginal and Torres Strait Islander approaches to interacting and communicating (showing genuine care, concern and interest), they were better able to strengthen relationships and build trust. Staff noted that embracing and incorporating Aboriginal and Torres Strait Islander ways of communicating such as Yarning into their practice helped to maintain their connection with participants. Yarning is a way of communicating used by Aboriginal and Torres Strait Islander people where 'information is embedded within the story or yarn being told, with the onus on the listener or receiver of the yarn to hear and make meaning of the information being imparted'.[21] Staff from an adolescent mental health program reported that when they took the time to 'have a Yarn' (staff_34), the adolescents were more responsive to counsel. Similarly staff from some clinical programs reported that when they engaged in Aboriginal and Torres Strait Islander methods of communication at the start of their consultation they were able to build relationships and achieved 'good relation' with carers and children, improving participation in their program – 'they actually coming back, and many families ...they don't have severe problems, they're just coming back for check-ups' – staff_11.

3.1.2 | Empowered to optimise child's development

Carers expected staff to recognise and demonstrate confidence in their capacity to help their child reach their developmental potential while providing them with the skills to self-manage their child's condition – 'What I expected from the speech pathology program is to give me skills to teach him at home, what we can work on' – carer_05. Some staff understood the importance of 'partnership' (staff_16) with the family when providing care to a child.

3.1.3 | Feeling heard and known

Carers wanted to feel heard and know that theirs and their child's concerns would be taken seriously and responded to by health
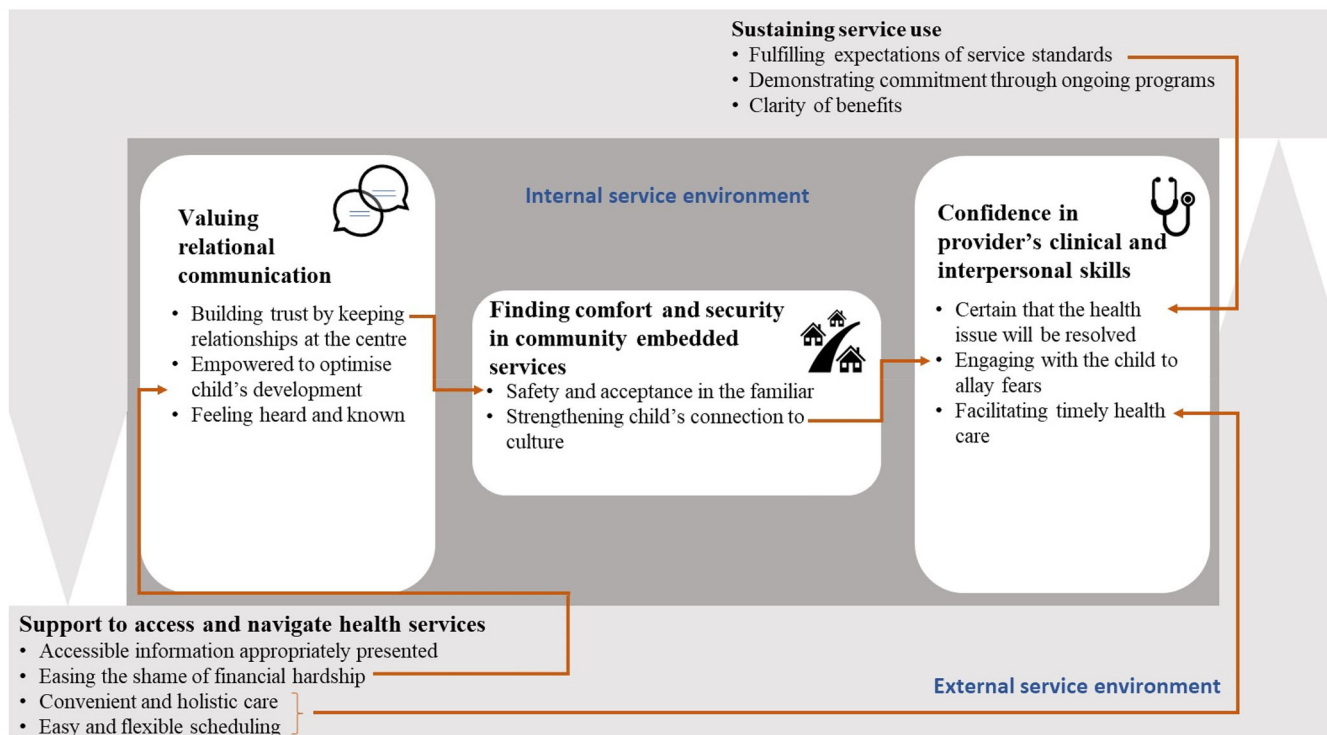
TABLE 2 Themes, sub-themes and selected illustrative quotes

Theme	Quote
Valuing relational communication	
Building trust by keeping relationships at the centre	'What's important for the child, is that mom and dad are spoken to respectfully, as well as them. And that there is, respectful conversation that occurs right from that initial meeting, because the children often watch how we as professionals talk to their parents and judge that as a reason to engage with us or not. And, I find that is really important … of course, body language is massive, how you hold yourself, how your hands are, …tone of voice, and your ability to listen' – (staff_16).
	'Sometimes they'll come and, just little conversations they have with you is just like they need to get something off their chest and then as soon as they have that conversation, how they act after they've opened up to you …like the burden's been lifted off their shoulders' –(staff_06).
	'It's trust and consistency. So, once you trust the people and they have shown, like they have proven [themselves] …you have respect for them' – (carer_07)
Empowered to optimise child's development	'And, we can all learn something from the professionals in their areas … I think that's the most important thing is to educate us as caregivers, parents … To help us learn different skills, learn different ways for bringing up our kids' – (carer_05).
	'…the parents as well needs education and awareness on preventing these things, you know … depression and mental health' – (carer_23).
	'It's about skills with adolescents. Sadly there are, you know, some parents that will come in that don't necessarily learn all the skills. They may be reaching out because they're aware that they're not coping' – (staff_29).
Feeling heard and known	'… that personal relationship that you have with them, in a sense, or they know what's happening with you' – (carer_31).
	'See, we sort of listen to the kids though, instead of us trying to think of ideas, and they don't want to do it' – (staff_34).
	'She [staff] knows me, I know her. Now she knows my daughter …I found it easier because I didn't have to really explain myself …She already knew, you know? Yeah that's nice. It's nice to not have to go through, fill out forms and explain everything again' – (carer_26).
Confidence in provider's clinical and interpersonal skills	
Certain that the health issue would be resolved	'They call me and say, "Can you get me an appointment for doc – with Dr.[doctor's name]," knowing that he's hard to get a hold of. That shows me that they want their kids to have the best. They want to make sure their kids, when they take their kids, that when they're checked over they can trust that opinion. That's what it says to me … They would rather wait even though a doctor or someone else would say, "Why didn't you … they should've gone in sooner." No, a parent saying Dr. [doctor's name] means they want the best' – (staff_16).
	'Well I think the people who run the program are really important, their knowledge of what the, you know, um they're talking about, they need to make sure like they're up to date on everything' – (carer_04).
Engaging with the child to allay fears	'So, I think having that interaction with the kids is important. Um letting them have fun, if it's an activity where they can engage themselves in. Um, not making them scared …' – (carer_04).
	'… when the girls waiting for their appointment, I heard the ladies … [say], "How's your little brother going? What have you been doing? Have you been helping mom?" So, I that little conversation with them as they're sort of walking off … they love it' – (carer_31).
	'Instead of, like, just getting them all up, sitting them down, making that person [staff] to talk. We'll get that person going around and having a yarn, engaging with them … so the kids know who it is and then they get that rapport … they can get that person one on one, go, "Oh, a little bit of trouble with this. You reckon you'd be able to help me?"' – (staff_34).
Facilitating timely health care	'… I just think, like, if we didn't have this program, a lot of the ones that are in need … and need that extra help and guidance … Would slip through the gaps' – (staff_02).
	'We have picked up on a lot of health issues with kids that parents haven't … things like speech, if it's mum's first child and she hasn't really been around other kids before and you know, the kid's talking but not really well for their age and things like that. We might go, maybe it's a good idea to book little [child's name] in to have a speech assessment and things like that so these programs are important for us to pick up on these things' – (staff_18).
	'If it wasn't for [program] my son wouldn't have had his grommets done and I probably wouldn't have realised how severe his hearing issues are. Um so it has opened my eyes to you know what needs to be done and how serious it is' – (carer_17).
Finding comfort and security in community embedded services	
Safety and acceptance in the familiar	'The scariest thing for them (patients) … other people being judgemental. Not knowing the circumstances or the situation. There is, you know, people out there that can be like that … And that's not good, so it puts them off' – (staff_02).

TABLE 2   (Continued)

Theme	Quote
	'They understand you. They don't see you as like, a number. They see you as a person. They want to get to know you and things, and help you and not judge a book by its cover. They actually read the, open the book and read it … and then help instead of judging' – (carer_13).
	'I think he feels more comfortable around his own culture. Like his own people' – (carer_22).
	'As a parent … It's a big thing when you let your kids go. You trust people that you're handing your children over to. So that's a big thing as well as a parent and I felt like my kids were safe in the environment …' – (carer_23).
Strengthening child's connection to culture	'And they have a lot of … learning and everything like that, it's really based around Indigenous and everything like that, so I really thought that was important for them to be a part of' – (carer_12).
	'… because it's Aboriginal playgroup, we have to put cultural practices and that kind of stuff-in so the kids can learn their culture' – (staff_06).
	'It was also with his brothers and sisters you know community, um, members but you also teenagers … And just talking about um, being strong black, and deadly you know?' – (carer_01).
	'Without them [staff in the service], I don't think that we would have the connection to community that we have' – (carer_26).
Support to access and navigate health services	
Accessible information appropriately presented	'Um, and it needs to be, like, defined. You know, where they can understand it. Like, you know, not everyone's um, good that they're reading and writing and that sort of stuff' – (staff_02).
	'I take home homework. Every visit is homework to take home and I believe it's working cause he's talking a lot more' – (carer_05).
	'We'll put it on the table and then that's … that way that will gather their information that they need or if they have a question and we'll just send it to the table and like, "oh there's all information like help yourself"' – (staff_06).
Convenient and holistic care	'… hearing checks and eye testing, and everything like that. And if your, um, child needs help with their speech, they can offer that as well' – (carer_12).
	'We can refer them in house, which is a good thing' – (staff_02).
	'She came to play group on Wednesday with him, um, and signed her up for the doctors. So she can bring him down there' – (staff_02).
Easy and flexible scheduling	'[name] actually done his, his needles yesterday … she come late, but she got here' – (staff_02).
	'If I come in one week and I say like, "[child's name] is really sick, I need to get her to the doctor." They'll say, "Oh, we'll see, we'll see if someone can pick you up in like an hour, make sure you're ready"' – (carer_26).
Easing the shame of financial hardship	'But yeah like if, like if, if I'm struggling and I need baby milk, I can be like, "Look I'm struggling, I need baby milk." She'll be like, "Yeah, give me two, give me about an hour." She'll run around. She'll get me a tin of milk, the fancy milk. She'll go and get it for me' – (carer_26).
	'If they're not getting transported, they don't have an Opal card or they don't have the money to get up there that day or their pay week isn't until next week, that kid's going to miss out on those medical appointments and that's it. Then you've got to wait maybe a couple of months for the next appointment and by that time things have gotten worse and the kid's health has declined and mum's just going, oh, this is too much and I can't deal with it anymore and I don't know what to do. I'm just going to pretend it didn't happen' – (staff_18).
Sustaining service use	
Fulfilling expectations for service standards	'It would have been good to actually make sure the equipment was charged … because now we have to come back, so that means another day where he's going to be late for school' – (carer_04).
	'It's important to have set days on when certain programs are going to be at venues and set times and be consistent with that … people do lose faith in services if they're not reliable. Um, and you know, things happen but there always needs to be a back-up plan to make sure that people aren't let down … that's how we are. Like you know, a lot of our people go, ah nah, they're dodgy, I'm not going to use them because they cancelled my appointment, I'm going to go elsewhere. And you only get that one chance to prove your service and what you can do to help … they lose trust easy' – (carer_17).
Demonstrating commitment through ongoing programs	'Put them at a bit more continuous for other kids to have an opportunity at doing something like that. It's good to let other community have a go. I'm happy my kids got to have a go … Have it ongoing so other people can have another go too' – (carer_01).
	'… what could have been done better or differently was to keep the program running. It stopped because of funding. When the funding cut …, there was nothing here for the kids' – (carer_23).
Clarity of benefits	'Doctor said you know about this program and wasn't sure whether or not he'd get the antibiotics I was a little bit hesitant …' – (carer_01).

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FIGURE 1 Thematic schema. Carers of Aboriginal children participating in child health programs expected to find comfort and security in the community embedded services they attended, be cared for by familiar staff and where they can be immersed in activities that strengthen their connection to culture. When staff valued relational communication, carers felt heard and known, trusting and empowered to optimise their child's development. Carers wanted to be confident that providers had the clinical and interpersonal skills to resolve their child's health issue and could engage with their child to allay fears of treatment and provide timely health care. Some carers required support to access and navigate health services which involved ensuring that: The information they needed was accessible and presented appropriately, the location of the health services was convenient and care holistic and that they would not be subjected to feeling shame about any financial hardship they may be experiencing. Service use could be sustained by: Fulfilling expectations of service standards, demonstrating a commitment to the community by keeping programs ongoing and clarifying the benefits of treatments

service providers – '… I thought, when I first took him, they're gonna turn around and say, "He's too young… we won't worry about it until he's three or four." But she did not do it. That was my biggest worry' – carer_05. Staff, particularly those working with adolescents perceived that feeling like 'someone is listening to me' (staff_29) was important to participants and made them more receptive to receiving care.

3.2 | Confidence in provider's clinical and interpersonal skills

3.2.1 | Certain that the health issue will be resolved

Some carers felt that to be confident in the care provided to their child, the health care providers had to be knowledgeable about their child's health issue, keeping – 'up to date on everything' (carer_04) and have the necessary clinical skills to address it. '… as long as I know he's getting the help that he needs from qualified people …' – carer_17.

3.2.2 | Engaging with the child to allay fears

Carers felt encouraged when health services providers developed a good rapport with their child and encouraged them to participate. For some carers relating to children demonstrated competence and was important to allay fears and anxieties about treatment that could potentially impair their child's future health-seeking behaviour – 'the engagement with the kids for me is more so the top priority because you need to have that rapport for them to feel safe and to feel comfortable so that they don't get fear' – carer_04.

3.2.3 | Facilitating timely health care

Carers felt staff should know how to identify problems early and either make recommendations to resolve them or refer them to someone who could. The need for timely advice motivated some carers to attend programs where health staff could observe their child regularly. Some staff understood that they were well positioned to facilitate the early detection of issues for the children in their care – 'If an

Aboriginal kid comes to playgroup and the parents ...[say] "I think that my kid's [a] bit slow in this and that ..." I'll go back to work and I'll have a talk with my boss then, we'll sort of go back and forth to see what can we do to help them' – staff_06.

3.3 | Finding comfort and security in community embedded services

3.3.1 | Safety and acceptance in the familiar

Carers felt that having Aboriginal and Torres Strait Islander staff who were from their community, 'our own kind' (carer_23), made them feel comfortable and safe in a way that services with unfamiliar staff failed to do. Participants liked being able to regard Aboriginal and Torres Strait Islander staff as an extension of their family and felt that the staff should provide program environments where they could express themselves freely, use language they are familiar with and be comfortable observing their cultural traditions – '...the staff there, they're really friendly as well. But because they're Indigenous it's almost like they're a family, if you know what I'm saying. Like, the bus driver, his name is [name] but they [the children] call him Uncle' – carer_12.

3.3.2 | Strengthening child's connection to culture

Carers wanted their children to be part of something that made them proud of their heritage and their Aboriginal and Torres Strait Islander identity, 'talking about being strong black, and deadly' (carer_01), and helped them to connect to their culture. For some programs, staff perceived that incorporating 'cultural practices' into the programs helped the children 'learn their culture' (staff_06).

3.4 | Support to access and navigate health services

3.4.1 | Accessible information appropriately presented

Carers wanted to know that the information they needed to manage their child's health successfully would be available to them at the time they needed it and in a format that made the information easy for them to understand and follow – 'Easy flowing. Not overwhelmed with a lot of information and like, big words, and basic that you can understand' – carer_23.

3.4.2 | Convenient and holistic care

Carers valued having all the relevant health services for their child in the community they lived in and close to each other so they could link in to all the services easily. Staff felt that holistic approaches to health were important to carers because they simplified the process of keeping up with their child's health needs, 'everything's under the one umbrella so you don't have to go from here, there and everywhere all over town you just come to the one place' – staff_03.

3.4.3 | Easy and flexible scheduling

Carers appreciated providers who understood that their commitments to their community such as 'sorry business' (funerals) were very important and gave them the space to attend to their responsibilities even if it meant they missed a health appointment. Staff felt that when they accommodated changes to carers' schedules, carers were more self-motivated to re-engaged with services and resume health care – 'We don't engage the families during ... sorry business [period of mourning as a community] ... I notice when after a couple of weeks they'll call me and say, '[name], thanks for giving us that time' – staff_16. Carers also liked being able to rely on services to support them in emergency health situations and ensure their child received timely care.

3.4.4 | Easing the shame of financial hardship

Some carers needed help when their financial situation made it difficult to attend health services because they struggled to afford transport or did not have childcare. Some staff viewed relieving the shame associated with financial difficulties as integral to their role while being thoughtful and responsive to the participant needs – 'We ring up parents the day before [to say] don't forget this appointment's due for the kid today. Then they might say, "I'm really not feeling too well today" but really what that's saying is they do not have the money to catch a bus up here, they do not have a car [or] petrol so then we go, do you want me to transport today?' – staff_18.

3.5 | Sustaining service use

3.5.1 | Fulfilling expectations for service standards

Carers wanted health services to appreciate their need to feel satisfied with the quality of the service they received particularly with regards to timeliness and reliability influenced their decisions to use health services. Carers expressed frustration with delays to their child's care due to providers being unprepared to receive them or outreach health services being cancelled pushing their child's health appointment back 'another two, three months'. Particularly with outreach services, carers felt that the extended periods without care were 'just a long time' and that 'people lose faith in services if they are not reliable' – carer_17.

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3.5.2 | Demonstrating commitment through ongoing programs

Some carers felt it was unfair when kids missed out on experiencing the benefit of a health service because a program was only offered short term. Carers wanted the health services to be ongoing and sustainable so other children in the community would have the opportunity to learn about how to improve and maintain their health and wellbeing, '…you know it's sometimes things are just a one-off. It's good to let other community have a go. You know? Um, I'm happy my kids got to have a go …Have it ongoing so other people can have a go too' – carer_01.

3.5.3 | Clarity of benefits

Carers wanted to clearly understand how a proposed treatment would improve their child's health. Especially when the care was provided as part of a broader program of research – 'doctor said you know about this program and wasn't sure whether or not he'd get the antibiotics, I was a little bit hesitant' – carer_04.

4 | DISCUSSION

Our findings suggest that engaging with Aboriginal and Torres Strait Islander carers to learn about their experiences and expectations of health care provided to their children, can generate data to guide how processes are operationalised. Health services that partner with carers to identify the process characteristics that they and their children value, can develop service delivery models for health care that centres culture (particularly in communication), is accessible, responsive and sustainable. Information from carers about their experiences can also drive the policy-driven aspects of access and sustainability which inform the frameworks that underpin the design and development of health care for Aboriginal and Torres Strait Islander children.

This study builds on research into the delivery of health services for Aboriginal and Torres Strait Islander people, and contributes towards identifying the processes within child health services that are valued by families.[22] Broadly, staff and carer views around what was important were similar, especially around communication. While previous research confirms that for Aboriginal and Torres Strait Islander people, verbal and nonverbal communication with health care staff can influence decisions to engage with health services,[1,3] there are insufficient data to pinpoint the moments during child health service delivery when communication is particularly important.

Our findings highlight several instances during the provision of health care when appropriate communication is critical. One such moment is during discussions on managing their child's health. Carers wanted providers to use empowering language, equipping them to manage their child's health care which they viewed as an extension of their parental responsibility. This desire for partnership with providers and knowledge of the technical skills to manage their child's health

supports evidence around Aboriginal and Torres Strait Islander people actively seeking opportunities to participate in decisions relating to their health and wellbeing.[23]

It is imperative to recognise the centrality of culture when providing health care to Aboriginal and Torres Strait Islander people especially within tertiary hospitals which continue to struggle to embed Aborginal and Torres Strait Islander ontology into service delivery.[24,25] Misunderstanding cultural practices and protocols in communication can generate feelings of disempowerment and cause some Aboriginal and Torres Strait Islander people to refrain from fully participating in decisions about their health care.[26] The importance of strengths-based approaches in Aboriginal and Torres Strait Islander health is well established.[22] However, our findings suggest that not all providers communicate in ways that are empowering or supportive of Aboriginal and Torres Strait Islander carer's right to self-determination concerning their child's health care.

Issues around power imbalances and feelings of judgement remain significant barriers to shared decision making in Aboriginal and Torres Strait Islander health care and may be more pronounced in child health.[27] Some researchers have suggested incorporating culturally appropriate approaches to communication in health services when working with Aboriginal and Torres Strait Islander people. For example clinical Yarning has been identified as a communication method that can reduce misunderstandings, but its use in mainstream health services remains limited.[21]

Racism and discrimination continue to negatively impact on the delivery of health services to Aboriginal and Torres Strait Islander people and globally to Indigenous or First Nations people.[4,28] By taking the time to critically reflect on their attitudes and behaviours towards patients to discard biases or misconceptions that prevent them from listening and discerning carer's concerns, health care staff could help to reduce inequities in access to health care.[7] Considering such approaches when providing care could prepare staff to respond to carers using appropriate communication and ensure they provide the relevant information and resources that carers need to action their learning. Further research is required on techniques to guide staff training in embedding reflexivity and strengths-based communication into their practice. Additionally, increased access to appropriate health education material for carers which considers their health literacy.

Consistent with our findings, previous research indicates that carers of Aboriginal and Torres Strait Islander children are increasingly aware that some health services provided by ACCHSs are offered as part of a larger program of research conducted in their community.[29] They recognise that these research projects facilitate having the services they need for their children. A key challenge for research programs is appropriately communicating the benefits of the research so that participants appreciate that participation will be positive for their children. Maintaining clear and appropriate communication between researchers and health care staff will ensure that staff are able to provide participants with answers to questions and are willing to participate in research sponsored health care.

A notable difference between responses from the staff and carers was that carers described their expectations of health services. Along with those descriptions, carers explained how a services ability to satisfy those expectations influenced their decisions to participate in the

health service. Additionally, carers described their hopes for their child's experiences, specifically how providers engaged with them and what programs could do to help children feel better connected to their culture.

Carer expectations around feelings of safety and confidence in programs were linked to the presence of Aboriginal and Torres Strait Islander staff. Previous research has shown that having Aboriginal and Torres Strait Islander staff facilitates a trusting relationship with

TABLE 3 Implications of findings

Domain	Service activities	Related process characteristics	Implications
Communicating to: build trust, create welcoming environments, ensure safety, support culture, empower to participate in care	• Receiving participants into service • Administering treatment • Health education sessions • Managing the service environment	• Use of culturally acceptable approaches to communication with carer and child • Attitude of health worker • Presence of Aboriginal staff • Verbal and written messaging on the value of culture • Language used to communicate health education during clinical consultations	• Recognise and allow time for all staff to prioritise developing and strengthening relationships throughout the service delivery process • Encourage Aboriginal approaches to communication at all stages of staff and participant interactions • Support clinical staff to routinely engage in critical reflection of their attitudes and behaviours towards carers and their children • Maintain and expand state and federal policies that help services support and retain Aboriginal health workers • Collaborate with the community to incorporate messaging around the value of culture into health education programs • Support clinical staff to learn strategies and develop skills in strengths-based communication with carers and children
Instilling confidence in providers	• Administering treatment	• Thoroughness of assessment and demonstration of knowledge and understanding of health issue • Rapport and interaction with the child • Staff attentiveness to child and responsiveness to carer concerns	• Understand the competencies carers value to increase their confidence in health care providers • Regularly engage with carers to determine the interpersonal skills they expect and include in recruitment decisions • Ensure staff can identify health issues among children in their programs
Facilitating access	• Location of education material • Presentation of educational material • Getting participants to the health service • Scheduling appointments • Getting to know the carer and child • Advocacy	• Availability and accessibility of health education material • Material published using the appropriate format and health literacy level • Availability of staff to explain health education material • Transport to health services • Ability to discern participant needs and address barriers without injuring the carer's dignity	• Increasing support to improve the availability of appropriate health education material and training staff to provide additional learning support to carers when needed • Support for services to allocate funding to transport and other impacts of financial hardship on access to care
Sustaining service use	• Using equipment during health visit • Program planning • Administering treatment	• Functioning equipment • Delivering scheduled programming • Verbal and written communication about treatment options	• Routine assessment of process efficiency • Funding to support reliable programming • Clear and consistent communication about treatment benefits

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participants and encourages participation in health services.[3,22] Although health service that provide health care for Aboriginal and Torres Strait Islander people recognise the value in employing Aboriginal and Torres Strait Islander staff, the ability to do this is limited by the shortage of health workers and difficulty retaining staff.[30] Long-term programs to support and retain Aboriginal and Torres Strait Islander staff working in the community should continue to be a priority.

The importance of accessible health services for Aboriginal and Torres Islander people is well established in the literature.[22] Our findings illuminated the intricacies of health care access for carers. Reports on feelings of embarrassment about financial hardships and the implications of those feelings on a carer seeking health care for their child adds to the understanding of the complexity of barriers to access. Further, our findings again highlight the value of culturally appropriate communication from staff and the profound effect it can have on an Aboriginal and Torres Strait Islander carer's willingness to and seek assistance to improve access.

In Australia, funding through the Indigenous Australians' Health Program supports care coordination and navigating the health care system, particularly during pregnancy and for some chronic conditions.[31] However, our findings suggest that not all services related to child health benefit from this policy. Further evaluation of which child health services would most benefit from additional resources to improve access and regarding funding models that provide health services the flexibility to determine how to use those funds to support families is required.

Other notable aspects of service delivery brought forward by carers in this study were around their reluctance to compromise on the quality and efficiency of health services. Although most urban Aboriginal and Torres Strait Islander people use mainstream health services more than Aboriginal specific care,[32] using these services may expose them to racism and discrimination. As such, Aboriginal and Torres Strait Islander specific care services in urban regions, that want to maintain high levels of satisfaction, must consistently invest in understanding how their operations both positively and negatively affect participation. This is particularly important for community-run services if they want to retain participants and secure funding to keep programs running.

An ongoing challenge for health services designed for Aboriginal and Torres Strait Islander people is sustainability. As indicated by our findings, failure to sustain programs is an area of concern for carers and staff who view programs ending prematurely as a social injustice. Children were unfairly disadvantaged when they missed out on programs that clearly benefitted other children. Staff attributed changes in programs or their abrupt end to funding cuts and confirmed that the community felt the effects of those measures. Failure to support ongoing funding of successful health programs erodes community trust and has damaging effects on the sustainability of health services.

Strength of this study was the inclusion of clinical and nonclinical programs which provided a broad appreciation of the processes that carers value in health services. Interviewing both carers and staff enriched the data and helped to further contextualise the findings. Potential limitations of the study were its limited geographical scope making transferability beyond our study population uncertain and that

we only interviewed carers and staff and did not interview the children receiving the health care. However, the decision to engage with a health service often rests with carers, particularly for young children. Future research can build on our findings and begin developing relevant theory grounded in the perspectives of carers and their children. For services such as mental health which involves older children, hearing directly from the children themselves would be informative. Implications of the findings of this study are outlined in Table 3.

5 | CONCLUSION

Carers and staff highlighted the operational aspects of delivering health services for Aboriginal and Torres Strait Islander children that may influence both the carer's and child's present and future engagement with health services. Carers emphasised the importance of staff approaches to communication, the content of that communication, how access is facilitated and how the service environment is managed. With these data, decision-makers can better support monitoring and evaluation of Aboriginal and Torres Strait Islander child health programs to improve participant experiences and focus quality improvement resources.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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REFERENCES

1. Aspin C, Brown N, Jowsey T, Yen L, Leeder S. Strategic approaches to enhanced health service delivery for Aboriginal and Torres Strait Islander people with chronic illness: a qualitative study. BMC Health Serv Res. 2012;12:143. https://doi.org/10.1186/1472-6963-12-143

2. Davy C, Harfield S, McArthur A, Munn Z, Brown A. Access to primary health care services for indigenous peoples: a framework synthesis. Int J Equity Health. 2016;15(1):163. https://doi.org/10.1186/s12939-016-0450-5

3. Hayman N. Strategies to improve indigenous access for urban and regional populations to health services. Heart Lung Circ. 2010;19(5):367–71. https://doi.org/10.1016/j.hlc.2010.02.014

4. Zambas SI, Wright J. Impact of colonialism on Māori and Aboriginal healthcare access: a discussion paper. Contemp Nurse. 2016;52(4):398–409. https://doi.org/10.1080/10376178.2016.1195238

5. Australian Institute of Health and Welfare. Towards better indigenous health data. AIWH. 2013. Available from: https://www.aihw.gov.au/getmedia/b424d472-2e23-4624-a669-22c7e1180036/15020.pdf.aspx?inline=true

6. Australian Institute of Health and Welfare. Patient experience of health care. 2020. Available from: https://www.aihw.gov.au/reports/australias-health/patient-experience-of-health-care

7. Rix EF, Barclay L, Wilson S, Stirling J, Tong A. Service providers' perspectives, attitudes and beliefs on health services delivery for Aboriginal people receiving haemodialysis in rural Australia: a qualitative study. BMJ Open. 2013;3(10):e003581. https://doi.org/10.1136/bmjopen-2013-003581

8. Australian Institute of Health and Welfare. Cultural safety in health care for Indigenous Australians: monitoring framework. 2019. Available from: https://www.aihw.gov.au/getmedia/153ec5b7-35fd-4348-9166-b13d458befa0/Cultural-safety-in-health-care-for-Indigenous-Australians-monitoring-framework.pdf.aspx?inline=true

9. Fennell ML. Health care delivery services. In: Smelser NJ, Baltes PB, editors. International encyclopedia of the social & behavioral sciences. Amsterdam: Pergamon; 2001. p. 6515–20.

10. Australian Institute of Health and Welfare. Culturally safe health care for indigenous Australians. 2020. Available from: https://www.aihw.gov.au/reports/australias-health/culturally-safe-healthcare-indigenous-australians

11. Gibson O, Lisy K, Davy C, Aromataris E, Kite E, Lockwood C, et al. Enablers and barriers to the implementation of primary health care interventions for indigenous people with chronic diseases: a systematic review. Implement Sci. 2015;10(1):1–11.

12. Rix L, Moran C, Kapeen R, Wilson S. 101:'I just don't wanna be there!': improving cultural safety and competence within renal units for indigenous Australian patients. Ren Soc Australas J. 2016;12:48–8.

13. Australian Institute of Health and Welfare. Australia's children. 2020. Available from: https://www.aihw.gov.au/getmedia/6af928d6-692e-4449-b915-cf2ca946982f/aihw-cws-69-print-report.pdf.aspx?inline=true

14. Elarde P, Tilbury C. The experiences of Aboriginal and Torres Strait Islander carers in the child protection system. Child Aust. 2007;32(2):8–14.

15. Strobel N, Moylan C, Durey A, Edmond K, McAuley K, McAullay D. Understanding an Aboriginal and Torres Strait Islander child's journey through paediatric care in Western Australia. Aust N Z J Public Health. 2020;44(2):95–101.

16. Dawson J, Augoustinos M, Sjoberg D, Canuto K, Glover K, Rumbold A. Closing the gap: examining how the problem of Aboriginal and Torres Strait Islander disadvantage is represented in policy. Aust J Soc Issues. 2020;56:522–38.

17. Chando S, Howell M, Young C, Craig JC, Eades SJ, Dickson M, et al. Outcomes reported in evaluations of programs designed to improve health in Indigenous people. Health services research. 2021;56(6):1114–25.

18. Jamieson LM, Paradies YC, Eades S, Chong A, Maple-Brown LJ, Morris PS, et al. Ten principles relevant to health research among indigenous Australian populations. Med J Aust. 2012;197(1):16–8.

19. SEARCH Investigators. The study of environment on Aboriginal resilience and child health (SEARCH): study protocol. BMC Public Health. 2010;10:1–8.

20. QSR International Pty Ltd. NVivo [version 12.0]. 2018. Available from: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

21. Lin I, Green C, Bessarab D. 'Yarn with me': applying clinical yarning to improve clinician-patient communication in Aboriginal health care. Aust J Prim Health. 2016;22(5):377–82.

22. Harfield SG, Davy C, McArthur A, Munn Z, Brown A, Brown N. Characteristics of indigenous primary health care service delivery models: a systematic scoping review. Glob Health. 2018;14(1):12. https://doi.org/10.1186/s12992-018-0332-2

23. Janine M. Health: the power of self determination. LSJ. 2021;79:50–1.

24. McGaw J, Vance A, Patten UH. A 'holding place': an indigenous typology to mediate hospital care. J Archit Educ. 2022;76(1):75–84.

25. Vance A, McGaw J, Winther J, Rayner M. Towards an Aboriginal knowledge place: cultural practices as a pathway to wellness in the context of a tertiary hospital. Int J Indig Health. 2016;11(1):244–61.

26. Shahid S, Finn LD, Thompson SC. Barriers to participation of Aboriginal people in cancer care: communication in the hospital setting. Med J Aust. 2009;190(10):574–9. https://doi.org/10.5694/j.1326-5377.2009.tb02569.x

27. Durey A, Thompson S, Wood M. Time to bring down the twin towers in poor Aboriginal hospital care: addressing institutional racism and misunderstandings in communication. Intern Med J. 2012;42(1):17–22.

28. Gatwiri K, Rotumah D, Rix E. BlackLivesMatter in healthcare: racism and implications for health inequity among Aboriginal and Torres Strait Islander peoples in Australia. Int J Environ Res Public Health. 2021;18(9):4399.

29. Young C, Gunasekera H, Kong K, Purcell A, Muthayya S, Vincent F, et al. A case study of enhanced clinical care enabled by Aboriginal health research: the hearing, EAr health and language services (HEALS) project. Aust N Z J Public Health. 2016;40(6):523–8. https://doi.org/10.1111/1753-6405.12586

30. Lai GC, Taylor EV, Haigh MM, Thompson SC. Factors affecting the retention of indigenous Australians in the health workforce: a systematic review. Int J Environ Res Public Health. 2018;15(5):914. https://doi.org/10.3390/ijerph15050914

31. Health Policy Analysis. Review of Care Coordination within the Integrated Team Care (ITC) Program (Summary report, Commonwealth Department of Health. 2018. Avaliable from: https://www1.health.gov.au/internet/main/publishing.nsf/Content/indigenous-funding-lp

32. Ware V-A. Improving the accessibility of health services in urban and regional settings for Indigenous people (Produced for the Closing the Gap Clearinghouse. 2013. Available from: https://www.aihw.gov.au/getmedia/186eb114-8fc8-45cc-acef-30f6d05a9c0c/ctgc-rs27.pdf.aspx?inline=true

APPENDIX

Interview guides
Family interview guide (20-30 minutes).

- Thank you for participating.
- There is no right or wrong answer and you can stop at any time or skip questions.
- We will be recording this interview so that we do not miss anything you say. The recordings are confidential and what you say will not be linked to you.

Introduction

I'm going to ask you some questions about your thoughts on the programs that your child has participated in. I would like you to think back to a time when your child participated any health program offered in your community. (*Give participant moment to think offer some suggestions based on the program or service they were recruited from – proceed when ready*.)

Questions

A. Motivations for accessing the program

1. Why did you decide to involve your child in the program?
2. When your child attended the program what did you hope the staff would do for your child? (You can have more than one answer?)
   Prompt: you can think about why you thought taking your child to that program would help?

   i. What were the things that you hoped the staff would do for you as a parent/carer?

   Prompt: other parents generally mention things like: provide reassurance about child's health, provide information, eg, child's condition or how to care for child

A. Engagement – experience from point of contact with the program

3. Thinking back to the last time your child participated in a program at the AMS, can you walk me through your experience and tell me about what stood out to you about the program that you really liked?
   Prompt: you can think about your experience during the visit and the specific things that happened that made you feel good about the visit, eg, interaction with staff or clinicians.

   i. What parts of the visit do you think your child liked?

4. Again when you think back on the experience of your child going a program, was there anything else that could have been done to make yours or their experience better?

A. Impact – what they got out of the program

5. Did you feel like taking your child to the program was worthwhile? Why?
   Prompt: After your visit can you think of reasons you were happy that you went to the program?
6. Was the experience of going to the program what you had expected? In what way?
7. Overall what do you think makes a child health program successful in your community?

A. Closing

8. Is there any additional information you would like to provide?

Provider interview guide (20-30 minutes)
- Thank you for participating.
- There is no right or wrong answer and you can stop at any time or skip questions.
- We will be recording this interview so that we do not miss anything you say. The recordings are confidential and what you say not be linked to you.

Introduction

I'm going to ask you some questions about your perspectives on child health programs provided in your community.

Questions

A. Value of child health programs and motivations for access

1. Do you think child health programs are important for your community? Why?
   Prompt: there are no right or wrong answers, you can just tell me the reasons you personally think having child health programs are important.

A. Engagement – the experience of contact with the program

2. I would like you to think about what happens when the child attends the health program you are involved in or a family walks in to receive care for their child at the service you work in. As a staff member, what parts of the child or family's visit do you think are important?

Prompt: you can think about the experience families have during their visit and the specific things that happen while they are at the program. Examples can be: receiving treatment, waiting time to see GP, friendliness of staff, clean environment …

i.   Are there specific parts that you think are particularly important for the children?
ii. Do you think there are any differences in what families view as important and what providers view as important? Why?

A. Impact – what the program does for those that use it and the community at large

3. When a patient leaves the program what outcomes to you think are important to achieve for the patient and their family?
    Prompt: what do you think should be the result of a visit to a child health program for a patient and their family?
4. Overall what do you think makes a child health program successful in your community?

A. Closing

5. Do you have any additional comments you want to share?