

Establishing an enduring co-production platform in Aboriginal health

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Key points

- Co-produced Aboriginal health research involves active participation by both researchers and the research users throughout the research process and ensures the evidence generated is used to produce effective programs and policy
- The Coalition for Research to Improve Aboriginal Health (CRIAHA), an Aboriginal-led, multidisciplinary, co-production model of research, has produced high quality evidence that has resulted in positive health outcomes for Aboriginal children and their families. Key features of CRIAHA include trust, respect, sharing of power and strong Aboriginal leadership

Abstract

Co-production in Aboriginal health research builds on participatory, strength-based approaches where Aboriginal knowledge, expertise and priorities are valued and used to generate evidence to drive improvements in Aboriginal health and healthcare. The Coalition for Research to Improve Aboriginal Health (CRIAHA), led by a partnership between the Aboriginal Health & Medical Research Council (AH&MRC), Sax Institute and six Aboriginal Community Controlled Health Services (ACCHSs) in NSW, has a long history of successfully co-producing evidence to guide policy and program planning. Data collected through CRIAHA's first project, the Study of Environment on Aboriginal Resilience and Child Health (SEARCH), a cohort of urban Aboriginal children, has been effectively used to improve child health outcomes. An evaluation of CRIAHA's co-production model highlighted trusting relationships, sharing of power, valuing Aboriginal knowledge and expertise, respectful communication, strong Aboriginal leadership, and ongoing investment and collaboration as instrumental to the success and longevity of this multidisciplinary partnership. In recent years, CRIAHA's co-production platform has responded to emerging areas of need identified by participating ACCHSs. This paper highlights three initiatives driven through the co-production platform: 1) examining how local mental health service systems are working for Aboriginal children and young people and how they can be improved; 2) understanding how the cancer care system is working for older Aboriginal people to develop scalable and sustainable approaches to improving cancer care; and 3) finding effective ways to measure the impact of innovative, Aboriginal-led primary health care programs. These initiatives represent co-produced, fit-for-purpose research aimed at driving tangible improvements in Aboriginal health.

Key points (cont.)

- Successful co-production in an Aboriginal health context is possible and recommended. It is critical that such research programs build capacity, prioritise Aboriginal leadership, respect the culture and expertise of Aboriginal partners and promote self-determination

Background

There is increasing acknowledgment that co-produced research – where researchers and research users (including community members, policy makers and service providers) work together, sharing their unique knowledge, skills and perspectives – results in more meaningful outcomes that are beneficial to the users and relevant for health policy. This is particularly important for Aboriginal health research which has been historically conducted by non-Aboriginal researchers according to their priorities and needs, resulting in few measurable improvements to health and leading to mistrust of research among many communities.^{1,2} Co-produced Aboriginal health research builds on participatory research methods that recognise power imbalances and where diverse forms of knowledge, experience and priorities are valued and used synergistically to produce practical outcomes. It is distinct from co-design as it involves active participation by the Aboriginal community (research users) throughout the research process, from idea generation to implementation and dissemination. The partnership between researchers and research users also ensures that the evidence generated is used to drive tangible improvements in Aboriginal health and healthcare.^{3,4}

Establishing a long-standing co-production platform in Aboriginal health research: CRIAH

In 2004, the Aboriginal Health & Medical Research Council (AH&MRC), the Sax Institute and six Aboriginal Community Controlled Health Services (ACCHSs) in NSW, formed the Coalition for Research to Improve Aboriginal Health (CRIAH). CRIAH brought together the expertise of the Aboriginal Community Controlled Health sector and a multidisciplinary team of researchers to address Aboriginal community research priorities, namely child ear health, speech and language development, social and emotional wellbeing, resilience, risk factors for chronic disease, housing and environment. In accordance with community priorities, CRIAH's first project involved establishing a cohort of urban Aboriginal children and their families through the Study of Environment on

Aboriginal Resilience and Child Health (SEARCH).⁵ Based on the partnership between the ACCHSs, researchers (both Aboriginal and non-Aboriginal), policy makers, and clinicians, CRIAH and SEARCH have built trusting relationships and utilised decolonising methods to consistently enable the informed and ethical engagement of community members in research processes and the translation of culturally relevant research findings into improved health outcomes.^{6,7}

Pivotal elements that have enabled the research partnerships established through CRIAH to remain strong for ongoing co-produced research more than 15 years later include: clear and protective governance structures combined with strong Aboriginal leadership; a well-articulated shared vision; community empowerment through capacity building and respectful communication; mechanisms for connecting across cultures and ongoing investment and collaboration, in particular, 'the importance of following through'.⁴

In a recent dialogue, senior Aboriginal stakeholders in the partnership have reiterated that the robust governance structure established through CRIAH and SEARCH has provided a solid framework for building and maintaining the collaboration and determining priorities. This includes ACCHS CEOs holding Chief Investigator and Associate Investigator positions on all research grants and participating in regular decision-making forums. Memorandums of Understanding (MOUs) with each ACCHS were put in place to provide a framework for the program.⁷ Aboriginal knowledge, which is key in determining and driving the research agenda, is highly valued. Both Aboriginal and non-Aboriginal researchers bring skills to implement the research collaboratively. The partnership has always acknowledged the unique community needs of each ACCHS partner and tailors projects through fit-for-purpose research that feeds into policy and planning to effect real change in Aboriginal health.⁴

As two senior Aboriginal stakeholders in the program (also co-authors here) expressed during the development of this paper:

"ACCHSs have no hesitation getting involved in research because of the level of trust that has developed. It supports evidence-based practice at each ACCHS and has re-invigorated these services to provide better care. The Coalition

sought after Aboriginal leadership in everything they did and there is respect for one another at a service and researcher level. When these principles are implemented in practice, outcomes will change. Outcomes may not be seen in the immediate term, but it will impact the generations to come.”

“After historical failures, this coalition brought together researchers and community to overcome past mistakes and work as a team and provides a ‘real world’ example of co-production in action.”

Frequent and respectful communication has been critical to the success of the partnership. This ongoing communication has allowed for new projects to emerge based on research findings and the priorities identified by ACCHS partners within their services and communities.

An expanded Aboriginal health program with co-production at its heart

The co-production platform established through CRIAH and SEARCH is now being applied to several new initiatives to address the changing research priorities of the ACCHS partners.

Recent initiatives undertaken include: 1) working together to improve social and emotional wellbeing among Aboriginal young people; 2) developing sustainable approaches to improving cancer care for older Aboriginal Australians; and 3) enhancing ACCHS capacity to measure the impact of innovative, community-designed primary health care programs. The three new projects are detailed below.

Focus on local mental health service systems for Aboriginal children and young people

Child and adolescent social and emotional wellbeing (SEWB) have been a longstanding priority area for partner ACCHSs. Work done as part of the SEARCH collaboration demonstrated that while most participating Aboriginal children had good SEWB, the proportion meeting criteria for ‘high risk’ was twice that of non-Aboriginal children in NSW.⁸ Our qualitative work with Aboriginal parents and ACCHS staff highlighted the lack of clear, accessible pathways to primary mental health care for Aboriginal children and young people.^{9,10} This was reflected in the high rates of emergency department presentations and hospitalisations for mental health noted among the cohort.¹¹ Despite a clear need for support around mental health and social and emotional wellbeing, there was little evidence about mental health service use among Aboriginal children and adolescents, or about what treatments, programs or services were effective.¹²

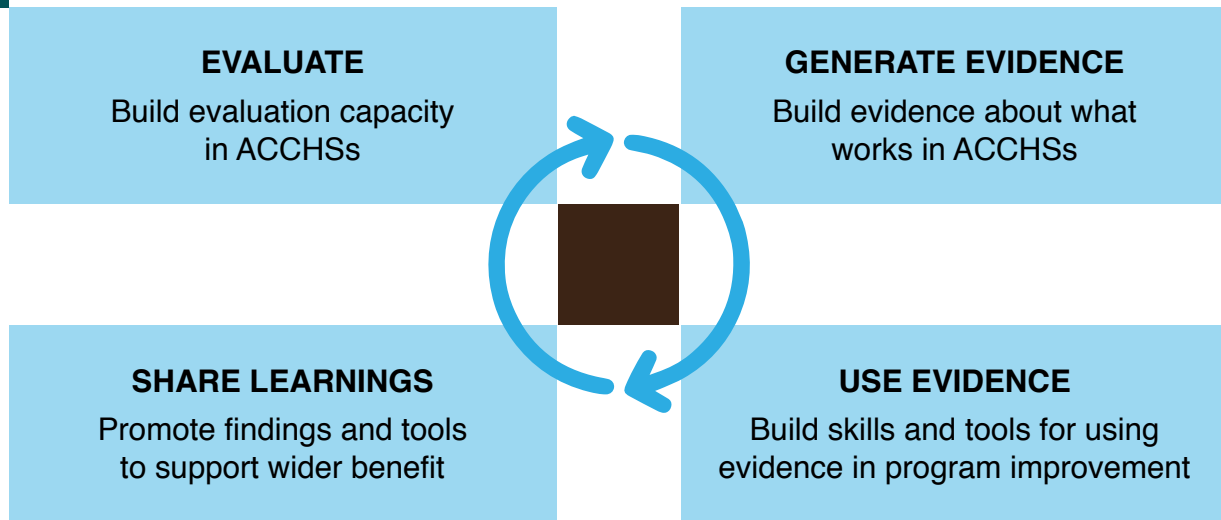
The co-produced evidence outlined above was successfully used by CRIAH to drive changes in mental health service delivery, with local governments funding more child and adolescent mental health services to be delivered at participating ACCHSs and exploring new models of care. Further work is being conducted to explore the views of local Aboriginal young people, parents and carers, ACCHS SEWB staff and mainstream mental health staff about how the mental health service system is or is not currently working, and priorities for change. While work is ongoing, our co-produced SEWB work has already delivered an unprecedented level of insight into Aboriginal community experiences of mental health care. It has led to changes in how emergency departments work with Aboriginal young people, prioritising Aboriginal staff in mental health settings and mental health service delivery models.

Understanding how the cancer care system is working for older Aboriginal people: CHANGES study

Cancer has been identified as the third leading cause of death among the Aboriginal population, with lower survival rates relative to other Australians.¹³ Approximately 3–5% of Aboriginal and Torres Strait Islander people are currently living with a diagnosis of cancer, with this proportion increasing with age.¹⁴ Relatively little is known about how to reduce the burden of cancer and improve cancer outcomes for Aboriginal people. Working in close partnership with the Cancer Institute NSW, five ACCHSs in urban, regional and remote NSW, mainstream health professionals and relevant agencies linked to cancer care in these areas, CRIAH has embarked on the Cancer and Healthy Ageing in Aboriginal NSW Older Generations Study (CHANGES) to gain a detailed understanding of Aboriginal people’s views about healthy ageing, cancer and cancer care, and to develop scalable and sustainable approaches to improving care for older Aboriginal Australians.

Using CRIAH’s co-production model, this Aboriginal community-led research will explore the views of Aboriginal people aged over 50 with a cancer diagnosis, their families and caregivers, ACCHSs and mainstream health professionals who provide cancer care about how the cancer care system is working for Aboriginal people. It will identify strengths and how best to tailor prevention, diagnosis, treatment and support services for this group. The study interviews and focus groups have taken a yarning approach to give people the time, respect and space to tell their health stories in their own way. Yarning is “a conversational process that involves the sharing of stories and the development of knowledge. It prioritises Indigenous ways of communicating, in that it is culturally prescribed, cooperative, and respectful”.¹⁵ This local input is vital as the unique circumstances of each community mean that what works in one setting may not in another. Cancer services and programs are being mapped in

Figure 1. ILEAP aims



ACCHSs = Aboriginal and Community Controlled Health Services; ILEAP = Indigenous Led Evaluation of Aboriginal Programs

the five local areas to understand how the cancer care system is working or not for older Aboriginal people.

Findings from the yarning and analysis of population-level epidemiological data about the causes of poorer survival from cancer and the cancer care pathways, will provide the first detailed data about how cancer care is provided to older Aboriginal people in NSW and how this meets their needs and preferences. Through CRIAH's community and research networks, this evidence will be disseminated to key policy makers and stakeholders to identify opportunities for improved care that will be grounded in culturally responsive strategies and will obtain agreement about actions for meaningful improvements in cancer care for older Aboriginal people.

Measuring the impact of innovative, Aboriginal-led primary health care programs: ILEAP project

ACCHSs provide innovative, holistic primary health care programs and services that reflect their unique understanding of the communities they serve.¹⁶ Despite this wealth of innovation, these services and programs are seldom evaluated, largely due to a lack of resourcing and capacity, resulting in a dearth of high-quality evidence from the evaluation of Aboriginal community-based programs. This makes it difficult for ACCHSs to harness evidence to improve their own practice, share their learnings with other services and inform policy and practice.^{17,18} Responding to the ACCHS's long-recognised need to build evaluation capacity and expertise in their sector, CRIAH is co-producing a research project entitled Indigenous Led Evaluation of Aboriginal Programs (ILEAP). This work is led by three partner ACCHSs and the Sax Institute, which are committed to creating the evidence base for ACCHS-designed innovative programs.

The project has four interconnected aims: 1) build the capacity of staff in the three ACCHSs to undertake real world evaluation; 2) generate new evidence through real-world evaluation of innovative ACCHS-led programs; 3) use this evidence to build capacity in ACCHSs to translate evaluation findings for continuous program improvement; and 4) provide urgently needed evidence about what works in priority areas in Aboriginal primary health and mobilise action at local, state and national levels. (Figure 1).

Enhancing the capacity of ACCHSs to design and lead evaluations and mobilise their findings represents a pivotal opportunity to improve the national evidence base around Aboriginal-led health programs. ILEAP will lay the foundations for ongoing innovation in Aboriginal-led primary health service delivery and improvement in the health outcomes for Aboriginal people.

Conclusion

Colonial practices, including in health and health research, have created harm and a lack of trust in many Aboriginal communities. Aboriginal health research co-produced with Aboriginal communities can inform culturally safe and responsive healthcare. When driven by Aboriginal community priorities, it creates an environment for Aboriginal knowledge and wisdom to shape high quality, usable research, which is more likely to produce effective Aboriginal health policy and practice. The CRIAH experience suggests that successful co-production in an Aboriginal health context is possible and recommended. It is critical that such research programs build capacity, prioritise Aboriginal leadership, respect the culture and expertise of Aboriginal partners and promote self-determination. Such a process has enabled CRIAH to emerge as an enduring platform for Aboriginal

health research that addresses emerging community priorities and generates evidence that informs culturally responsive Aboriginal health policy and practice.

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Peer review and provenance

Externally peer reviewed, invited.

Competing interests

None declared.

Author contributions

SM led the writing, editing and revision of the manuscript. SB, DK and AW contributed to writing and editing, and JNi, DW, JNe and MM edited and reviewed the manuscript. Four of the authors in the paper are Aboriginal (SB, JNi, DW, JNe) and four are non-Aboriginal (SM, DK, AW, MM).

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