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SPECIAL ISSUE • Co-creative approaches to knowledge production and implementation

research

Building trust and sharing power for co-creation in Aboriginal health research: a stakeholder interview study

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Background Historically, Aboriginal health research in Australia has been non-participatory, misrepresentative, and has produced few measurable improvements to community health. The Study of Environment on Aboriginal Resilience and Child Health (SEARCH) was established to co-create and co-translate research. Over the past decade, SEARCH has built a sustainable partnership across policy, research, clinical and Aboriginal community sectors which has resulted in improvements in Aboriginal health through enhanced services, policies and programmes.

Aims and objectives This study describes the critical success factors behind SEARCH, focusing on how SEARCH was established, and continues to build trusting co-creative relationships. It also explores some continuing challenges and considers how the partnership might be strengthened.

Methods Semi-structured interviews were conducted with 26 stakeholders, purposively selected to obtain maximum diversity of roles and perspectives. Interview questions explored concepts that informed the development of SEARCH such as trust, transparency, leadership, governance, reciprocity and empowerment. Data was analysed thematically and written up using the qualitative description approach.

Findings and discussion Nine critical success factors were identified: shared power; strong credible leadership; shared vision, shared goals; willingness to take risks; connecting across cultures; empowering the community; valuing local Aboriginal knowledge; ongoing investment and collaboration; and adaptability. While each of these factors has areas for ongoing improvement, this case example demonstrates that co-creation and co-translation of research in Aboriginal health is achievable and, indeed, necessary to improve health outcomes.

key words Aboriginal and Torres Strait Islander Research • participatory research • public health research • co-creation

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Introduction

The need for co-creation

Co-creation is a primary mechanism for producing meaningful research for health policy and practice. Co-creation can facilitate critical thinking and cross-sector communication, integrate diverse forms of knowledge, generate local ownership of programmes (Armitage et al, 2011), and harness frontline expertise in implementing and evaluating programmes in complex health systems (Hawe, 2015; Holmes et al, 2017). The genuine involvement of service users can have transformative effects on services (Osborne and Strokosch, 2013), paving the way for ‘... increased health outcomes, enhanced patient satisfaction, better service innovation, and cost savings’ (Palumbo, 2016, 72).

Co-creation builds on participatory research methods that recognise power imbalances brought about by social inequities and use strength-based empowerment approaches to address community needs (Bergold and Thomas, 2012; McDougall, 2012). These models aim to treat service users as active agents rather than recipients, and establish equal relationships where diverse forms of knowledge and experience are valued and used synergistically to produce practical outcomes (Greenhalgh et al, 2016; Prager, 2016). Such participative approaches are especially appropriate when working with Aboriginal people and other Indigenous groups as they address power imbalances and privilege epistemological knowledge forms not typically acknowledged in research (Bishop, 1996; Gibbs, 2001; Green et al, 2013).

The history of research in Aboriginal health

Historically, research involving Australian Aboriginal people has been problematic and has often been exploitative and invasive (Fredericks, 2008; Street et al, 2007), consistently failing to recognise the diversity of Aboriginal cultures, values, kinship and spirituality (NHMRC, 2003). Moreover, it has failed to acknowledge

the profound trauma of massacres, forced removal of children, dislocation from traditional lands and the ongoing impact of post-colonial experiences. As a result Aboriginal communities have been misrepresented in research findings (Anderson, 2011) and researchers have ‘ridden roughshod over our communities, cultures, practices and beliefs’ (Cruse in Fredericks, 2008). Similar experiences have been observed globally in research with other Indigenous groups (Koster et al, 2012; Smith, 1999).

In recent years there has been superficial compliance with ethical guidelines resulting in ‘poor consultation, lack of communication and infringement of deeply held values arising from cross-cultural insensitivity’ (NHMRC, 2003, 4). A 2017 systematic meta-review found most reviews in Aboriginal health had poor methodology and were conducted by non-Aboriginal researchers (Kinchin et al, 2017). Much research has reinforced a deficit view of Indigenous people (Thomas et al, 2014), and many so-called evidence-based policies and programmes have been experienced as paternalistic and punitive (Anderson, 2011). Further, research has primarily targeted rural and remote populations, despite more Aboriginal people living in urban and regional areas (Eades et al, 2010). Culturally inappropriate data collection and de-contextualised interpretation have not produced meaningful findings and Aboriginal communities report receiving few benefits, despite being one of the most researched populations in the world (Brands and Gooda, 2006; Kinchin et al, 2017). In fact, Aboriginal people continue to experience much poorer health and wellbeing than the general Australian population as reflected by lower life expectancy, education and employment rates, and higher rates of hospitalisation, homelessness, family violence and incarceration (Australian Institute of Health and Welfare, 2017).

Given this history there is, understandably, an often deep distrust by Aboriginal people towards research purporting to be for the good of their communities (Brands and Gooda, 2006). As Anderson notes,

... research was something carried out ‘on’ us as Aboriginal people, not ‘with’ us and certainly not ‘by’ us. Worse still, despite the large volumes of research to which we were subjected, very little seemed to be translated into practice; the research projects came and went, but health service delivery and policy remained the same. (Anderson, 2011)

It is now accepted that Aboriginal health research should be co-created with Aboriginal communities (Anderson, 2011; Jamieson et al, 2012; Street et al, 2007). These communities have long recognised the need for high-quality, culturally-attuned evidence to improve health and, in recent years, there has been a growing push towards greater involvement in research that affects them (Brands and Gooda, 2006; Fredericks, 2008; Thomas et al, 2014). Aboriginal people have contributed to important improvements in research governance and regulatory safeguards (NHMRC, 2003, Todd et al, 2000) and, increasingly, are active partners in co-created research (Aboriginal Affairs NSW, 2017; Green et al 2013). However, there are few published examples detailing the real-world co-creation of Aboriginal health research, policy and practice.

This progress has been supported in Australia by the Aboriginal Community Controlled Health Service (ACCHS) sector which is a mechanism by which

communities can exercise control over their health services (Panaretto et al, 2014). The sector comprises of individual ACCHSs governed by community-elected boards, and peak bodies at the state and national level that facilitate engagement with researchers and provide advice on ethical conduct.

The Study of Environment on Aboriginal Resilience and Child Health (SEARCH)

SEARCH is a cohort study of 1669 Aboriginal children and their caregivers from urban and large regional areas of New South Wales (NSW), designed to address community-identified priorities, enable the informed and ethical engagement of community members in research processes, and facilitate the translation of culturally relevant research findings into improved health outcomes (SEARCH Investigators, 2010). Longitudinal data has been collected since 2008 with the aim of describing and investigating the causes of health and illness in Aboriginal children, with a focus on healthy environments and holistic health.

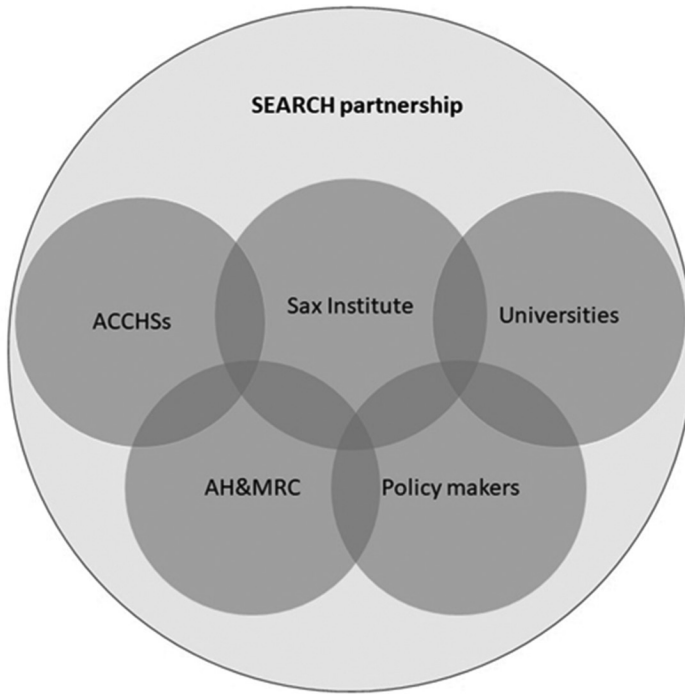
SEARCH is underpinned by a cross-sector research partnership established in 2008 between the Sax Institute (a non-government knowledge mobilisation organisation and coordinating centre for SEARCH), the Aboriginal Health & Medical Research Council (AH&MRC), several universities including the Australian National University and the University of Sydney, and four urban and regional ACCHSs in NSW: Tharawal Aboriginal Corporation (Campbelltown), Riverina Medical and Dental Aboriginal Corporation (Wagga Wagga), Awabakal Ltd (Newcastle), and Greater Western Aboriginal Health Service (formerly the Aboriginal Medical Service Western Sydney) (Mt Druitt) (Wright et al, 2016). Other partners include government policy and non-government health agencies, and research organisations. See Figure 1 for an illustration of this partnership.

To date, SEARCH has successfully contributed to enhanced children's access to specialist clinical services such as the Hearing, Ear Health and Language Services (HEALS) programme through which 1047 Aboriginal children have received care, including 7830 occasions of speech and language pathology services and 314 Ear Nose and Throat (ENT) surgeries (Young et al, 2016; Young et al, 2017). Findings from SEARCH have been used to redesign ACCHS services, and new models of mental healthcare for Aboriginal children and adolescents are being introduced in some health districts. SEARCH's high-quality data has been used to advocate for further funding for research and services; for example, it was used in a grant which resulted in \$1 million for smoking cessation programmes and was instrumental in attracting funds for a speech pathologist at two ACCHSs. The dissemination of SEARCH findings has fostered the creation of closer working relationships between mainstream and Aboriginal services which, in turn, has strengthened pathways to services (Gunasekera et al, 2011; Reed and Williams, 2015; SEARCH Investigators, 2010; Wright et al, 2016).

Aims

The aim of this study was to address the shortage of published literature on co-creation partnerships by exploring SEARCH stakeholders' perceptions of how a co-creation partnership in Aboriginal health research can be established and sustained long-term, and ultimately improve health outcomes for Aboriginal people.

Figure 1: SEARCH partnership



ACCHSs: Aboriginal Community Controlled Health Services; AH&MRC: Aboriginal Health & Medical Research Centre; Universities: University of Sydney, The Sydney Children's Hospitals Network, Australian National University, University of Melbourne, Flinders University, University of Wollongong; Policymakers: NSW Ministry of Health, NSW Family and Community Services, NSW Health Local Health Districts, NSW Department of Education.

Methods and research design

Methodology

This research was informed by Indigenous research methodology which ‘involves coming to an agreement about a mutually understood idea’ (Wilson, 2001, 179). Consequently, we did not use a predetermined framework. Rather, we used sensitising concepts (van den Hoonaard, 2008) to develop the interview schedule and inform the analysis, and strove to stay close to the voices of interviewees and let their perspectives shape the results as much as possible. Our theoretical perspective was underpinned by realism: a belief that the social and structural environment is experienced differently by people depending on history, culture, lived experience and myriad other factors (Maxwell, 2012). This means that while we can never fully know the ‘truth’ of a situation, we can get closer to it by listening to, and triangulating, the views of people who live it. Within SEARCH and throughout this paper we respectfully use the term Aboriginal to refer to the traditional owners of lands within NSW, in line with current guidelines (NACCHO, 2018).

Participants

ACCHS staff, researchers and policymakers involved in SEARCH were purposively selected to obtain maximum diversity of experiences and perspectives based on

role, location, and involvement in the project (Table 1). Both Aboriginal and non-Aboriginal stakeholders were included. Participation was voluntary and informed written consent was provided.

Table 1: Interview participants

Stakeholder group	Who this group includes	Number of interviewees
Researchers	SEARCH chief investigators, researchers based at universities / Sax Institute, clinician-researchers	9
SEARCH Coordinating Centre	Study director, project staff who liaise and support ACCHSs	3
Polymakers	Partners based at: The Aboriginal Health and Medical Research Council (AH&MRC), NSW Ministry of Health, NSW Centre for Aboriginal Health, NSW Family and Community Services	6
ACCHS staff / research officers	CEOs, medical directors, research officers, Aboriginal health workers	8

Data collection

Interviews were conducted between August 2017 and October 2017 by SS (an Aboriginal researcher based at the Coordinating Centre) and HM (a non-Aboriginal affiliated university researcher). Depending on stakeholders' locations and preferences, interviews were conducted face-to-face or by telephone. All interviews but one with frontline Aboriginal workers were conducted in person at their ACCHS by SS. Interviews were audio-recorded and transcribed verbatim.

Interview questions (Additional file 1) derived from (a) concepts that had guided the establishment of SEARCH; (b) recent studies on partnering in Aboriginal health (Armitage et al, 2011; Brands and Gooda, 2006; Fredericks 2008, Jamieson et al, 2012; Martiniuk et al, 2010; NHMRC, 2003; Panaretto et al, 2014; Street et al, 2007); and (c) from the experience of the researchers who work with and are members of local Aboriginal communities. This favoured concepts such as self-determination, transparency, trust, leadership, governance, equity and empowerment.

Interviewees were treated as deliberative partners rather than research subjects, and rough causal theories about how co-creation was working (or not) in SEARCH were presented for interviewees to critique and refine (Manzano, 2016). The focus of interviews was to identify concrete details about how the partnership was built and sustained, including areas for improvement. We guarded against confirmation bias by asking interviewees for their own ideas about why SEARCH functions as it does, including providing examples.

Data analysis

Three authors (SS, HM, AH) each independently read the interview transcripts and developed preliminary themes relating to co-creation in SEARCH. The concepts

underpinning the interview schedule guided deductive analysis whereby data was examined for examples of co-creation in-action. Inductive analysis was used to nuance, critique and refine these concepts, and to identify novel perspectives related to SEARCH's functioning (Thomas, 2006).

Coding workshops were used to compare themes and establish consensus for a coding frame that best represented the data. This frame was modified iteratively in response to ongoing data collection. Each code was populated with data from the transcripts by SS, HM and AH, and themes were further refined through analytical discussions, including conversations with AT and SM.

Findings were written up following Sandelowski's *qualitative description* approach (Sandelowski, 2000), which aims to represent data in a way that most stakeholders would agree is valid and to stay close to the data by summarising it in participants' everyday terms. (Sandelowski, 2000).

Ethical approval for this project was granted by the Aboriginal Health and Medical Research Council, project #892/12.

Findings

Interviews were conducted with 26 participants with an average of 35 minutes. A large proportion of the participants were female (Table 2), which broadly reflects the sex distribution of stakeholders involved in SEARCH.

We identified nine overarching themes for trusting co-creation partnerships in SEARCH: shared power; strong credible leadership; shared vision and goals; willingness to take risks; connecting across cultures; empowering the community; valuing local Aboriginal knowledge; ongoing investment and collaboration; and adaptability. A thematic schema of how these concepts relate is shown in Figure 2.

Table 2: Stakeholder characteristics

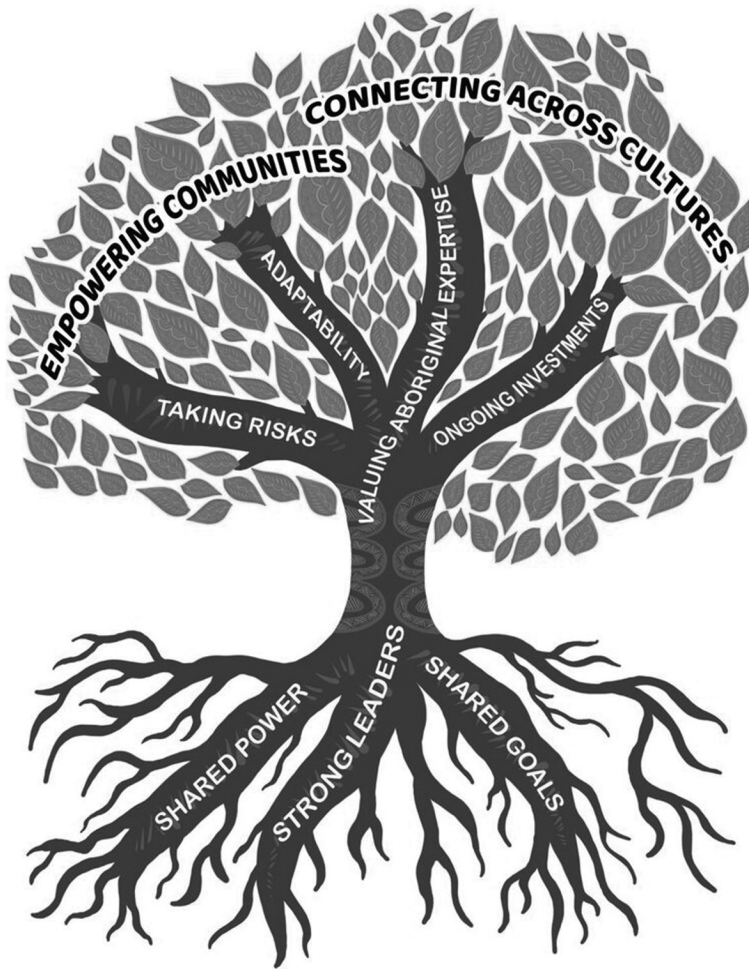
Characteristics	<i>n</i>	%
Gender		
Male	8	31
Female	18	69
Aboriginal status		
Aboriginal	12	46
Non-Aboriginal	14	54
Stakeholder group		
ACCHS staff	8	31
Researcher	12	46
Policymakers	6	23

Shared power

Balancing control

Collective control, enshrined in SEARCH's strong governance arrangements, was viewed as integral to co-production. As an Aboriginal knowledge broker said: "the

Figure 2: Thematic schema of key components of co-production in SEARCH



Thematic Schema: Shared power, strong credible leadership, and shared vision and goals provide the foundation for trusting relationships. A willingness to take risks, ongoing investment and collaboration, valuing local Aboriginal expertise, and adaptability of the model ensure it is meaningful and sustainable. The reward is mutual learning achieved through connecting across cultures, and empowerment of Aboriginal communities through building capacity and improving health services.

ownership of data is not just seen as university owned, research owned or Sax [Institute] owned. It's owned by the AMSs [ACCHSs] and [they] use that data to their best advantage”.

Early in the partnership, agreements were made that decision making would be shared, but that data would be owned by the ACCHSs (see Additional file 4 for details of decision-making forums). Memoranda of Understanding (MoU) between the investigators and each ACCHS detail partners' rights and responsibilities, funding levels and service provision; and the composition and function of governance bodies (see Additional file 2 for an example of a MoU). MoUs were informed by principles of equity, transparency, constructive reporting, protection of privacy, and respect for community autonomy.

Shared responsibilities

Governance in SEARCH is designed to facilitate the involvement of ACCHSs in decision making and data collection without overburdening them. For example, ACCHS-based research staff are funded by SEARCH and co-managed, thus the service has responsibility for data collection but does not lose out financially or deal with the administrative side of management. As an ACCHS CEO said: “you’re sharing the financial issues, you’re sharing the problem”. Accountability is taken very seriously on both sides to “keep each other honest” (ACCHS CEO). Several interviewees felt this governance structure helped them work through conflicts. The importance of goodwill and belief in the others’ commitment to SEARCH was also emphasised.

Interviewees identified a sense of collaborative problem solving: “we work through problems together” (ACCHS worker), and noted that co-creation was not about tackling every task collectively, but sharing decision-making power.

Strong credible leadership

Diverse expertise

Interviewees regarded SEARCH as successful in building and maintaining productive partnerships and identified the involvement of Aboriginal people in senior leadership roles (including chief and associate investigators) as a key factor. The inaugural study director was the first Aboriginal medical doctor to be awarded a doctorate in Australia and has extensive experience in Aboriginal health, giving her credibility in both Aboriginal research and medical communities. Similarly, the CEO of the AH&MRC was a founding member and chief investigator, elevating the partnership’s status with ACCHSs and easing concerns about potential risks. ACCHS CEOs have been investigators from the start and other partners bring expertise in medicine, epidemiology, health services, knowledge brokering, and frontline service delivery of ACCHSs. SEARCH’s team of investigators had experience working with Aboriginal communities, medical and scientific knowledge, and well-established links with funding and policy agencies. Moreover, policy interviewees felt the involvement of the Sax Institute, an organisation that works at the interface of research and policy, was integral to SEARCH’s successful engagement with government.

Distributed leadership

Interviewees regarded SEARCH’s leadership as “shared but not uniform” (Researcher), with people leading different areas of work, and coming together regularly for reporting and decision making. This ensures everyone has a voice and diversifies the partnership’s perspective, as an Aboriginal knowledge broker said: “when you’re led by many you have many directions that you need to look at”.

Shared vision and goals

A values-based foundation

SEARCH was founded by a coalition whose goals were to facilitate equal partnerships with ACCHSs and work long-term towards empowering Aboriginal communities to control research that affects them. Interviewees from all sectors of the partnership repeatedly explained: “the people that we’re working with share the same values”. The

belief that “we’re in it together” has been critical for developing strong relationships. As a researcher said:

‘if we didn’t like each other as people, if we didn’t trust what the others were doing, if we didn’t think that we all had the intentions and ultimately had the same goal, I think people on both sides would be like, “this isn’t worth it, it’s not worth our time”‘.

Making a difference

All the partners within SEARCH aim to drive real change in Aboriginal health. A researcher explained: “we want to make a difference. We don’t want to just collect data. About ten years ago I remember in a document we said: ‘No survey without service’ ... every facet of this is about making a practical difference”. This is also what engages policy partners: “a lot of the philosophy behind what SEARCH does certainly is consistent with my world view and how I think research should be conducted... it’s like minds meeting” (Policymaker).

Seeing it through

This shared commitment to effecting change has withstood many challenges. For example, several interviewees recounted a time when the investigators were unsuccessful in obtaining funding. The investigators felt they had jeopardised the project and failed their Aboriginal partners until:

[the CEO of an ACCHS]... gave a really fantastic speech about difficult times being when collaborations are tested. He said, ‘Well, I know you guys are surprised, but we’re not surprised because the experience for us of having something valuable that is funded and then the funding stops, that’s just normal’. I felt that day an enormous pride in the fact that we were in the process of transitioning into these very trustful relationships... and it was more than about the money. (Investigator)

Willingness to take risks

A leap of faith

Given the history of Aboriginal research in Australia, and the deep distrust of research, SEARCH represents a considerable, ongoing risk for all involved. Aboriginal communities and services risk exposure and judgement during sensitive data collection, inflammatory misrepresentation of their community, and a perceived risk of enforced interventions by statutory authorities as a result of revealing their life circumstances. As an ACCHS research officer said: “they’re handing their life over to us”. Therefore, the involvement of every single participant in SEARCH represents “a massive leap of faith” (Investigator). For ACCHSs, who take responsibility for the conduct of SEARCH, this required a similar leap of faith. An AH&MRC manager recalled the assessments of risk made early in the engagement process:

people would... say, ‘Can we trust this? Do we own this information? Who is going to be using this and accessing this? What are they going to be writing? Does it come back to us? Do we get to use the data?’

Many of SEARCH's initial and ongoing strategies have been developed with this risk in mind. These include:

Acknowledging the history: Investigators talked openly about the history of Aboriginal research, conducted deep consultation to identify community perceptions, and used this feedback to develop ethical principles for the project. Conversations about past breaches of trust sensitised researchers to community concerns: "you have to have an appreciation and an understanding of the history of the detrimental impact that research has had" (Researcher).

Formally agreed protections: Embedding shared power in SEARCH's governance structure includes explicit protections regarding ownership: "confidentially of data, and that we'd be very, very respectful of people and their privacy" (Researcher).

Honouring trust: Investigators knew they must respect the trust of Aboriginal services and communities: "... we felt that really heavily. We'd often say to each other, 'We can't let the ACCHSs down'" and "We need to get it right". Consequently, SEARCH researchers and coordinating staff ensure they do not make empty promises. An ACCHS worker noted:

the relationship is so close because we've honoured each other's agreement in terms of better communication, the release of data, the approval for stuff written up on the database and all that sort of stuff.... They've proven themselves.

Transparency: A key strategy for building trust was honest communication: "people have tried to be pretty frank about what's happening" (Investigator). This includes being realistic about SEARCH's limitations, and informing policymakers of emergent findings. As a policy interviewee explained,

...what's unique is there's a trusting relationship... you guys come and have a chat with us about what the results are... [so] we're prepared when it does come out in the media and... we have a response to it. It also starts dialogue around how we can fix some of these problems. I think that's... a clear description of what I would define as trust... it's really collaborative and collegiate in how we approach these issues. We might not always agree but we also are continuing to communicate.

Delivering outcomes: Interviewees felt that ultimately trust was honoured by SEARCH's emphasis on delivering services and outcomes. As an ACCHS worker said: "some people just go into those services and take. I think that you've given back".

Risks for researchers

Initially, SEARCH posed professional risks for investigators who were committing to a long-term unfunded project in which tangible outcomes were distant. However, these shared risks were instrumental in forming bonds that have helped to sustain the partnership. A researcher recalled the initial agreement: "... let's commit to an ongoing partnership irrespective of project funding, and then let's work out what

projects we want to work on. I reckon that's probably contributed to the ongoing relationship”.

Further, the potential pay-offs of such a model were a key attraction for many partners, as one researcher explained: “I dropped everything for something that had no funding at that stage... based on the fact that it was community led, because that wasn't common back then... [but] everybody really wanted to do it”.

Connecting across cultures

Relationship building

Aboriginal interviewees indicated that both the quality and quantity of interaction was important for building and sustaining trusting relationships. The onus on relationship-building means that researchers and the Coordinating Centre team strive to be as closely connected to the ACCHSs and their communities as possible. Small, frequent and informal meetings are key, as an Aboriginal policymaker explained: “it might just simply involve sitting down for a cuppa, and not even talking about the project, because it is about building that trust and that rapport”. Other facilitators are frequent telephone contact between partners at all levels; formal events including an annual forum, community events; and when Coordinating Centre staff assist ACCHSs with data collection and engage directly with the community, “that's building trust within the families because they're meeting the researchers” (ACCHS worker). Aboriginal partners appreciated SEARCH researchers who listened and were patient, non-judgmental, friendly, and “not pushy”. Over time, linkages have been embedded; the Coordinating Centre and senior researchers maintain regular communication with policymakers who, in turn, facilitate communication between SEARCH researchers and other government contacts. However, both policymakers and researchers felt that engagement across their domains could be increased, and one policymaker said that researchers could play a larger role in helping government incorporate findings more effectively into policies and programmes.

Mutual learning

An essential component and benefit of co-creation was mutual learning. The Aboriginal community learns about research, while ACCHSs and Coordinating Centre staff educate researchers on cultural competence. Every non-Aboriginal researcher who participated in this study remarked that their capacity to work with Aboriginal communities and their knowledge of Aboriginal culture and history had been dramatically improved through SEARCH. Learning is also broadened by clinician and policymaker partners who bring different expertise and practice cultures to the mix. Over time, understanding between partners has been facilitated by cross-sector mobility: SEARCH researchers have moved into policy positions, and ACCHS staff have moved to the Coordinating Centre. As one researcher reflected: “exchange between organisations is critical to maintaining strong relationships between organisations... It guards against people getting siloed, but it also means that you build an understanding of each other within the organisation”.

Understanding motivation

Aboriginal interviewees felt researchers had taken the time to understand what motivated communities and so were better able to engage with them meaningfully.

For example, there is an understanding that recognising Aboriginal partners in grants and on academic papers is important but that ACCHS staff do not achieve community respect this way, particularly if they are not genuine contributors. As an ACCHS worker said: “[some researchers] think what we want to hear is... ‘Your name will be on the publication’, [but] most blackfellas will go, ‘Shame!’”. Building on individuals’ strengths and interests was seen as a key strategy to engage Aboriginal staff. An ACCHS worker explained that for one staff member “the fact that her opinion is valued” was the most important part of being involved, while another was motivated to “get better services or funding or money”. Understanding motivation leads to meaningful participation.

Empowering the community

Equipping communities for action

Interviewees felt that communities often already know what needs to change in their communities but lack the resources to carry out programmes or advocate for services. SEARCH research and evaluation data has equipped participating communities to critique and revise their current programmes, develop new programmes, make persuasive cases for additional funding, and advocate more effectively for policies that impact on community health and wellbeing.

Building research capabilities

SEARCH supports ACCHS staff to gain skills in collecting, managing, interpreting and using data for service design and improvement, and to undertake formal higher education. A policymaker remarked that in terms of commitment to: “... building capability and capacity in those communities – you were one of the first studies to do that systematically and to adhere to those principles all the way through the process”. The importance of a tailored approach to capacity building was emphasised by an Aboriginal knowledge broker: “it’s not a one-size-fits-all... you have to be looking at where people are and what the next step is for them”. The additional support required for Aboriginal people to pursue further education was also noted. ACCHS staff determine what areas of local capacity should receive attention, but also whether they have scope. An ACCHS worker recalled: “you had ideas on how you could build capacity within our organisation, but you also asked us ‘Is that something you want?’... You listened to us when we said, ‘No, I haven’t got time’”. Researchers felt they should do more capacity building but ACCHS staff explained that their service delivery workloads were too high to further engage in research activities. Greater inclusion of parents and caregivers on writing papers, project planning and steering committees was suggested by researchers, and several interviewees expressed a desire to see SEARCH led by an Aboriginal principal investigator.

Demystifying research

SEARCH’s communication strategy has been strongly informed by the information preferences of ACCHS staff and community members. ACCHS workers felt that SEARCH had helped to “demystify” research by providing accessible data feedback without academic jargon, increasing community confidence to not only participate in research, but to voice their opinions about it.

Saying 'No'

Interviewees felt SEARCH had given ACCHSs the confidence and knowledge to critically assess research, empowering them to decline involvement in other research projects that were not participatory, and call out SEARCH researchers who might try to dominate proceedings or embark on research of purely academic or individual interest. An Aboriginal member of the Coordinating Centre explained that when researchers try to peruse their own agendas,

... they're brought back into the whole system with us saying "No, we're all one when we're doing this"... "If you want to be a part of [SEARCH] you need to trust the system that we have, and the system is that we're all equal. We share the data. We give the data. We own the data."

Valuing local Aboriginal knowledge

Equity and respect

Interviewees repeatedly commented that everyone involved in SEARCH is treated as an equal with valuable knowledge to contribute. For example, several talked about how researchers had discussed a draft questionnaire with Aboriginal community members, received considerable feedback, and then worked collaboratively to produce a more culturally sensitive design. These actions have demonstrated that researchers are willing to listen, understand and act on community advice, and genuinely value their input. As an ACCHS worker said: "the researchers, whether they were Aboriginal or not, had that respect for our community, our culture, and you valued our opinion whether we had a degree or not".

Local interpretation

Interviewees noted that the SEARCH model of employing local Aboriginal staff to provide guidance throughout the research design, conduct, analyses and translation was unique. Local Aboriginal interpretation of results ensures data are interpreted in context and is critical to maintaining trust. ACCHS workers described previous exposure to research where researchers had sought their involvement in a tokenistic manner. They argued that if data collected is analysed and translated without their input, essential lived knowledge about local culture and context – which makes sense of the data – is lost. As an ACCHS worker put it: "you might have a PhD but I'm an Aboriginal person from that community... who understands [the local] context and why [things are happening]".

Ongoing collaboration and investment

An ongoing commitment

When SEARCH was established the community wanted a long-term study rather than the fragmented approach to research and programmes common in Aboriginal health. A researcher explained that this commitment was important to relationship-building: "there are no shortcuts to developing trust with people. You have to spend the time and put in the effort and prove again and again why people should trust you". The mere fact that SEARCH researchers and Coordinating Centre staff have maintained regular contact with the communities seemed critical. When asked

how trust was being built, one ACCHS worker explained: “you come back”. Some difficulties in ongoing engagement were noted; researchers talked about the need for “perseverance” and “patience” in relation to building trust and developing mutually satisfactory partnership processes with under-resourced Aboriginal services; while ACCHS staff spoke about the frustration of research timescales, particularly the lag between initial data collection and feedback. However, all agreed that co-creation was the right approach: “It might take a really long time, but it will be worth it in the end”.

Resourcing and reciprocity

Interviewees argued that the project was sustainable partly because SEARCH employs an Aboriginal workforce within the services to engage with families and collect data, and resources this position (for example, providing a car for outreach work), rather than adding to the heavy workload of ACCHSs. One ACCHS worker described the help their service received from SEARCH to resolve a system failure that had interfered with their government reimbursements. ACCHS interviewees appreciated that SEARCH partners were active in “identifying some of our challenges at the organisation and saying to us, ‘This is how we could help with that’. But also... you had boundaries and guidelines to say ‘Enough is enough. This is as far as we can take it’”. Several interviewees emphasised the difficulty in appropriately resourcing projects in Aboriginal health, as an Aboriginal researcher explained: “the actual process of engaging with people and making sure that you are applying an Aboriginal way of doing business long term, in a stable way, it’s... often not properly considered and it’s often not properly funded”. Staff turnover was seen as a significant threat to SEARCH’s sustainability as knowledge and relationships could be lost.

Following through

Interviewees felt SEARCH was unique in keeping community partners involved with all projects. This included having a dedicated Aboriginal knowledge broker working to articulate emergent findings, support collaborative interpretation and, importantly, to co-create policy and practice solutions. An ACCHS worker said: “I’ve never come across a programme that has offered to come in and finish things off for you... It’s always been, ‘Here’s a report – wish you all the best’”.

Adaptability

Emergent project design

SEARCH has an emergent design that is responsive to community needs. It began as a community-driven longitudinal programme of research in which the health targets, methodology and administrative processes were unspecified. One researcher recalled: “We presented a rough protocol for what we wanted to achieve and said, ‘Let’s work with you [ACCHSs] to find out how it can work’. We had to change a lot of things”. The investigators and funders were willing to diverge significantly from traditional approaches to research and accept that community ownership could not be pre-defined: “trial and error all the way” (Investigator). A clinician also stated: “We thought it was important and would lead to good stuff, on both sides, [so] everyone was happy to sit back and follow the ride where it took us and for as long as it took to get there”. The need to revise the project goals into the future was acknowledged by a senior investigator who said: “You design things at the beginning [but] you really

do need to review them periodically to make sure that they're working... you need to be responsive to the stage that things are at".

Local adaptation

As the core business of ACCHSs is providing healthcare and they are often overburdened due to poor resourcing, it has been essential to accommodate each ACCHS's requirements. SEARCH has adapted to diverse priorities, infrastructures and preferences for participation and research translation. As an ACCHS worker said: "Aboriginal people have shared experiences but different interpretations, so data is used differently in each community". Individual services negotiate on matters such as regularity of meetings and degree of involvement in decisions. Some attend monthly face-to-face meetings, others prefer key agenda items to be discussed formally in decision-making forums. Some ACCHSs are involved in research meetings where they discuss data analysis, interpretation and writing, while others prefer to be sent draft manuscripts and provide input at that stage.

Adaptations have also been made in response to the evolution of trust and familiarity within SEARCH. For example, draft manuscripts were initially sent to the ACCHS CEOs and board for formal comments and sign off, but some ACCHSs found this burdensome and, having seen that earlier manuscripts were respectful and were co-authored by their own staff, increasingly viewed it as an unnecessary precaution. Now, at two ACCHSs the board have delegated approval to the CEO who is sent a one-page summary of key findings to approve, followed by a phone call or meeting to discuss any queries. CEOs now seldom feel the need to consult their board.

Consequently, SEARCH's governance has a firm core structure but supports local modification. The Coordinating Centre are responsive to requests for support and resourcing, and work with communities within their preferred model to ensure that the integrity of the data is maintained, and services are reaching their targets. As one Aboriginal member of the Coordinating Centre said: "Negotiation with Aboriginal communities is completely different to when you negotiate with non-Aboriginal communities... you have to adapt to changes in the community, see where they're coming from and what their approach is".

Challenges for ongoing co-creation in SEARCH

There are some areas for ongoing improvement to ensure that SEARCH is sustainable and improving Aboriginal health outcomes. These include: continuing development of Aboriginal research capacity; greater sensitivity and frequency in communications; more contact between non-Aboriginal researchers and Aboriginal communities; and methods for embedding shared ownership of the programme's ethos and activities.

The partnership has withstood considerable changes to resources, networks and infrastructure, and has survived misunderstandings, funding droughts and the flux associated with health service 'reforms'. The strong reciprocal relationships between partners at multiple levels appears to have created a resilient platform that is not dependent on any one person or process. However, if experienced at a larger scale, or in combination, future challenges could prove insurmountable. The difficulty in appropriately resourcing projects in Aboriginal health in an ongoing challenge. Continuous work must be done to ensure that current partners are engaged with and committed to the programme's ethos and activities, that established relationships

are nurtured, and that strategic relationships with new, values-driven partners are actively forged.

While decision making in SEARCH aims to be highly inclusive, and the strong governance structure provides a solid structure for the partnership, it cannot eradicate power differentials in day-to-day operations. Organisational and disciplinary hierarchies can make it hard for junior partners, and some ACCHS staff, to have a voice in meetings where the onus on research can privilege those with technical knowledge, and which, due to the dispersed locations of partners, are usually held by teleconference. Most forums focus on senior members of the partnership and this can leave important partners, such as ACCHS research officers (who function as frontline leaders of SEARCH within the community) out of the loop. SEARCH still has work to do in ensuring that decision making accommodates 'bottom-up' ideas and critiques. Holding more meetings locally at ACCHS sites, and chairing by Aboriginal partners, might help. Additionally, researchers occasionally default to conventional research strategies, use jargon and fail to ensure that community members have real opportunities to contribute. All partners need to remain vigilant to this slippage, with senior researchers taking responsibility for modelling and correcting practices.

There is more work to do in developing community ownership of SEARCH. For example, building research capacity in the ACCHSs has been moderately successful, but more Aboriginal people could be supported to complete higher education degrees and work as researchers on SEARCH projects.

As SEARCH has matured, structures and processes have been adapted, but the partnership is probably not as reflexive as it could be. Greater focus on reviewing structures and processes, in relation to current needs and goals, might enhance the partnership's functioning and effectiveness.

Discussion

This study illustrates how SEARCH, a co-creative partnership between Aboriginal services, researchers, policymakers, and clinicians, has built trusting relationships that have led to tangible outcomes for Aboriginal communities. Success factors for building trust and sharing power include: clear and protective governance structures; strong credible leadership; a well-articulated shared vision; willingness to take risks; mechanisms for connecting across cultures; community empowerment strategies; valuing local Aboriginal knowledge; ongoing reciprocal investment; and adaptability.

This 'real world' case example of a sustained and productive partnership in Aboriginal health demonstrates how co-creation principles can be operationalised through ethically-informed structures and processes (Wilson, 2001). To date, much has been written about the difficulties of research collaboration (for example, Boyle and Harris, 2009; Rycroft-Malone et al, 2016), and of cross-sector partnerships in Aboriginal health (for example, Brands and Gooda, 2006; Green et al, 2013). As this literature suggests, it is one thing to describe the vision of co-creation, but another to put it into practice. Our findings include an honest account of areas for improvement.

Importantly, SEARCH has succeeded in areas where some other partnerships have failed. For example, the extent of collaboration by non-researchers in setting the research agenda can make or break a partnership (Rycroft-Malone et al, 2016; Wehrens et al, 2010). SEARCH's investigators insisted that their research priorities be community-driven, resulting in a broader portfolio of work than they had anticipated.

The trusting relationships described by participants contrast markedly with accounts in the literature. Given Australia's history of research and institutionalised racism, Aboriginal people tend to be suspicious of researchers (Anderson, 2011; Street et al, 2007). Meanwhile, policymakers are often sceptical about the value of working closely with researchers (Gollust et al, 2017), and researchers, who have few incentives to invest in co-creation, sometimes view it as a transgressive practice that can contaminate their work and reputation (Flinders et al, 2016). SEARCH has done well to transcend such obstacles, but more can be done.

The relationship between our results and other models

In many respects, our findings align with the wider empirical and theoretical literature on collaboration and co-creation. For example, they support the importance of empowerment, leadership, trust, reciprocity and adaptability (for example, Armitage et al, 2011; Greenhalgh et al, 2016; Rycroft-Malone et al, 2016). They are also consistent with concepts from other Indigenous research studies in Australia, New Zealand and Canada such as power sharing via formal governance agreements, acknowledging the history of research, capacity building, addressing community priorities, and honouring 'insider' knowledge and cultural safety (for example, Jamieson et al, 2012; NHMRC, 2003; Street et al, 2007). In Additional file 5 we comment on the resonance of our findings with seven dimensions of partnership outlined by Mitchell et al (2009).

We note some potentially important additional areas in this literature. For example, our findings aligned with Jamieson et al's (2012) ten principles of research with Aboriginal communities, with the exception of 'preparing for Indigenous leadership turnover' which, as they point out, is a significant challenge in relationship-based partnership. Similarly, our data suggest that SEARCH has addressed most of the structural and process barriers identified by Street et al (2007), but does not emphasise conflict resolution to such a degree. We found Ofahengaue Vakalahi and Taiapa's (2013) concept of 'cultural humility' helpful but note that this is not an explicit stance for non-Aboriginal researchers in SEARCH. Ball and Janyst (2008) found that larger research collaborations in Indigenous health present increased challenges for relationship building and managing expectations, but there was no mention in our data of how SEARCH is managing its growth. The SEARCH partnership may benefit from considering these areas.

Our findings add to this body of literature by providing detail about how co-creation has been operationalised in an established co-creative partnership in Aboriginal health. They also emphasise the importance of risk minimisation mechanisms, and of mobilising resources and flexible support to community partners. Lastly, they indicate that the dimensions of partnership outlined above should not be regarded as static; co-creative partnerships change over time and must remain attentive and responsive to change within the partnership and in the wider systems they are trying to influence.

Strengths and weaknesses

Our findings provide insights into the workings of a sustained and productive co-creation partnership in Aboriginal health. The triangulation of stakeholder views from all sectors of the partnership, at different levels, and with a diversity of experiences

of SEARCH, provides a rich picture of the partnership's genesis, internal arrangements and day-to-day operations.

Two SEARCH researchers (one Aboriginal) conducted the interviews. While this ensured they were culturally appropriate it may have increased the risk of socially desirable responses. We attempted to counter this by inviting interviewees to describe challenges and suggest areas for improvement. However, independent coding, collaborative analysis workshops and stakeholder checks support the veracity of the findings (Thomas, 2006).

Aboriginal communities are extremely varied and exist in diverse systems that have profound effects on what can and cannot be achieved. For example, the model of co-creation described here leverages a pre-existing infrastructure: the ACCHSs through which SEARCH is conducted are specific to Australia and are lacking in many communities (NACCHO, 2014). However, we believe the processes and principles identified here will have resonance in other settings where co-creation partnerships between research, policy and community sectors are needed to advance research-informed community health improvements.

Conclusions

Although there is a growing body of literature illustrating the benefit of co-created research, there are few practical examples of sustained and productive co-creation, especially in Aboriginal health. Improvement of health outcomes for Aboriginal communities and increased Aboriginal ownership of research is a long-term investment. Our findings illustrate how building trust and sharing power can be operationalised, and how essential they are in co-creation. Partners must be willing to take risks, share leadership, value local Aboriginal knowledge, and build adaptability into programme models. SEARCH demonstrates that co-creation in Aboriginal health research is achievable, and highlights significant benefits including two-way capacity building and mutual learning, and empowerment of the community leading, ultimately, to improved health outcomes.

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Conflict of interest

The authors declare that they have no conflicts of interest.

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