



Australian
National
University



Building better research partnerships by understanding how Aboriginal health communities perceive and use data: a semi structured interview study

Young C, Tong A, Sherriff S, Kalucy D, Fernando P,
Muthayya S, Craig JC

ACKNOWLEDGEMENTS

This research is a project of the Australian Primary Health Care Research Institute, which is supported by a grant from the Australian Government Department of Health. The information and opinions contained in it do not necessarily reflect the views or policy of the Australian Primary Health Care Research Institute or the Australian Government Department of Health.

We thank the SEARCH participants, their communities and the staff at participating ACCHSs. This work was supported through grants to SEARCH from the Australian Primary Care Research Institute, the National Health and Medical Research Council of Australia (grant numbers 358457, 512685, 1023998 and 1035378), the NSW Ministry of Health, beyondblue and the Rio Tinto Aboriginal Fund. The CRE and SEARCH are conducted in partnership with the AH&MRC and four Aboriginal medical services across NSW: Awabakal Limited, Riverina Medical and Dental Aboriginal Corporation, Sydney West Aboriginal Health Service, and Tharawal Aboriginal Corporation.

CITATION

Young C, Tong A, Sherriff S, Kalucy D, Fernando P, Muthayya S, Craig J. *Building better research partnerships by understanding how Aboriginal health communities perceive and use data: a semi structured interview study*. 2016; Centre for Urban Aboriginal Child Health. Australian National University. Australian National University: Canberra.

Professor Emily Banks
Research School of Population Health
62 Mills Rd
The Australian National University
Canberra Acton 2600

E: emily.banks@anu.edu.au

Contents

Background.....	4
Methods.....	5
PARTICIPANT SELECTION AND SETTING.....	5
DATA COLLECTION.....	5
ANALYSIS.....	6
Results.....	7
OCCUPATIONAL ENGAGEMENT.....	9
Day-to-day relevance.....	9
Contingent on professional capacity.....	9
Emphasising clinical relevance.....	9
TRUST AND ASSURANCE.....	10
Protecting ownership.....	10
Confidence in narratives.....	10
Valuing local sources.....	11
MOTIVATION AND EMPOWERMENT.....	11
Engaging the community.....	11
Influencing morale.....	12
Reassuring and encouraging clients.....	12
BUILDING RESEARCH CAPACITY.....	13
Using cultural knowledge.....	13
Promoting research aptitude.....	14
Prioritising specific data.....	14
OPTIMISING SERVICE PROVISION.....	15
Necessity for sustainable services.....	15
Guiding and improving services.....	15
Supporting best practice.....	16
ENHANCING USABILITY.....	16
Ensuring ease of comprehension.....	16
Improving efficiency of data management.....	17
Valuing accuracy and accessibility.....	17
Discussion.....	19
Summary of findings.....	21
References.....	23

Background

The average life expectancy of Australian Aboriginals is estimated to be at least 11 years lower than their non-Aboriginal counterparts.¹ In response, the Australian government has pledged to reduce the health disparities and to “Close the Gap” in health between Aboriginal and non-Aboriginal people by 2030. A key component of this initiative is advancing the understanding of physical, mental, environmental, and social determinants of Aboriginal health through focused research.²⁻⁵

Historically, Aboriginal health research has originated from ‘outside’ the Aboriginal community, often conducted in a manner that is insensitive, inconsequential, or without explanation to Aboriginal people. This practice has left many Aboriginal people wary of research, prompting a call for more Aboriginal involvement, and control, over health research practices.⁶⁻⁹ Greater control is likely to empower the Aboriginal community in ways that traditional ‘top-down’ research methods cannot, building research capacity, and instilling ownership over research data.¹⁰

Aboriginal Community Controlled Health Services (ACCHSs) are primary care service providers that are critical to improving the health of the Aboriginal people. They provide holistic care to families within a culturally appropriate context and are used by many families who find it difficult to access mainstream services.^{11, 12} ACCHS are therefore in a strategic position to facilitate research using data from their own and from external sources. While ACCHS often participate in research, there are relatively few examples of research initiated and led by the ACCHS themselves,^{13, 14} despite the ongoing importance placed on building Aboriginal research capacity.

Effective and sustained collaborations between the ACCHS and external researchers provide an impetus for mutual knowledge sharing and have the potential to ‘Close the Gap’ both in health outcomes and in research capacity.⁶ However, while effective research capacity-building relies on a solid grasp of the importance of, and ability to use, data, there is scant research to date specifically investigating how clinical and research data are perceived by ACCHS staff,^{15, 16} especially in urban/regional locations. Understanding how Aboriginal health communities perceive and use data may assist research collaborations with the ACCHS, and enhance training opportunities that have the potential to facilitate more Aboriginal-led research.

The aim of this study is to describe the perspectives of ACCHS health staff towards data and to identify potential strategies that can maximise the efficient transfer and usage of data collected through collaborative research with the ACCHS, and enhance the capacity to effectively use research data for healthcare improvement and advocacy.

Methods

PARTICIPANT SELECTION AND SETTING

ACCHS are government-funded health services run by a board of directors who are elected by the community they serve. Participants were recruited from three ACCHS (2 urban and 1 regional) participating in the Study of Environment on Aboriginal Resilience and Child Health (SEARCH)¹⁷: Awabakal Newcastle Aboriginal Cooperative, Riverina Medical and Dental Aboriginal Corporation, and Tharawal Aboriginal Corporation. SEARCH, a large cohort study of urban Aboriginal children and their carers investigating community identified health priorities, aims to support the ACCHS to effectively use research data generated from the study and clinical data collected at the ACCHS. The SEARCH study aims and guidelines were developed with extensive consultation from the partner Aboriginal communities, of which greater data dissemination was identified as a priority.

The ACCHS participating in this study are all large multifunctional services that employ health professionals capable of delivering a range of primary healthcare and specialist services under 'one roof'. Participants were eligible if they were employed by the ACCHS as medical practitioners, nurses, senior administrators, health service managers, Aboriginal Health Workers or allied health staff. Purposive sampling was used to ensure that a broad representation of the organisation roles typically employed by the ACCHS was included in this study. Both Aboriginal and non-Aboriginal people were included. Participation in the study was voluntary and informed consent was provided by each participant before interviews took place.

DATA COLLECTION

An interview guide was constructed using instruments employed in SPIRIT (Supporting Policy In health with Research: an Intervention Trial)¹⁸ that assess attitudes towards research and discussion among the investigator team. Interview questions targeted four key areas of interest: 'general perspectives on data', 'accessing data', 'using data' and 'research data optimisation and enhancement'. Face-to-face semi-structured interviews were conducted by CY, SS, DK, PF and AT between November 2013 and May 2014; all interviews were conducted at the ACCHS. Interviews typically consisted of two researchers (including at least one Aboriginal researcher) who took it in turns to lead each interview. SEARCH guidelines state that it is necessary for an Aboriginal person to be present at all interviews conducted with Aboriginal people. This is to ensure that the interviews are conducted in a culturally appropriate manner, to guide the line of questioning and to aid the correct interpretation of answers given by Aboriginal people. In some cases, Aboriginal participants may feel more comfortable talking to an Aboriginal researcher, facilitating richer insights than would have been elicited by non-Aboriginal researchers alone. Participant recruitment ceased when theoretical saturation was reached. Interviews were audio-recorded and transcribed.

ANALYSIS

The analytic process drew from the principles of grounded theory. The transcripts were coded line by line to capture the participant's beliefs, values and attitudes towards data. CY coded all the transcripts; SS and DK coded half each. The codes were used to conceptualise and interpret the data to inductively identify emerging concepts.¹⁹ These were discussed among the research team to refine the concepts into themes and subthemes. This form of investigator triangulation can help to ensure that the findings captured the full range and depth of the data collected. The lead author CY entered all transcripts into HyperRESEARCH (V.3.5.2; Research-ware Inc), a software program used to manage qualitative data. CY coded the transcripts into themes and subthemes and the coding choices were discussed with the research team. Participants were provided a summary of the preliminary findings and asked to contribute feedback; however, no feedback was received.

Results

Participant characteristics are provided in Table 1.

Table 1. Participant characteristics (N=35)

Characteristic	Total (n=35)	%
Gender		
Male	4	(11.4)
Female	31	(88.6)
Age (years)		
20-29	4	(11.4)
30-39	9	(25.7)
40-49	10	(28.6)
50-59	7	(20)
60-69	2	(5.7)
Age withheld	3	(8.6)
Occupation		
Aboriginal Health Worker	6	(17.1)
Allied Health Professional	2	(5.7)
Nurse	6	(17.1)
Health Service Manager	9	(25.7)
Doctor	7	(20.0)
Administrator	5	(14.3)
Highest level of education		
School certificate	8	(22.9)
HSC/equivalent	4	(11.4)
Diploma	6	(17.1)
University degree	17	(48.6)

Of the 44 health professionals invited, 35 (80%) participated in the study. Non-participation was due to illness, scheduling conflicts, and non-response. Six themes emerged based on the interviews with ACCHS staff,

- > building research capacity
- > enhancing usability
- > optimising service provision
- > occupational engagement
- > motivation and empowerment, and
- > trust and assurance.

The thematic schema shown in Figure 1 illustrates conceptual links between the themes. Illustrative quotations follow each major theme that arose from the analysis.

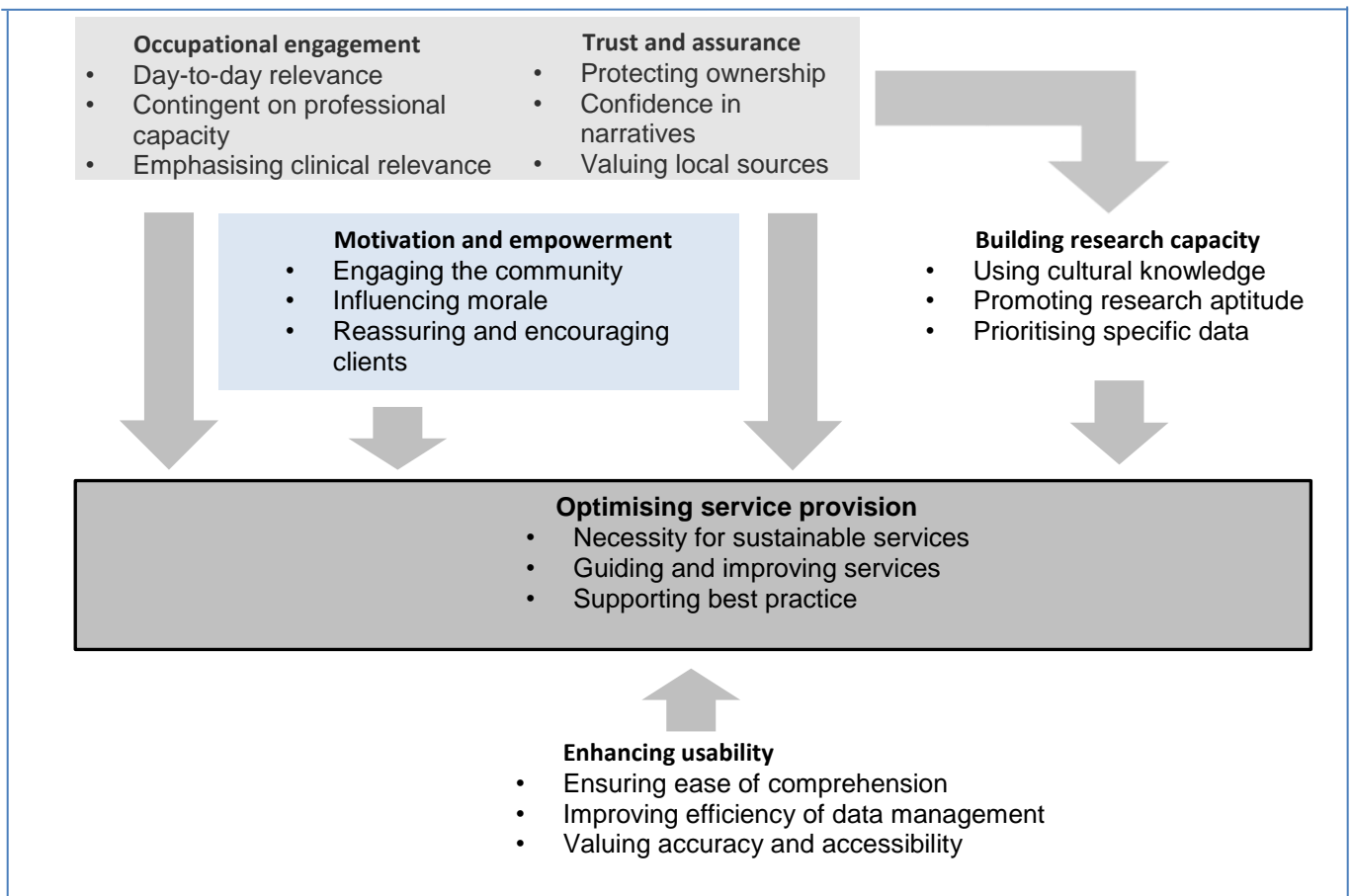


Figure 1. Thematic schema

OCCUPATIONAL ENGAGEMENT

Day-to-day relevance

Participants perceived data as a necessary tool which allowed them to perform their daily duties at the ACCHS. Despite this, not all data were seen as relevant; participants felt that staff who were less aware how data was being used would place lower importance on data collection and access. Others noted that having greater access to data was irrelevant if their workload prevented them from using it.

What does that mean to me? Well it's a necessity. We need it to record our information and to look back and make changes - be able to hand over. How would I define it? It's a useful, necessary tool that we need. (Nurse)

When you have the data but can't really change it (the procedure). I can't change my work practice; I can't see more people than I'm seeing (Nurse)

Every individual session relies on data. Planning for future services relies on data. I'm doing statistics all the time for multiple different sites. So it's important in my day-to-day stuff but it's also important at a management level. (Allied Health)

Yeah it's like another job I have to do, you know, and I know and some people don't give it [data collection] as much importance where the people back here know that they're doing it for a reason, it could change the way they work. (Manager)

Contingent on professional capacity

Ability to use and access data was influenced by staff member's job requirements and professional or tertiary-level training. Despite this variation, participants often expressed confidence using data in their roles and felt they had learnt considerable data-handling skills while working at the ACCHS.

As a GP, having been through a number of years and university and postgrad training, it's pretty uncommon for us to be stumped by languages because we're used to citing medical jargon, epidemiology, and sociology stuff. If we're talking about people that haven't done as much tertiary training - so maybe enrolled nurses and Aboriginal health workers and practitioners may be put off by jargon. (Doctor)

When I was studying, I went away to this one week course. It was called Introduction to Statistics. It achieved something that I didn't realise I could achieve. It achieved that I was no longer scared of the words. (Doctor)

I actually designed my own spread sheet. I'm getting cleverer as I go with my dropdown boxes. Initially it was like whoa, that's lots of information and then once you got into it, it was okay, it was easy to understand. (Manager)

So if you've got a university background I think you're better prepared for being able to read data and understand how data is collected and how it's presented. But if you're the layman you're going to have a very limited capacity to understand. (Administrator)

Emphasising clinical relevance

Collecting data for clinical record-keeping purposes was considered a fundamental practice within the ACCHS. Consequently, participants largely conceptualised data as descriptive clinical statistics and patient demographics and were confident using electronic databases designed specifically for recording and storing patient information (Patient Information

Management Systems, PIMS). Having access to research data was seen as important, but less relevant.

(Facilitator: What does data mean to you? What's the first thing that pops into your head?)

Interviewee: My clinical notes. (Aboriginal Health Worker)

(Facilitator: Rate the importance of having clinical data on a scale from 1 to 10.) Clinical data, a 10. I need that to do my job. Research data, in day to day practice, it's not as vital and not as called to mind. (Allied Health)

Easy data is very important, stuff that you can directly measure, like HbA1c and heights and weights. I guess the more nebulous data like surveys of attitudes I think is potentially very useful, but I personally am not sure how to actually then use it and apply it, but then I'm not a researcher. (Doctor)

I mean, it's still important [research data], but my every day role is using clinical data, and if I can get some research data to mix in there, great - but if I don't have it, I still use the clinical data. (Nurse)

TRUST AND ASSURANCE

Protecting ownership

Some participants were wary of external researchers accessing ACCHS' data. They were frustrated that, despite extensive participation, the Aboriginal community rarely received feedback, or saw tangible benefits of research. Other participants held skepticism towards academics who they felt were promoting their own career using data collected from the ACCHS without acknowledging or giving back to the community.

The problem that we had about that is once all the research was completed, we were getting no feedback coming back, and they were presenting their research to all these conferences. A presentation wasn't dealt with here with us first. We've cut down a lot with people coming in here researching, because none of the information has ever come back to us. (Manager)

You know when they come in [researchers] or they make an agreement with you, oh yes it's the Aboriginal tick this month. We're the Aboriginal tick. I'm quite happy to cooperate with people, but I'd like something back. Even if it is a better working relationship with somebody. (Nurse)

(Facilitator: How do you feel about other researchers accessing the data of people involved with your organisation?) Interviewee: I'm suspicious. I'm conscious that we work in an Aboriginal organisation, and that data for Aboriginal people holds different meanings for the people, than it does for outside researchers. (Doctor)

We've been researched and studied that much and we're still in the same position I think. How much do you need to tell us what we already know? (Allied Health)

But for us I would like to see more collaboration because I think the service you're working in can add value to the research and I think it should be more collaborative because in my experience it's just very one-sided. (Administrator)

Confidence in narratives

Though research data were valued among ACCHS' staff members, some participants felt that Aboriginal staff and clients were more willing to accept anecdotal data (i.e. stories) on

“face value”. They felt that verbal information shared among peers would be more readily trusted even if it had not been derived from empirical sources.

He presented his study to some non-Aboriginal people who were saying, oh I get it. It was like the evidence - they liked that evidence. Whereas I think a lot of Aboriginal people will accept it on face value and your story and your tale. But they like the figures, the numbers and they like the science behind it. I like the science behind it too because that now gives me more proof and I'm not just talk. (Manager)

Whereas black fellows, if you're telling me that story, well I believe you, it's true. Especially too because I think too it's the way we're brought up. That oral history is told to us and we - I don't need to see a bit of paper to know that. (Manager)

Valuing local sources

Data collected from the participant's own ACCHS, or from the local area, was often trusted more than data derived from more distal sources (e.g. Australian Bureau of Statistics). Participants commented that data collected from non-local sources were often incongruent with their own perceptions of the health needs and characteristics of their clients.

I don't trust the Census data, not for any Aboriginal data that I want. I want to know how many Aboriginal families in [our area]. (Aboriginal Health Worker)

She's done a program on keeping kids - Koori kids - safe. Her data is more relevant to me than the New South Wales Health data or whatever because it's more local - yeah. (Nurse)

Yeah, you read things from small projects within our area, yeah. I trust it, yeah, heaps more. Because usually we're involved in it, so you know what the process has been and you sort of know that it's true and yeah. (Nurse)

MOTIVATION AND EMPOWERMENT

Engaging the community

Some participants noted that Aboriginal health data predominantly reflected poor outcomes. They believed it was important for the ACCHS to inform their local community of data that showcased positive health gains, and expected that this would empower the community and encourage greater health service use.

If there's - whether the results are positive or not, the community needs to be informed but usually participation [in] programs and that, the results have improved and it's something that a community has to be proud of as well. (Manager)

*I suppose then those families would be able to say oh sh*t I did this and this is what's happened...and we can relate it back to absolutely what happened with our families. Thirty people smoked in their pregnancies and then 25 of those kids got ear problems. That's probably how we could use it [data] really, really effectively to go back to the community and say look we've recorded it all, this is actually what's happening. People would hopefully change their behaviours so that they have better outcomes. (Nurse)*

I don't know, because I think that a lot of it is negative. Because I hear in the media stuff and you think it's negative and you don't need to hear that all the time. If it was somehow changed around in the way it's delivered that it was showing the positive rather than this is

all bad stuff. Showing that we think coming out of this, if we do this, this and this, we're going to have that outcome. Rather than staying on the negatives like you're more likely to die or, compared to other Australians blah, blah, blah. I just don't like all that. (Nurse)

It gives you geographical information, it gives you age, it gives your life expectancy, it breaks down the Aboriginal to non-Aboriginal and it [sees] where the gaps are, shows us where the gaps are and helps us identify - and that's over obviously a longer term of when we're thinking and being strategic planning. This is still a very big issue for our people in our community and we need to continue to work a lot harder. (Manager)

Influencing morale

Participants often felt a sense of pride in the data they had collected, particularly if this data demonstrated the positive impact the ACCHS's services were having on the health and wellbeing of their clients. This data was seen to motivate and boost morale among staff. Some felt that more data could be provided back to the ACCHSs so that they can see whether they are performing well and determine where more work is needed. However, some were discouraged by excessive data collection. This was attributed to onerous reporting requirements, a lack of understanding regarding the purpose of data collection, or because they were not convinced that the data would translate into improved services.

But if you get a bit of a bigger picture of what you're doing, it seems to make more sense. That's something that I found has helped maintain my motivation to continue the work that I'm doing. (Doctor)

Even if they are still on 50 per cent and there's an AMS that's on 80, automatically it's like a competition. We want to get to where they are. It does, it uplifts the morale here and people want to work harder to get where they are. (Manager)

Because without access (to data) you - well you can't prove a lot of things. You - even the fact that you can't prove that you're actually a valuable, useful person in the organisation. (Nurse)

So if you look at every year the KPI data we send back to the Commonwealth or the State government, we have no idea how that compares to other AMSs or how that compares nationally, how does that compare to Close the Gap efforts? We have no clue. (Administrator)

The problem with that is that staff don't make the connection as to why that's important because the information is not fed back into the system. What you have is you've got staff just sitting there going, here I go, doing another one of these reports and having to send it to the government, blah blah blah. (Administrator)

Because for me, it's about planning. It's that bigger picture stuff. (Manager)

Reassuring and encouraging clients

Data was used to educate clients about lifestyle risk factors (e.g. smoking) associated with poor health outcomes, and to encourage healthier lifestyle choices. Participants also used data to reassure and provide information to clients about their own health. This was thought to promote treatment adherence and facilitate more engagement with the services provided at the ACCHS.

So we just had a diabetic patient looking at his feet, and I said, did you know that 85 diabetics every week in Australia lose a foot or lower limb? So that was data that I got elsewhere from Diabetes Australia, and I was able to pass that on to the patient, as a statistic, that he needs to take care of his feet. (Nurse)

Fitness assessments are done every three months. So we look at strength, cardio, endurance, flexibility and core strength. Then we just look at the change within the three months of how they've improved. Yeah and it's a personal thing and it's used as a motivational tool. (Allied Health)

Well the data that I - we use data to explain results to clients. So after we do the hearing test, we go through the process of looking at their - the three different sets of results and we explain that to them. We use data when we're - when I'm doing health promotion education. So whether that is looking at some statistics from my clinic, from what I do here or whether that's a little bit broader and it's just otitis media stats. So we use it for education and health promotion. Yeah, I think that that's probably the biggest - the two biggest areas. (Aboriginal Health Worker)

BUILDING RESEARCH CAPACITY

Using cultural knowledge

The ACCHS's unique knowledge of the Aboriginal culture and the local community was believed to have the potential to enhance data collection practices within the Aboriginal community. Participants thought that the community engaged more with culturally appropriate research materials and with staff they knew and trusted, thus enabling greater and more accurate data collection and dissemination.

The assessment was a DoCS assessment. It wasn't culturally appropriate for us as a team. What we did, we redeveloped it to suit us. Other people, other agencies have rang us and asked if they can use it. We have shared it. It was doing a lot of research on how do we ask this? (Manager)

I think sometimes people don't consider - the typical research methodology will not always yield the best result. So there has to be at times a bit more of a flexible way of collecting data because some of the things that we do it's not always very easy to quantify. We'll be able to tell you if it's going to work or not. (Administrator)

I would be interested in learning to do it because then that helps me make the decisions on whether someone comes to me with an idea and says, I think this is the best way our mob's going to engage, I know this. I can say, well we've already done that in the past and it hasn't. Or if you're saying that, let's - and also I could help teach them how to collect that data to say - because that's sometimes - I think with that we're collecting the wrong thing. (Manager)

I think sometimes people don't consider - the typical research methodology will not always yield the best result. So there has to be at times a bit more of a flexible way of collecting data because some of the things that we do it's not always very easy to quantify. We'll know, we'll know. We'll be able to tell you if it's going to work or not. (Administrator)

Promoting research aptitude

Participants believed that data collected at the ACCHS were under-utilised for research purposes. They were often involved in research though some described their ability to use this data as limited. Some wanted further training to enhance their ability to conduct, and use research data, while others did not see these skills as being relevant to their job. Lack of time was identified as a major barrier to research training and data use.

Plus from journals, especially when we're looking at healthy lifestyle and connecting that, we don't have enough people who know how to do the research or collect data. Or sometimes we collect all this stuff but we don't know how to use it. (Manager)

They're inputting it and it's collected and inputted on different things, either on Excel spread sheet or some people use a Word. From a manager's perspective, I would love that we could use that data. I think we're just giving but not interpreting it ourselves even. (Allied Health)

For example, when I do education out in the community - and this is very, very basic - but I'll do pre and post surveys and I look at their knowledge around a few different things and get them to write it pre and post. I use it for continuous improvement but that's about it. I know that there probably could be other stuff extracted from that but I just have no idea where to even start. (Aboriginal Health Worker)

Oh the bits of the maths, and bits and pieces is not going to make any difference to my job. The outcomes of what the maths said, is. But learning how to do the maths, I'm sorry. There are experts around that, that they're quite willing and able to do that. I don't see why I should. (Nurse)

Very important but we have to transfer that data into something. I think that it's good to have that data as long as it doesn't sit up on the shelf. (Administrator)

Prioritising specific data

Participants wanted current research data that was relevant to their own work and/or addressed the health concerns of the Aboriginal community. Such data would enable them to keep up-to-date with the latest healthcare interventions/practices in their field.

I'd want more data - the most important thing - I want the data that will tell me why we need AMSs or what works with an Aboriginal Medical Service to say how the impact that Aboriginal people have working with their own people and culture and that resilience. (Manager)

Well with Close the Gap, I'd like to know a lot more about that, about what's worked, what's been looked at? Yeah, what is - or any data that has been collected, what does it show? If it hasn't been collected, why not? (Nurse)

I like to know about the lived experience. I'd ask the families, what did you think of the program? ... I'm more keen to know, how did you feel about what happened to you in the process? So that's the data that I really am interested in. (Nurse)

So not so much maternal and health stats, but programs that have shown outcomes by using data. Like not so much stats so this is how we've got this many people with, but programs where they show improvements. (Aboriginal Health Worker)

OPTIMISING SERVICE PROVISION

Necessity for sustainable services

Participants stated that data was essential to the process by which the ACCHS acquired and maintained funding. Because of this, participants saw data as being crucial to the longevity of services and programs the ACCHS provided to the community. They noted that data collected within the ACCHS justified both the number and type of staff, allowing the ACCHS to expand its services to meet the growing needs of the community.

I always say that data is key. Data is always the key to the longevity of services and programs. It's the way in which we capture and deliver the data that is the most instrumental part of any review process. (Administrator)

When you're competitive, yes, you can have someone write nice words, but at the end of the day it's the data that is irrefutable and gets you the money. (Doctor)

I think at times the research data would be useful for, especially as more and more programs are going to be cut and it's going to be a justification of why to keep those programs running. (Doctor)

I've been here for five years now, knowing the importance of how we've got to report back to our government to maintain our money here, because we're not mainstream. We're government-funded, so our funding can get pulled from us at any time if we're not doing the right thing. (Manager)

Guiding and improving services

Data was valued as it enabled participants to monitor a range of health service outcomes, guide decisions about resource allocation, plan for the future, and illuminate areas for improvement. This information was seen to as vital to maintaining the high standard of care offered at the ACCHS. Data also allowed the ACCHS to benchmark its services with other local healthcare providers in order to assess performance and remain competitive.

It's a reflection on the staff appraisals, and it's a reflection on how good our organisation is going in servicing our community and what can be improved. So it's just what can be improved, what we're doing, what's going really well and what's not, how we can make it work. (Manager)

I think the data that's captured generally doesn't - I don't think it's got a strong focus on the difference between having that all-person approach to health. But that's where I think it starts first and that all other of your health issues are affected by that. (Manager)

I typically only look at data when I'm trying to benchmark to see how we're progressing in terms of previous month performance or previous year's performance and I'm generally looking very broadly and at very high level. (Administrator)

Well, it's helpful for planning. It's also helpful for working out what the needs are for the community. So that's basically really what we want to do. We want to plan for us to grow as a business but then we also want to make sure the needs are met for the community. So that's all I can see data's for, really. That's the most important. (Manager)

Supporting best practice

Participants described the importance of data to provide up-to-date health service guidelines and to ensure that the ACCHS was following the latest evidence-based practices. This was necessary in order to justify healthcare decisions made by clinical staff members and to ensure ACCHS' clients received the best quality treatment. However, some participants believed that clinical data was limited as it did not provide a holistic view of a person, or their family's health.

I talked about medication, about research that's been done, and I've talked to people each day about evidence-based practice. (Nurse)

So I think our perspectives can be slightly off at times and when we get the hard data that can change our opinion. Some people it wouldn't change their opinion, but others might say, well okay. Sometimes we get it wrong, but without the data we've got nothing. We've got no basis to work from. (Doctor)

Or sometimes we might - we'll think, I think this happens but it actually gives you the evidence for what it is that captures what we need to know. But it also gives you new directions where we should head. We can tell whether that evidence, are we doing it right? Are we getting it? Are our programs targeted in the right direction? (Manager)

ENHANCING USABILITY

Ensuring ease of comprehension

Participants believed that data should be presented clearly, concisely, and in plain language. They wanted to be able to understand and use data quickly, minimising time and resource wastage. Visual data (e.g. graphs) were seen as the clearest and most efficient way to communicate data within the ACCHS and to clients; overly statistical data was not desired.

[Data] needs to be presented in a way that's easily readable, and I don't need to sit down there in a quiet room, trying to get my head around it. I'm sorry; I just do not have the time. Most of the stuff I do and what I bring out on, is done in-between clients. I need to be able to look at something that's readable. (Nurse)

What kinds are less important? I think maybe a lot of deeply statistical stuff - all that kind of stuff. I'd like - I'm a bit more visual, I'd like to perhaps look at it set out in a graph or something, and very clear. (Nurse)

No, look, I mean, for somebody at my level typically you want things that are very, very quick snapshot stuff because time is something we don't generally have enough of on a day-to-day basis. So really consolidated data is always the better option. Because typically when we do get some time and some peace and quiet we will then sit down and go through the document in more detail. (Administrator)

Seeing it visually is a better way of - well for me, visual ways of presenting the results or the data is a better understanding than a written... Because we already know why you're using the data and what it's going to be used for. So we don't need 100 page reports because nobody [wants to read it]. (Aboriginal Health Worker)

Improving efficiency of data management

The majority of data was stored, transferred and retrieved using PIMs. Participants were confident using these databases but suggested that further training with the ACCHS' current data systems could promote more efficient data handling. Linking databases within the ACCHS was also suggested as a means to reduce redundant data entry.

Just presenting someone else's PowerPoint on data and data management. I saw everyone's face and they were like, they thought I was God, but it wasn't me who was doing it. But they were like, yes we want this - people are wanting it. They just don't know how to do it. (Manager)

(Facilitator: Can you describe any barriers you face in accessing clinical data and research data?) Interviewee: Poor IT, poor hardware, software. (Doctor)

You've got to work out a [data] system that works. Just not for us at a high level, but it's on the ground. How does it work for the staff on the ground? You've got to make sure that they understand the process too - which they have. You want to simplify it, so that it's easy for the doctors. Not have staff stressed out and going this is too hard. (Manager)

I think there needs to be a system where all programs are linked in some way to keep data, because we might be over there in child care, but some of those families might be accessing other services, even family services or the play group [or things]. So there needs to be something where we link and see who's working with this person and where to now and this is not happening. (Manager)

So data management is something that we're going to invest heavily in over the next 12 months, to try and - not just for funding reasons but for staff to validate the work that they do, because they do a lot of work but it's not actually being captured. So we've got to spend a lot of time and energy on our health workers in training them in Medical Director and make sure that they're capturing everything that they do. (Administrator)

Valuing accuracy and accessibility

Data that were inaccurate and difficult to access prevented efficient use, which caused frustration and reduced productivity. Some struggled to access data from external organisations (such as hospitals) and urged for more data to be shared within the ACCHS. More training and awareness of the purpose of data collection were suggested to reduce error when data was collected.

It's extraordinarily difficult to get much organized data out of the hospital. (Doctor)

If they haven't coded it in correct sections, it's not collectible data that I can use to go against my reporting. (Doctor)

But if we actually did that [update addresses] at our reception desk, with every patient, it would make my life so much easier. But the data that we've got on people's addresses and phone numbers is often out of date. (Doctor)

(Facilitator: What do you think would help the AMS make best use of data for its programs and services?) Interviewee: Definitely ease of access. I guess I always find data collection a big barrier, rather than data use. So just making sure that the data collection side of it is easy to do. I know that there's been a lot of emails running around the AMS recently about this hasn't been filled in, this data needs to be collected, but I think it's just not easy, it's not clear on the systems to do that (Allied Health)

*I think it's really important for us all to have access to it, because if there's only one person having access - like if I was the only person to have access to my notes then the other people aren't going to see what I've been doing, it's just not holistic care for our clients.
(Aboriginal Health Worker)*

Discussion

Health professionals serving the Aboriginal community view data as a resource that is crucial to the effective and efficient provision of health services, and to the funding processes by which these services are sustained. Data that demonstrated improved health outcomes within the local community are believed to positively influence morale and motivation. However, there are concerns about excessive data collection by external researchers. Aboriginal health professionals believed that data collected from the ACCHS belong to the Aboriginal community. They urged that the results of data should be fed back in a meaningful way that translates into services to benefit Aboriginal people. Data is viewed, not only as a tool to sustain and deliver services, but also as a source of motivation, pride and empowerment.

Participants were confident handling and interpreting descriptive clinical/demographic data and using PIMS; however using data to conduct quantitative research (e.g. creating scales/measures, quantifying outcomes, and making statistical inferences) seemed more challenging. While many believed that data collected at the ACCHS were under-utilised for research purposes, participants were divided in their attitudes towards learning more about conducting research themselves. Limited time was seen as the most common barrier to using data beyond everyday purposes.

These findings accord with recent literature highlighting progressive gains in ACCHS' data use^{11, 20, 21}, and the importance of overcoming time burdens to facilitate greater research participation from primary healthcare practitioners.^{22, 23} Research has indicated that health professionals often use limited time as a 'socially acceptable excuse'^{24, 25} masking attitudes that place diminished value on research participation. However, this study suggests that many ACCHS staff are open to learning research practices that can enable greater data use, providing time burdens can be eased and training provided. This attitude is encouraging, given the push to build greater research capacity within the Aboriginal community²⁶ and the number of qualities, conducive to this aim, that ACCHS staff possess, including: experience collecting and managing electronic health data, frequent research participation, the ability to use cultural knowledge to enhance and safeguard data collection, extensive engagement with the Aboriginal community, a desire for more localised data, and the motivation to use data to improve Aboriginal health and research practices. External researchers often capitalise on these skills when collaborating with ACCHS.^{13, 14, 27} However, partnerships that comprise a 'two-way street', allowing ACCHS staff the opportunity to gain practical research skills through the involvement with experienced researchers and research institutions, constitute an achievable strategy to boost Aboriginal research capacity.

Importantly, any initiative designed to provide further training for ACCHS staff needs to align with the priorities of the ACCHS and be provided in a manner that impacts minimally on staff workloads. Identifying strategies for flexible, informal and face-to-face training through consultation with the ACCHS could provide opportunities to build research capacity through enhanced data collection, interpretation and dissemination (including opportunities for co-authorship), and initiate new or expanded roles at the ACCHS. While such collaborations require more commitment and resources from external researchers and ACCHS, both parties are likely to benefit from mutual collaborations that produce high-quality research that addresses the health needs of the Aboriginal community.

ACCHS staff voiced concerns surrounding the lack of timely feedback and often unclear purpose of data collection, whether collecting data for researchers, funding bodies or for their own internal reporting requirements. These findings emphasise the need for greater communication and transparency of the purposes and outcomes of data collected at ACCHS. Ensuring that staff are aware of how routinely-collected data benefits the ACCHS is likely to improve engagement in data collection and potentially reduce error during collection. Researchers should ensure that the findings of data collected at the ACCHS are presented back to staff and participants (if possible) in a timely manner and in a format that is accessible and immediately comprehensible. Descriptive data that are clear, concise, visually represented and accompanied by a short verbal summary were indicated as being the most useful for ACCHS health professionals.

This study highlights the importance of ensuring that Aboriginal and non-Aboriginal research partnerships maintain a clear understanding of how data will be used if partnerships are to be sustained and successful. Current Aboriginal Health and Medical Research Council (AHMRC) guidelines recommend that Aboriginal research involves extensive input from, and benefits to, the Aboriginal community;²⁸ however, ACCHS health staff often believed that Aboriginal research was overly descriptive and inconsequential. Wariness that arises from a 'research without service' philosophy may weaken nascent research partnerships and contribute to the lack of research initiated and led by ACCHS health professionals, as well as limiting future opportunities for collaboration.

Beliefs surrounding the motivating effects of data reported by this study provide an opportunity to address concerns surrounding 'ineffective' data use. Staff members were aware of the disproportionate health burdens faced by the Aboriginal community and of the deficit models of research that measure them. Making positive health data more salient and encouraging research that is 'strengths-focused' is a potentially useful method of stimulating interest in data use at the ACCHS and within the Aboriginal community. For example, promoting data that illustrate improvements associated with ACCHS-led health initiatives through social media, community presentations and at regular staff meetings has the potential to motivate both community and staff members alike, encouraging engagement with future research projects that may lead to further growth in Aboriginal research capacity.

To the best of our knowledge, this is the first study specifically investigating the perspectives of Aboriginal health professionals on data. However, there are some potential limitations. This study collected qualitative data from a range of health professionals from three urban/regional ACCHS; therefore, the transferability of the findings beyond these ACCHS is uncertain. Also, only four participants were men (11.4%), though anecdotally this reflects the gender ratio at the three ACCHS in this study.

Despite increases in Aboriginal controlled research output, building research capacity within the Aboriginal community remains an important strategy to achieve the health goals laid out by the Close the Gap campaign.^{6, 9, 10} This study indicates that ACCHS staff view data as a means to achieve this goal, though there is room for assistance from research communities. ACCHS staff members' experience with health data and their knowledge and involvement with the Aboriginal community place them in an optimal position to expand their data handling abilities to facilitate service-improving research. Identifying ways to support ACCHS staff in these endeavours is a potential strategy for Aboriginal health research policymakers in order to improve Aboriginal health outcomes and build research capacity.

Summary of findings

This study found that health professionals serving the Aboriginal community view data as a resource that is crucial to the effective and efficient provision of health services, and to the funding processes by which these services are sustained. Amongst ACCHS staff data is viewed not only as a tool to sustain and deliver services, but also as a source of motivation, pride and empowerment. Many ACCHS staff members are open to learning research practices that can enable greater data use, providing time burdens can be eased and training provided.

The ability to use and access data was influenced by ACCHS staff members' job requirements and professional or tertiary-level training. Many staff noted that undertaking a University degree had equipped them with the skills to understand data and papers based heavily on data.

Not all data were seen as relevant; participants felt that staff who were less aware how data was being used would place lower importance on data collection and access. Data collected from the participant's own ACCHS, or from the local area, were often trusted more than data derived from more distal sources. The findings emphasised the need for greater communication and transparency of the purposes and outcomes of data collected at ACCHSs. It was seen as crucial that data disseminated be back to ACCHSs and that this should occur in a format that is accessible and immediately comprehensible. Visual presentations of data were preferred by most participants.

Data that demonstrated improved health outcomes within the local community positively influenced morale and motivation. However, participants believed that data collected at the ACCHS were under-utilised and felt further training to enhance their ability to use data would be helpful. Aboriginal health professionals believed that data collected from the ACCHS belong to the Aboriginal community. They urged that the results of data should be fed back in a meaningful way and translate into services that would benefit Aboriginal people.

Note: This report is largely based on the published paper:

Young C, Tong A, Sherriff S, Kalucy D, Fernando P, Muthayya S, Craig JC. [Building better research partnerships by understanding how Aboriginal health communities perceive and use data: A semistructured interview study](#). *BMJ Open*. 2016;6(4):e010792.

References

1. Phillips B, Morrell S, Taylor R, Daniels J. A review of life expectancy and infant mortality estimations for Australian Aboriginal people. *BMC Public Health*. 2014;14(1):1.
2. Paul CL, Sanson-Fisher R, Stewart J, Anderson AE. Being sorry is not enough: the sorry state of the evidence base for improving the health of Indigenous populations. *Am J Prevent Med*. 2010;38(5):566-8.
3. Stewart J, Parter C, Maher L. Building a strategic approach to improve Aboriginal health research and evaluation in NSW. *NSW Pub Health Bulletin*. 2012;23(4):87-91.
4. Johnston L, Doyle J, Morgan B, Atkinson-Briggs S, Firebrace B, Marika M, et al. A Review of Programs That Targeted Environmental Determinants of Aboriginal and Torres Strait Islander Health. *Int J Environ Res Pub Health*. 2013;10(8):3518-42.
5. Eades S, Taylor B, Bailey S, Williamson A, Craig J, Redman S. The health of urban Aboriginal people: insufficient data to close the gap. *Med J Aust*. 2010;193(9):521-4.
6. Thomas D, Bainbridge R, Tsey K. Changing discourses in Aboriginal and Torres Strait Islander health research 1914–2014. *Med J Aust*. 2014;201(1):S15-S8.
7. Humphery K. Dirty questions: Indigenous health and 'Western research'. *Aust NZJ Pub Health*. 2001;25(3):197-202.
8. Walter MM. The politics of the data: How the Australian statistical Indigene is constructed. *IJCIS*. 2010;3(2):45-56.
9. Jamieson L, Paradies Y, S E, Chong A, Maple-Brown L, Morris P, et al. Ten principles relevant to health research among Indigenous Australian populations. *Med J Aust* 2012;197(1):16-8.
10. Walter M. Using the 'Power of the Data' within Indigenous Research Practice. *Australian Aboriginal Studies*,. 2005;2:27-34.
11. Hayman NE, White NE, Spurling GK. Improving Indigenous patients' access to mainstream health services: the Inala experience. *Med J Aust*. 2009;190(10):604-6.
12. Baba JT, Brolan CE, Hill PS. Aboriginal medical services cure more than illness: a qualitative study of how Indigenous services address the health impacts of discrimination in Brisbane communities. *Int J Equity Health*. 2014;13(1):56.
13. Bailey J, Veitch C, Crossland L, Preston R. Developing research capacity building for Aboriginal & Torres Strait Islander health workers in health service settings. *Rural Remote Health*. 2006;6(4):556.
14. Couzos S, Lea T, Murray R, Culbong M. 'We are not just participants--we are in charge': the NACCHO ear trial and the process for Aboriginal community-controlled health research. *Ethn Health*. 2005;10(2):91-111.
15. Gardner KL, Dowden M, Togni S, Bailie R. Understanding uptake of continuous quality improvement in Indigenous primary health care: lessons from a multi-site case study of the Audit and Best Practice for Chronic Disease project. *Implementation Sci*. 2010;5(1):21.
16. Si D, Bailie R, Cunningham J, Robinson G, Dowden M, Stewart A, et al. Describing and analysing primary health care system support for chronic illness care in Indigenous communities in Australia's Northern Territory – use of the Chronic Care Model. *BMC Health Serv Res*. 2008;8(1):112.

17. The SEARCH Investigators. The Study of Environment on Aboriginal Resilience and Child Health (SEARCH): Study Protocol. *BMC Public Health*. 2010;10:287.
18. Williamson A, Redman S, Haynes A, Barker D, Jorm L, Green S, et al. Supporting Policy In health with Research: an Intervention Trial (SPIRIT)—protocol for a stepped wedge trial. *BMJ Open*. 2014;4(7).
19. Corbin J, Strauss A. *Basics of qualitative research: techniques and procedures for developing grounded theory*. Sage Publications; 2014.
20. Panaretto K, Wenitong M, Button S, Ring I. Aboriginal community controlled health services: leading the way in primary care. *Med J Aust*. 2014;200(11):649-52.
21. Aboriginal Health and Medical Research Council of NSW. *ACCHS data in ACCHS hands*. 2013.
22. Brodaty H, Gibson LHR, Waine ML, Shell AM, Lilian R, Pond CD. Research in general practice: a survey of incentives and disincentives for research participation. *Mental Health Fam Med*. 2013;10(3):163-73.
23. Boase S, Kim Y, Craven A, Cohn S. Involving practice nurses in primary care research: the experience of multiple and competing demands. *J Adv Nurs*. 2012;68(3):590-9.
24. Cvijovic K, Boon H, Jaeger W, Vohra S. Pharmacists' participation in research: a case of trying to find the time. *Int J Pharm Pract*. 2010;18(6):377-83.
25. Salmon P, Peters S, Rogers A, Gask L, Clifford R, Iredale W, et al. Peering through the barriers in GPs' explanations for declining to participate in research: the role of professional autonomy and the economy of time. *Fam Pract*. 2007;24(3):269-75.
26. Guthrie M. The shape of things to come: visions for the future of Aboriginal and Torres Strait Islander health research. *Med J Aust*. 2014;200(11):618.
27. Hecker R. Participatory action research as a strategy for empowering Aboriginal health workers. *Aust NZJ Pub Health*. 1997;21(7):784-8.
28. AH&MRC Ethics Committee. *Guidelines for Research into Aboriginal Health: Key principles*. 2016.