

# BMJ Open Building better research partnerships by understanding how Aboriginal health communities perceive and use data: a semistructured interview study

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## ABSTRACT

**Objective:** To describe the attitudes and beliefs of health professionals working in Aboriginal Community Controlled Health Services (ACCHS) towards the access, usage and potential value of routinely obtained clinical and research data.

**Design, setting and participants:** Face-to-face, semistructured interviews were conducted with 35 health professionals from 2 urban and 1 regional ACCHS in New South Wales. The interviews were transcribed and themes were identified using an adapted grounded theory approach.

**Results:** Six major themes were identified: occupational engagement (day-to-day relevance, contingent on professional capacity, emphasising clinical relevance), trust and assurance (protecting ownership, confidence in narratives, valuing local sources), motivation and empowerment (engaging the community, influencing morale, reassuring and encouraging clients), building research capacity (using cultural knowledge, promoting research aptitude, prioritising specific data), optimising service provision (necessity for sustainable services, guiding and improving services, supporting best practice), and enhancing usability (ensuring ease of comprehension, improving efficiency of data management, valuing accuracy and accessibility).

**Conclusions:** Participants were willing to learn data handling procedures that could further enhance health service delivery and enable more ACCHS-led research, but busy workloads restrict these opportunities. Staff held concerns regarding the translation of research data into beneficial services, and believed that the outcome and purpose of data collection could be communicated more clearly. Promoting research partnerships, ensuring greater awareness of positive health data and the purposes of data collection, and communicating data in a user-friendly format are likely to encourage greater data use, build research capacity and improve health services within the Aboriginal community.

## INTRODUCTION

The average life expectancy of Aboriginal people in Australia is estimated to be at least

## Strengths and limitations of this study

- This is the first study to specifically describe the attitudes and perspectives of Aboriginal Community Controlled Health Service (ACCHS) staff towards clinical and research data.
- Study participants represented a range of health-care professionals typically employed by ACCHS.
- The study recruited participants from three urban/regional New South Wales ACCHS; therefore, the transferability of the findings to other ACCHS is uncertain.

11 years lower than that of their non-Aboriginal counterparts.<sup>1</sup> In response, the Australian government has pledged to ‘Close the Gap’ by 2030 and reduce the health disparities between Aboriginal and non-Aboriginal people. A key component of this initiative is advancing the understanding of physical, mental, environmental and social determinants of Aboriginal health through focused research.<sup>2–5</sup>

Historically, Aboriginal health research has originated from ‘outside’ the Aboriginal community, often conducted in a manner that is perceived to be 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.<sup>6–9</sup> 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.<sup>10</sup>

Aboriginal Community Controlled Health Services (ACCHS) are primary care service providers that are critical to maintaining and improving the health of 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.<sup>11 12</sup> ACCHS are therefore in a strategic position to facilitate research using data from their own and external sources. While ACCHS often participate in research, there are relatively few examples of research initiated and led by the ACCHS themselves,<sup>13 14</sup> 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.<sup>6</sup> 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,<sup>15 16</sup> 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):<sup>17</sup> 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)<sup>18</sup> 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 semistructured 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.<sup>19</sup> 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

Participants represented a range of occupational roles employed by ACCHS and typified the gender ratio

observed at the participating services; participant characteristics are provided in [table 1](#). Of the 44 health professionals invited, 35 (80%) participated in the study. Non-participation was due to illness, scheduling conflicts and non-response. The average length of interviews was 43 min (range 20–93 min). Six themes emerged on the basis of the interviews with ACCHS staff: occupational engagement, trust and assurance, motivation and empowerment, building research capacity, optimising service provision, and enhancing usability. Online supplementary table S1 provides illustrative quotes for each of the subthemes.

## 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 of how data were 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.

### Contingent on professional capacity

Ability to use and access data was influenced by the staff member's job requirements and professional or tertiary-level training. Despite this variation, participants often expressed confidence using data and felt they had learnt

considerable data-handling skills while working at the ACCHS.

### 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/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.

### 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 scepticism towards academics who they felt were promoting their own career using data collected from the ACCHS without acknowledging or giving back to the community.

#### Confidence in narratives

Although research data were valued among ACCHS staff members, some participants felt that Aboriginal staff and clients were more willing to accept anecdotal data (eg, 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.

#### 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 (eg, 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.

### 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.

#### Influencing morale

Participants often felt a sense of pride in the data they had collected, particularly if these data demonstrated a positive impact that the ACCHS was having on the health and well-being of their clients. These data were seen to motivate and boost morale among staff.

**Table 1** Participant characteristics

| Characteristic             | Total (n=35) | Per cent |
|----------------------------|--------------|----------|
| 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            | (20.0)   |
| 60–69                      | 2            | (5.7)    |
| Withheld                   | 3            | (8.6)    |
| Aboriginal status          |              |          |
| Aboriginal                 | 22           | (62.9)   |
| Non-Aboriginal             | 13           | (37.1)   |
| 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)   |

HSC, Higher School Certificate.

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.

#### Reassuring and encouraging clients

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

#### Building research capacity

##### Using cultural knowledge

The ACCHS' unique knowledge of the Aboriginal culture and relationship with the local community was believed to enhance data collection from ACCHS' clients and their families. 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.

##### Promoting research aptitude

Participants believed that data collected at the ACCHS were underutilised for research purposes. They were often involved in research, though some described their ability to use these 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.

##### Prioritising specific data

Participants wanted current research data that were relevant to their own professional interests 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.

#### Optimising service provision

##### Necessity for sustainable services

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

#### Guiding and improving services

Data were valued as they 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 as vital to maintain 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.

#### 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 that ACCHS clients received the best quality treatment. However, some participants believed that clinical data were limited as they did not provide a holistic view of a person or their family's health.

#### 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 (eg, graphs) were seen as the clearest and most efficient way to communicate data within the ACCHS and to clients; overly statistical data were not desired.

#### Improving efficiency of data management

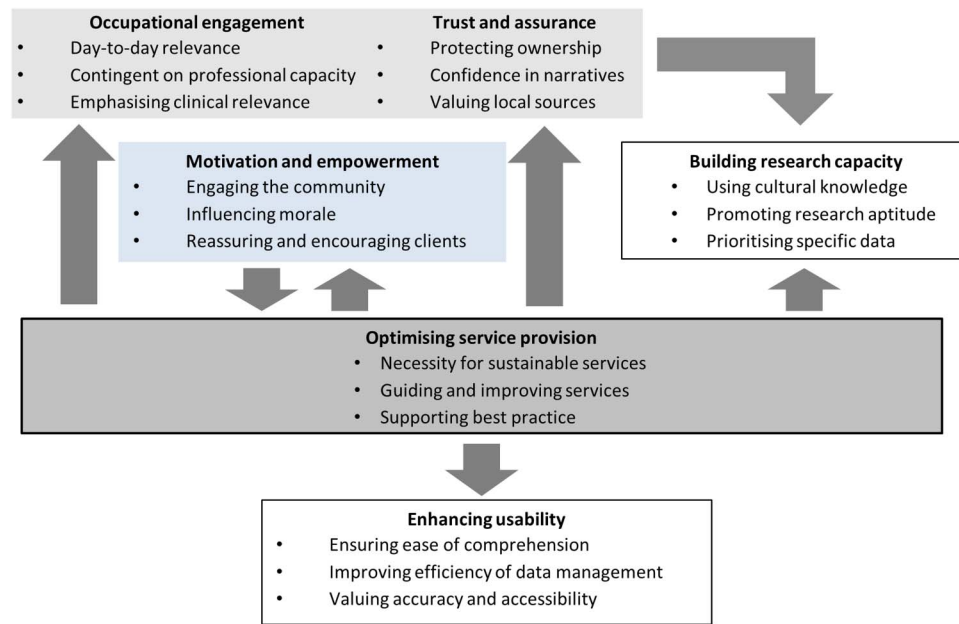
The majority of data were stored, transferred and retrieved using PIMS. Participants were confident using these databases but suggested that further training with the ACCHS' current data systems could promote more efficient data handling. Linking databases within the ACCHS was also suggested as a means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

#### 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 were collected.

The thematic schema shown in [figure 1](#) illustrates conceptual links between the themes. The arrows indicate an aetiological 'flow' that was inferred from the participant's perspectives on data. For example, participants believed that the ultimate 'purpose' of data was to ensure the provision of high-quality sustainable services to the Aboriginal community. In this way, the theme 'optimising service improvement' influenced all other





**Figure 1** Thematic schema.

themes. Attitudes towards ‘Building research capacity’ were also influenced by the participant’s occupation and their beliefs about research practices. Data that showed improvements in service provision were thought to inspire staff and aid positive engagement with clients. This, in turn, was believed to ‘feed-back’ into the provision of high-quality and sustainable services.

## 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 and translate into services that would benefit Aboriginal people. Data are viewed as a tool to sustain and deliver services, as well as a source of motivation, pride and empowerment.

Participants were confident handling and interpreting descriptive clinical and demographic data and using PIMS, but using data to conduct quantitative research (eg, creating scales/measures, quantifying outcomes and making statistical inferences) was regarded as more challenging and beyond their expertise. While many believed that data collected at the ACCHS were underutilised 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,<sup>11 20 21</sup> and the importance of overcoming time burdens to facilitate greater research participation from primary healthcare practitioners.<sup>22 23</sup> Research has indicated that health professionals often use limited time as a ‘socially acceptable excuse’,<sup>24 25</sup> 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 community<sup>26</sup> 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.<sup>13 14 27</sup> 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 coauthorship), 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.

Concerns surrounding the lack of timely feedback and often unclear purpose of data collection were voiced by ACCHS staff, 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;<sup>28</sup> 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.<sup>6 9 10</sup> 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.

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