



PROJECT REPORT

Participatory research with a rural Aboriginal Community Controlled Health Organisation: lessons learned using the CONSIDER statement

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PUBLISHED

8 February 2022 Volume 22 Issue 1

HISTORY

RECEIVED: 11 March 2021

REVISED: 23 September 2021

ACCEPTED: 5 October 2021

CITATION

Beks H, Amos T, Bell J, Ryan J, Hayward J, Brown A, McKenzie C, Allen B, Ewing G, Hudson K, Clark R, Morphet B, Allender S, Creighton D, Johnstone M, Versace VL. Participatory research with a rural Aboriginal Community Controlled Health Organisation: lessons learned using the CONSIDER statement. *Rural and Remote Health* 2022; 22: 6740. <https://doi.org/10.22605/RRH6740>

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ABSTRACT:

Context: In Australia, Aboriginal Community Controlled Health Organisations (ACCHOs) are geographically proximal to where Aboriginal and Torres Strait Islander People reside and are valued for providing holistic and culturally safe primary health care. Partnering with ACCHOs in research is appropriate for redressing health inequities experienced by Aboriginal and Torres Strait Islander People, which includes a high burden of chronic disease. Historically, some approaches to Aboriginal and Torres Strait Islander health research have been unethical. Greater

accountability in the research process, transparency in reporting, and use of culturally appropriate research methodologies are key recommendations to improving the ethical integrity of research. The need for strengthening the reporting of health research involving Aboriginal and Torres Strait Islander People and Indigenous peoples globally led to the development of the CONSolidated critERia for strengthening the reporting of health research involving Indigenous peoples (CONSIDER statement), which is a synthesis of international ethical guidelines. This project

report uses the CONSIDER statement to critically reflect on participatory research undertaken in partnership with an ACCHO in the rural context and to identify lessons of value for future research.

Issue: By using the CONSIDER statement as a tool for critical reflection, it was identified that processes used to establish a research partnership with an ACCHO were key to setting the research agenda, including identifying ethical issues, the needs of local Aboriginal and Torres Strait Islander People, and expectations from the research. The participation of Aboriginal community members throughout the entire research process was not only methodologically important but was also ethically appropriate. Research activities in this project included opportunities for Aboriginal community members to directly share their perspectives and experiences and develop local solutions to issues affecting them. Outcomes included evidence to support future funding applications, community-derived priorities that assisted with government reporting, and locally identified methods for addressing chronic disease management. Key to this was building the research capacity and capability of local Aboriginal community

members, which also reflected the ethical principles of reciprocity and equity. This also provided opportunities for non-Indigenous researchers to learn from local Aboriginal community members and develop skills in culturally appropriate research.

Lessons learned: Using the CONSIDER statement was beneficial in enabling researchers to critically reflect on a participatory research project undertaken in partnership with a rural ACCHO. Researchers identified that participatory approaches can be used to generate research of relevance to local Aboriginal community members and their ACCHOs, and to support health service reporting, and future funding applications. Research timelines and activities needed to be flexible and adaptable, to allow for staff turnover and unforeseen events of cultural significance. Similarly, it is important for researchers to be receptive to change and open to learning. Although research partnerships are established on trust and mutual respect, it is recommended that greater formal provisions are required to protect the intellectual property of Aboriginal and Torres Strait Islander communities involved in research. These lessons are likely to be transferrable to other settings and are of value to researchers seeking to partner with ACCHOs in research.

Keywords:

Aboriginal and Torres Strait Islander, chronic disease, ethics, group model building, health services, Indigenous, Oceanic ancestry group, participatory action, research rural health services.

FULL ARTICLE:

Context

In Australia, there are more than 140 Aboriginal Community Controlled Health Organisations (ACCHOs) located geographically proximal to where Aboriginal and Torres Strait Islander People reside¹. Research evidence supports that ACCHOs are valued by Aboriginal and Torres Strait Islander People for providing holistic and culturally safe primary health care². Partnering with ACCHOs in research is appropriate for redressing health inequities experienced by Aboriginal and Torres Strait Islander People, which includes a high burden of chronic disease^{3,4}. Approximately 63% of Aboriginal and Torres Strait Islander People reside in geographical areas outside major cities; therefore, undertaking research in partnership with ACCHOs is important for improving the health of people living in these rural areas⁵.

Historically, some approaches to Aboriginal and Torres Strait Islander health research have been unethical, highlighting the need for culturally appropriate research methodologies (including Indigenous research methodologies) and ethical approaches to research conduct^{6,7}. This includes a greater participation in the research process, improved accountability and transparency in reporting^{6,7}. To meet the need for more culturally appropriate approaches to research, there has been a surge in the use of participatory research^{8,9}, particularly participatory research using Indigenous research methods (eg yarning)¹⁰⁻¹². As a research framework, participatory research involves a process of inquiry that aims to mitigate power imbalances by involving those affected by the phenomenon of interest, and has long been used to provide a voice for people otherwise excluded from the research process¹³.

The inclusion of 'action' into participatory research (PAR) emphasises a goal-orientated objective of generating actionable outcomes¹⁴. For Aboriginal and Torres Strait Islander health research, including Indigenous research methods such as yarning in PAR is understood to empower Aboriginal and Torres Strait Islander People to voice their perspective on complex health and social issues affecting their communities, and by doing so effect change^{10,12,15}.

To address the need for greater accountability and transparency in reporting, the CONSolidated crItERIA for strengthening the reporting of health research involving Indigenous peoples (CONSIDER statement) was developed¹⁶. As a synthesis of national and international statements and ethical guidelines for research involving Indigenous people, the CONSIDER statement provides a checklist of 17 items for researchers to report on¹⁶. The CONSIDER statement has recently been used to report on other research undertaken with Indigenous communities¹⁷ but has not been applied specifically in the rural health context or to participatory research or PAR projects.

'Let's have a yarn about chronic disease': research project overview

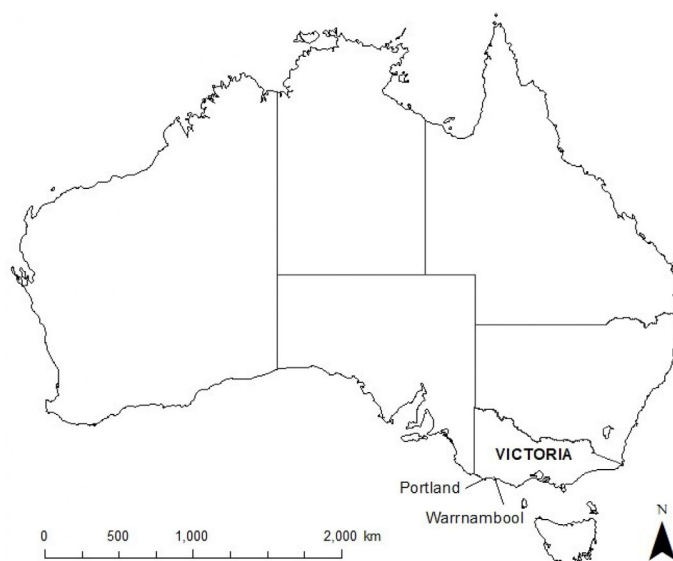
To respond to the burden of chronic disease in rural areas¹⁸ and high prevalence of chronic disease experienced by Aboriginal and Torres Strait Islander People¹⁹, Dhauwurd Wurrung Elderly and Community Health Service (DWECHS) and Deakin Rural Health (University Department of Rural Health (UDRH)), began conversations in 2016 about the management of chronic disease.

As an ACCHO, DWECHS is located on Gunditjmara Country (Fig1) and was established by Elders to address the paucity of accessible health services for Aboriginal people in the region²⁰. Gunditjmara Country is also home to the Budj Bim Cultural Landscape, which is of special significance, and has attracted UNESCO World Heritage status²¹.

Early in the partnership, Deakin Rural Health secured external funding to employ a senior project officer to coordinate research activities focusing on chronic disease. This position was based at DWECHS and was filled by a local Gunditjmara community member with experience in the health sector. It was this position that was the catalyst for a PAR research project titled 'Let's have a yarn about chronic disease: a collaborative multidisciplinary participatory action research approach to addressing Aboriginal health in South West Victoria' (LHAY). In late 2017, DWECHS and Deakin Rural Health, in collaboration with the Institute of Koori Education (since renamed National Indigenous Knowledges

Education Research Innovation Institute), the Global Obesity Centre (a designated World Health Organization Collaborating Centre for Obesity Prevention), and the Warrnambool Clinical School (a rural clinical school), were awarded funding for LHAY, which comprised four activities (Table 1²²⁻²⁶).

This project report uses the CONSIDER statement to critically reflect participatory research undertaken in partnership with an ACCHO in the rural context and identifies lessons of value for future research. Critical reflection is an important process, particularly for non-Indigenous researchers learning how to partner with Indigenous communities to undertake culturally appropriate research²⁷ and to improve on the ethical and scientific conduct of Indigenous health research internationally²⁸. For transparency and accountability, reporting for the LHAY project against each criterion of the CONSIDER statement is also provided (Appendix I).



[†] The campus is 110 km (by road) east of Dhauwurd Wurrung Elderly and Community Health Service in Portland.

Figure 1: Location of Deakin University Warrnambool Campus, Portland, Victoria, Australia.[†]

Table 1: 'Let's have a yarn' research project activities²²⁻²⁶

Activity	Description	Rationale
Systematic scoping review	The purpose of this review was to geographically examine where chronic disease programs for Aboriginal and Torres Strait Islander populations have been implemented and evaluated to identify geographical gaps in the literature [refs 22, 23].	This review was conceptualised after discussions with local Aboriginal stakeholders, who conveyed concern that there was less of a focus on Aboriginal people in inner regional and outer regional Australia.
Retrospective clinical audit of DWECHS clinical database	De-identified aggregate clinical data were extracted by the senior project officer at DWECHS, with support of a researcher, to ascertain the prevalence of chronic disease and modifiable risk factors in Gunditjmara Country.	It was understood that each Aboriginal and Torres Strait Islander community is unique. Therefore, it was important to understand the prevalence of chronic disease and modifiable risk factors in Gunditjmara Country, rather than relying on national data. This also served as a research-capacity training exercise for the senior project officer.
Yarning lunches using CBSD method	Involved engaging with Aboriginal community members through a series of yarning lunches held at DWECHS over a one-year period, to discuss barriers and enablers to chronic disease management using the CBSD method with the purpose of generating local solutions. CBSD is an established method for engaging communities in collaborative discussion on complex health issues [ref. 24] and has been applied in rural Victoria previously to explore problems, including childhood obesity [ref. 25]. The method was assisted by the use of Systems Thinking in Community Knowledge Exchange, an online platform that enables communities to address complex problems by supporting shared understanding through group model building and action through intervention identification [ref. 26].	Yarning over lunch at DWECHS was identified by local Aboriginal leaders as the most appropriate approach to engaging with Aboriginal community members. Listening to perspectives, experiences and feedback of community members was key to generating local solutions.
Clinical upskilling and leadership training workshops	Aboriginal health workers in the region were provided with clinical upskilling and leadership training opportunities as part of the research project.	Providing professional development to Aboriginal health workers was identified by local Aboriginal leaders as important for strengthening the management of chronic disease in the region. Further, this provided another platform for disseminating the outcomes of the CBSD yarning lunches.

CBSD, community-based system dynamics. DWECHS, Dhauwurd Wurrung Elderly and Community Health Service.

Issue

By using the CONSIDER statement to critically reflect on the LHAY project, three issues were identified: importance of a research partnership, actively engaging Aboriginal community members in research, and building research capacity and capability.

Importance of a research partnership

Establishing a research partnership between local Aboriginal leaders from DWECHS, and researchers (both Indigenous and non-Indigenous) from Deakin Rural Health and other Deakin University collaborating research groups, was the foundation for setting the research agenda and ways of working in the LHAY project. This partnership was embedded in the six core values (eg spirit and integrity, cultural continuity, equity, reciprocity, respect and responsibility) of importance to the ethical conduct of research with Aboriginal and Torres Strait Islander People^{6,7} – values not explicitly stated in the CONSIDER statement¹⁶. In practice, this was demonstrated by Deakin Rural Health and Deakin University researchers, including Indigenous academics, regularly meeting with DWECHS researchers (including Aboriginal community

members, leaders and health professionals) through the entire research process (including prior institutional ethics submission), to discuss local ethical protocols, the needs of Aboriginal community members and expectations of the research (see Appendix I – Relationships). These meetings served as a platform for researcher accountability and learning, and also provided an opportunity to adapt the research plan and timelines as per a PAR framework.

The research partnership was formalised under two Collaborative Research Agreements (CRAs) (see Appendix I – Governance), which were also submitted to Deakin University Human Research Ethics Committee (DUHREC) as part of the institutional ethical approval process. A weakness of this CRA was that there were no specific accountability and review mechanisms described. Further, there were no clauses in this CRA specifically protecting Aboriginal intellectual property and knowledge, as recommended by the National Health and Medical Research Council ethical guidelines^{6,7}. Rather, these issues were addressed in the DUHREC submission and through an ongoing authentic research relationship with DWECHS where issues were discussed and enacted on²⁹. It should

also be noted that in Victoria, there are no formal processes for having research projects reviewed by an Aboriginal ethics committee unlike in the neighbouring states of South Australia and New South Wales. In the LHAY research project, copies of the study protocol and all research documentation were provided to the DWECHS, who then provided a letter of support, which was attached to the DUHREC application.

Actively engaging Aboriginal community members in research

The research partnership was essential to informing the LHAY research aims, methodology and methods (see the Prioritisation, Relationships and Methodologies domains in Appendix I), which were based on the epistemological rationale that Aboriginal community members were the best people to participate and guide the research due to the knowledge they possessed³⁰. Although many PAR projects undertaken in partnership with Aboriginal and Torres Strait Islander People (and Indigenous peoples globally) are based on this epistemological rationale, the reporting of how participation occurred is often overlooked³¹. In the LHAY research project, Aboriginal community members and local stakeholders participated in all research activities (Table 1). To provide further illustration around the nature of this participation, the genesis of the systematic scoping review question arose in early discussions around geographical allocation of funding with local Aboriginal stakeholders who were concerned that Aboriginal people in inner regional and outer regional Australia received less funding than other geographical areas. The findings from the

scoping review identified that, of included programs, 32.1% were implemented in major cities and 29.6% in very remote areas of Australia, with less in inner regional (12.3%), outer regional (18.5%) and remote areas (7.4%) of Australia²³. Findings supported the need for a greater focus on chronic disease programs for Aboriginal people in inner regional and outer regional Australia²³ and were rapidly disseminated to local Aboriginal stakeholders to support funding applications.

Similarly, the community-based system dynamics (CBSD) method was chosen for the strong alignment with participatory systems thinking approaches and PAR³², and because DWECHS and Deakin University researchers mutually agreed its application would transparently and interactively engage Aboriginal community members in self-determination (see the Methodologies and Participation domains in Appendix I). Numerous in-depth stories were captured directly from participating community members. These described the vicious cycles and sources of policy resistance that have historically perpetuated poor chronic disease management³³. Owing to the setting within a specific health service, some of these stories related closely to local contexts; however, more broadly, the stories identified many common determinants of Aboriginal health. A strength of this approach was that the community collectively generated several actions in response to the local stories captured in the CBSD process. Actions also represent locally tailored responses to structural issues that affect Aboriginal people on a national scale (Fig2) (see the Analysis and interpretation and Dissemination domains in Appendix I).

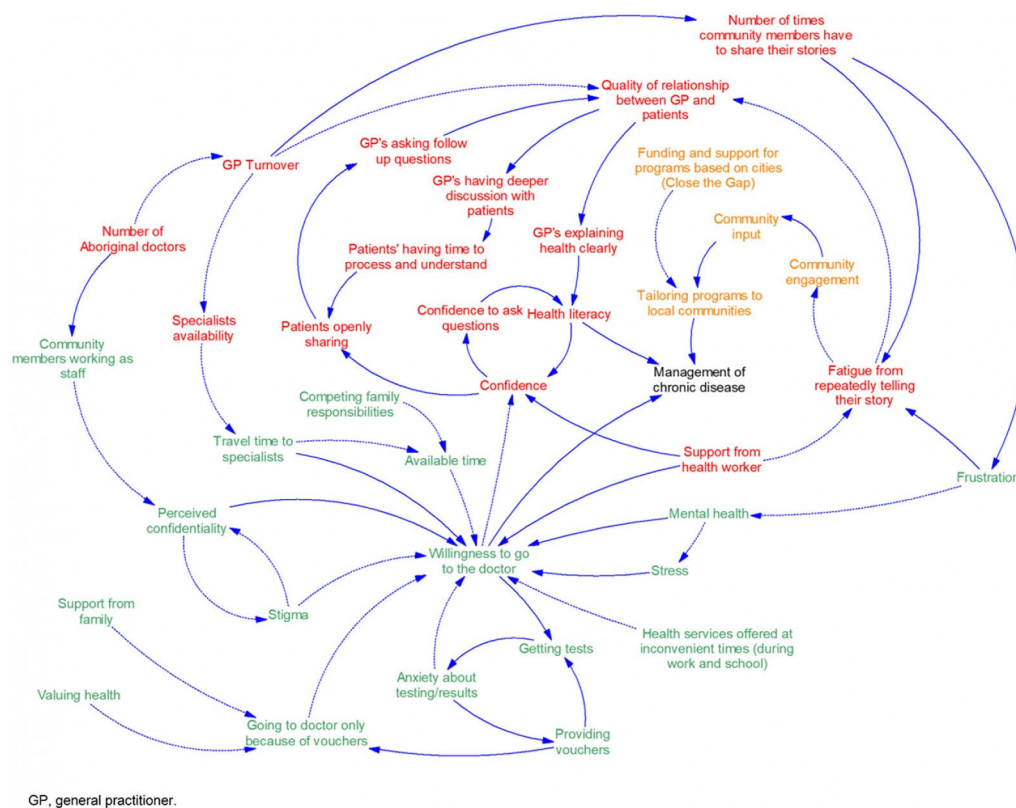


Figure 2: Causal loop diagram developed over eight community lunches using community-based system dynamics methods at Dhauwurd Wurrung Elderly and Community Health Service.

Building research capacity and capability

Providing opportunities to build the research capacity and capability of DWECHS researchers were included in the LHAY research plan and factored into the research budget (see the Prioritisation and Capacity domains in Appendix I). This included providing research support and mentoring to the senior project officer (eg in undertaking the retrospective clinical audit at DWECHS and one-on-one training in quantitative methods), and delivering training to researchers, including DWECHS researchers and Deakin University researchers, to deliver the CBSD component and facilitate the yarning lunches (see the Methodologies domain in Appendix I). Funding was also allocated for other research training, including higher tertiary education (Graduate Diploma of Indigenous Research) and associated travel costs to attend training, to build the research capacity of the senior project officer. Although positive informal feedback was provided at the time, it would have been beneficial to obtain formal feedback from researchers to evaluate whether training improved research capacity and capability – an approach used in other research evaluating programs to build research capacity in ACCHOs³⁴. Another strength of the LHAY research project, was that it provided an opportunity for Deakin Rural Health researchers and other Deakin University researchers to learn about ways of sharing knowledge, and gain skills in undertaking culturally appropriate research.

Ethics approval

A letter of support was provided from the DWECHS to support the ethics submission. Ethics approval was obtained through DUHREC (2018-009).

Lessons learned

Partnerships key to generating research of relevance

Each Aboriginal and Torres Strait Islander community in Australia is unique³⁵. However, there are some lessons learned from the LHAY research project using the CONSIDER statement that are of value to future research and transferrable to other settings. For too long, Aboriginal and Torres Strait Islander People have been involved in research without receiving any benefits, including participating in research and generating research evidence that is of relevance to them³⁶. Although not explicitly mentioned in the CONSIDER statement, establishing a partnership based on trust and reciprocity was key to setting the research agenda and expectations from the research^{6,7}. There is strong support in the research literature for taking the time to develop authentic partnerships and rapport with Aboriginal and Torres Strait Islander communities, prior to writing research protocols and submitting for institutional ethical review^{29,37-40}. Similarly, these ethical ways of working are also important when undertaking research within a PAR framework to mitigate power imbalances and to enable a free exchange of ideas between participants during the research process^{41,42}.

The use of CBSD methods coupled with Indigenous research

methods of yarning⁴³, and training of local Aboriginal community members to facilitate sessions, were key strengths of the LHAY research project to empower the voice of Aboriginal community members and develop actions for local implementation⁴⁴. Findings support the potential for CBSD methods to be a strong advocacy tool and research method for Aboriginal community members, bridging the needs for self-determination and greater participation of Aboriginal people in the research process⁸. Other research methods such as scoping reviews, can also be used as a tool to generate research of relevance to local Aboriginal stakeholders and ACCHOs, particularly when the research question is informed by community consultation^{22,23}.

Although not a focus of the CONSIDER statement, sharing how Aboriginal participants and ACCHOs used or intend to use research findings, is also of value to understanding the relevance of research undertaken and possible benefits³⁶. For example, the LHAY research project also yielded research evidence of immediate use to DWECHS in forming an organisational Statement of Intent as part of Safer Care Victoria's Partnering in Healthcare framework⁴⁵. The DWECHS Operations Manager (June 2019) identified the LHAY project as a key to formalising the organisational Statement of Intent, with the documented process of community engagement seen as a strength of the submission.

Importance of flexibility and adaptability in the research process

The LHAY project also supported the need for researchers to be flexible and adaptable to the needs of Aboriginal community members throughout the research process, particularly when using a PAR framework. Flexibility and adaptability have also been identified as important elements of the research process in other Aboriginal health research undertaken in rural Victoria⁴⁶. A PAR framework allowed for flexibility of research activities as relationships were developed between researchers, other needs were identified, and opportunities arose to link in with other activities occurring at DWECHS. However, a key challenge for the LHAY project, which required adaptation, was personnel changes throughout the project, which has been previously documented as a challenge in other Aboriginal research⁴⁴. The key personnel change with most potential to disrupt project delivery was the senior project officer because the coordination and inclusion of Aboriginal community members largely depended on senior project officer engagement. In future, effort needs to be made to find the balance between identifying and supporting suitable project coordinators from partnered organisations and allowing for flexibility in the research plan. This did not affect the timelines of the LHAY research project as extensions were sought and obtained from the funding body. However, in other Indigenous health research, meeting the timelines stipulated by funding bodies has been cited as a key challenge, particularly when extra time is required for community engagement⁴⁷.

Recommendation for greater provisions protecting intellectual property

A recommendation identified through the CONSIDER statement as

part of the LHAY project was the need for a specific clause in the CRA or another formal research agreement that explicitly protects the intellectual property of the partnered Aboriginal community. Although reporting research against the CONSIDER statement provides a mechanism for accountability retrospectively, prospective measures should be implemented. There is a growing awareness of the importance of data sovereignty and ownership in Indigenous health research⁴⁸.

Limitations

Limitations of using the CONSIDER statement to critically reflect on research include the risk of recall bias. No formal follow-up of Aboriginal community members who attended the CBSD lunches was conducted. Whether community participants were fatigued by the burden of CBSD lunches (a risk of PAR), felt rightfully empowered by the experience or otherwise is unknown, which is a limitation of the research⁴⁴. The CONSIDER statement could also be used prospectively as a guide for researchers when partnering with ACCHOs in the research process. This would require further consideration as to how the CONSIDER statement aligns with the National Health and Medical Research Council's Human Research Ethics Application⁴⁹ to not duplicate the use of guidelines.

Conclusion

Using the CONSIDER statement to undertake a structured, critical reflection on a PAR research project undertaken in partnership with a rural ACCHO was beneficial in identifying key issues and lessons learned. This included identifying that developing a research partnership with an ACCHO based on respect and reciprocity was key to setting the research agenda and expectations. Using a PAR framework allowed the research to be flexible and adaptable, with outcomes of relevance for the local community, and participating ACCHO. The types of research activities undertaken, key issues and lessons learned are likely to be transferrable to other settings. This includes the recognition for greater protection of Aboriginal intellectual property, data sovereignty and ownership in research through formal agreements.

Acknowledgements

The authors extend their gratitude to the community members, including Elders, who attended the lunches and provided insights throughout the project. They acknowledge Peter Harvey (Deakin Rural Health), Constance Kourbelis (Flinders University), and Annie Henry, Louis Delany and Allira Maes (DWECHS) for their input over different phases of the project.

REFERENCES:

- 1 National Aboriginal Community Controlled Health Organisation. *Annual Report 2018-2019*. 2019. Available: [web link](#) (Accessed 29 January 2021).
- 2 Gomersall J, Gibson O, Dwyer J, O'Donnell K, Stephenson M, Carter D, et al. What Indigenous Australian clients value about primary health care: a systematic review of qualitative evidence. *Australian and New Zealand Journal of Public Health* 2017; **41(4)**: 417-423. DOI link, PMID:28712137
- 3 Panaretto K, Wenitong M, Button S, Ring I. Aboriginal community controlled health services: leading the way in primary care. *Medical Journal of Australia* 2014; **200(11)**: 649-652. DOI link, PMID:24938346
- 4 Pearson O, Schwartzkopff K, Dawson A, Hagger C, Karagi A, Davy C, et al. Aboriginal community controlled health organisations address health equity through action on the social determinants of health of Aboriginal and Torres Strait Islander peoples in Australia. *BMC Public Health* 2020; **20**: 1859. DOI link, PMID:33276747
- 5 Australian Bureau of Statistics. *Estimates of Aboriginal and Torres Strait Islander Australians*. 2016. Available: [web link](#) (Accessed 29 January 2021).
- 6 National Health and Medical Research Council. *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities*. 2018. Available: [web link](#) (Accessed 29 January 2021).
- 7 National Health and Medical Research Council. *Keeping research on track II*. 2018. Available: [web link](#) (Accessed 29 January 2021).
- 8 Dudgeon P, Scrine C, Cox A, Walker R. Facilitating empowerment and self-determination through participatory action research: findings from the National Empowerment Project. *International Journal of Qualitative Methods* 2017; **16(1)**: 28 March. DOI link
- 9 Scrine C, Farrant B, Michie C, Carrington S, Wright M. Implementing genuine participatory action research with Aboriginal Elders: the Ngulluk Koolunga Ngulluk Koort project. *Action Research* 2020; 1 July. DOI link
- 10 Fredericks B, Adams K, Finlay S, Fletcher G, Andy S, Briggs L, et al. Engaging the practice of Indigenous yarning in action research. *Action Learning and Action Research Journal* 2011; **17(2)**: 8-20.
- 11 Peake R, Jackson D, Lea J. Meaningful engagement with Aboriginal communities using participatory action research to develop culturally appropriate resources. *Journal of Transcultural Nursing* 2021; **32(2)**: 129-136. DOI link, PMID:31948353
- 12 Walker M, Fredericks B, Anderson D. Improving Indigenous women's wellness through action research. *Action Learning and Action Research Journal* 2013; **18(2)**: 79-101.
- 13 Higginbottom G, Liamputtong P. *Participatory qualitative research methodologies in health*. London (UK): Sage, 2015. DOI link
- 14 Smith SE, Pyrch T, Lizardi AO. Participatory action-research for health. *World Health Forum* 1993; **14(3)**: 319-324.
- 15 Gwynn J, Lock M, Turner N, Dennison R, Coleman C, Kelly B, et al. Aboriginal and Torres Strait Islander community governance of health research: turning principles into practice. *Australian Journal of Rural Health* 2015; **23(4)**: 235-242. DOI link, PMID:25823497
- 16 Huria T, Palmer SC, Pitama S, Beckert L, Lacey C, Ewen S, et al. Consolidated criteria for strengthening reporting of health

research involving indigenous peoples: the CONSIDER statement. *BMC Medical Research Methodology* 2019; **19(1)**: 173. DOI link, PMID:31399058

17 Hedges J, Garvey G, Dodd Z, Miller W, Dunbar T, Leane C, et al. Engaging with Indigenous Australian communities for a human papilloma virus and oropharyngeal cancer project; use of the CONSIDER statement. *BMC Medical Research Methodology* 2020; **20**: 92. DOI link, PMID:32334519

18 Australian Institute of Health and Welfare. *Rural & remote health*. Cat. no. PHE 255. 2019. Available: web link (Accessed 29 January 2021).

19 Anderson I, Robson B, Connolly M, Al-Yaman F, Bjertness E, King A, et al. Indigenous and tribal peoples' health (The Lancet-Lowitja Institute Global Collaboration): a population study. *The Lancet* 2016; **388(10040)**: 131-157. DOI link

20 Dhauwurd Wurrung Elderly and Community Health Service. *About us*. 2021. Available: web link (Accessed 29 January 2021).

21 United Nations Educational, Scientific and Cultural Organization. *Budj Bim Cultural Landscape*. 2021. Available: web link (Accessed 29 January 2021).

22 Beks H, Binder M, Kourbelis C, May N, Clark R, Hudson K, et al. Geographical analysis of evaluated chronic disease programs for Aboriginal and Torres Strait Islander people in the primary healthcare setting: a scoping review protocol. *JBIM Database of Systematic Reviews and Implementation Reports* 2018; **16(12)**: 2268-2278. DOI link, PMID:30531481

23 Beks H, Binder MJ, Kourbelis C, Ewing G, Charles J, Paradies Y, et al. Geographical analysis of evaluated chronic disease programs for Aboriginal and Torres Strait Islander people in the Australian primary health care setting: a systematic scoping review. *BMC Public Health* 2019; **19(1)**: 1115. DOI link, PMID:31412846

24 Hovmand PS, Andersen DF, Rouwette E, Richardson GP, Rux K, Calhoun A. Group model-building 'scripts' as a collaborative planning tool. *Systems Research and Behavioral Science* 2012; **29(2)**: 179-193. DOI link

25 Allender S, Owen B, Kuhlberg J, Lowe J, Nagorcka-Smith P, Whelan J, Bell C. A community based systems diagram of obesity causes. *PLoS One* 2015; **10(7)**: e0129683. DOI link, PMID:26153893

26 Hayward J, Morton S, Johnstone M, Creighton D, Allender S. Tools and analytic techniques to synthesise community knowledge in CBPR using computer-mediated participatory system modelling. *Digital Medicine* 2020; **3(1)**: 22. DOI link, PMID:32133423

27 Nilson C. A journey toward cultural competence: the role of researcher reflexivity in Indigenous research. *Journal of Transcultural Nursing* 2016; **28(2)**: 119-127. DOI link, PMID:27072801

28 Hyett S, Marjerrison S, Gabel C. Improving health research among Indigenous Peoples in Canada. *CMAJ* 2018; **190(20)**: 616-621. DOI link, PMID:29789286

29 Bull J. Research with Aboriginal peoples: authentic relationships as a precursor to ethical research. *Journal of Empirical Research on Human Research Ethics* 2010; **5(4)**: 13-22. DOI link, PMID:21133783

30 Kowal E, Anderson I, Bailie R. Moving beyond good intentions: Indigenous participation in Aboriginal and Torres Strait Islander health research. *Australian and New Zealand Journal of Public Health* 2005; **29(5)**: 468-470. DOI link, PMID:16255450

31 Dadich A, Moore L, Eapen V. What does it mean to conduct participatory research with Indigenous peoples? A lexical review. *BMC Public Health* 2019; **19**: 1388. DOI link, PMID:31660911

32 Frerichs L, Hassmiller LK, Dave G, Corbie-Smith G. Integrating systems science and community-based participatory research to achieve health equity. *American Journal of Public Health* 2016; **106**: 215-222. DOI link, PMID:26691110

33 Sterman JD. Learning from evidence in a complex world. *American Journal of Public Health* 2006; **96(3)**: 505-514. DOI link, PMID:16449579

34 Stajic J, Harfield S, Brown A, Dawson A, Davy C, Aromataris E, et al. Evaluating a research capacity strengthening program for Aboriginal community-controlled health organisations. *Australian Journal of Primary Health* 2019; **25(1)**: 72-81. DOI link, PMID:30630588

35 Australian Institute of Aboriginal and Torres Strait Islander Studies. *Map of Indigenous Australia*. 2021. Available: web link (Accessed 29 January 2021).

36 Bainbridge R, Tsey K, McCalman J, Kinchin I, Saunders V, Watkin Lui F, et al. No one's discussing the elephant in the room: contemplating questions of research impact and benefit in Aboriginal and Torres Strait Islander Australian health research. *BMC Public Health* 2015; **15(1)**: 696. DOI link, PMID:26202429

37 Weetra D, Glover K, Miller R, Wilson R, Leane C, Stuart-Butler D, et al. Community engagement in the Aboriginal Families Study: strategies to promote participation. *Women and Birth* 2019; **32(1)**: 72-79. DOI link, PMID:29699794

38 Brunger F, Wall D. 'What do they really mean by partnerships?' Questioning the unquestionable good in ethics guidelines promoting community engagement in Indigenous health research. *Qualitative Health Research* 2016; **26(13)**: 1862-1877. DOI link, PMID:27179021

39 Snijder M, Wagemakers A, Calabria B, Byrne B, O'Neill J, Bamblett R, et al. 'We walked side by side through the whole thing': a mixed methods study of key elements of community-based participatory research partnerships between rural Aboriginal communities and researchers. *Australian Journal of Rural Health* 2020; **28**: 338-350. DOI link, PMID:32755008

40 Miller J, Knott VE, Wilson C, Roder D. A review of community engagement in cancer control studies among Indigenous people of Australia, New Zealand, Canada and the USA. *European Journal of Cancer Care* 2012; **21**: 283-295. DOI link, PMID:22369196

41 Maiter S, Simich L, Jacobson N, Wise J. Reciprocity: an ethic for community-based participatory action research. *Action Research* 2008; **6(3)**: 305-325. DOI link

42 Tobias JK, Richmond CAM, Luginaah I. Community-based participatory research (CBPR) with Indigenous communities: producing respectful and reciprocal research. *Journal of Empirical*

Research on Human Research Ethics 2013; **8(2)**: 129-140. DOI link, PMID:23651937

43 Bessarab D, Ng'andu B. Yarning about Yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies* 2010; **3(1)**: 37-50. DOI link

44 Gibson O, Lisy K, Davy C, Aromataris E, Kite E, Lockwood C, et al. Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review. *Implementation Science* 2015; **10(1)**: 71. DOI link, PMID:25998148

45 Safer Care Victoria. *Partnering in healthcare*. 2019. Available: web link (Accessed 29 January 2021).

46 Neville Isaacs A, Pepper H, Pyett P, Hilton G, Waples-Crowe P,

Oakley-Browne M. What you do is important but how you do it is more important. *Qualitative Research Journal* 2011; **11(1)**: 51-61. DOI link

47 Boffa J, King M, McMullin K, Long R. A process for the inclusion of Aboriginal people in health research: lessons from the Determinants of TB Transmission project. *Social Science & Medicine* 2011; **72(5)**: 733-738. DOI link, PMID:21316828

48 Walter M, Suina M. Indigenous data, Indigenous methodologies and Indigenous data sovereignty. *International Journal of Social Research Methodology* 2018; **22(3)**: 233-243. DOI link

49 National Health and Medical Research Council. *The human research ethics application (HREA)*. 2021. Available: web link (Accessed 29 January 2021).

Appendix I: Application of the CONSIDER statement

Domain	LHAY research project
Governance	
1. Describe partnership agreements between the research institution and Indigenous-governing organisation for the research (eg Informal agreements through to Memorandum of Understanding or Memorandum of Agreement).	- LHAY project partnership was formalised under two Collaborative Research Agreements (CRA) (July 2017-Dec 2018; Jan 2019-Dec 2019) – this was a standard Deakin University agreement. Two CRAs were required to align with the funding cycles of Rural Health Multidisciplinary Health Training Program that funded key project investigators at Deakin Rural Health. - Signing of the first CRA took place at DWECHS and was facilitated by an Indigenous Academic (a project co-investigator) from Deakin University who had reviewed the CRA. In the first CRA Annexure A was the Research Plan – this formed the basis of the submitted grant to the Western Alliance Academic Health Science Centre that included investigators from DWECHS (JB, TA). Annexure B was the Position Description of the Senior Health Officer employed by DWECHS (KH). - The second CRA was agreed upon verbally, sent via email, and signed and returned by DWECHS. (Further details describing how the project conception are described above under <i>Background</i>).
2. Describe accountability and review mechanisms within the partnership agreement that addresses harm minimisation.	- No specific mechanisms were contained in University's standard CRA. - Annexure A formed the basis of the Study Protocol submitted to Deakin University Human Research Ethics Committee (DUHREC). - The original ethics submission (January 2018) included the DWECHS CEO at the time, the Practice Manager, and SPO as Investigators.
3. Specify how the research partnership agreement includes protection of Indigenous intellectual property and knowledge arising from the research, including financial and intellectual benefits generated (eg development of traditional medicines for commercial purposes or supporting the Indigenous community to develop commercialisation proposals generated from the research).	- No specific clauses or provisions in the CRA addressed protection of Indigenous intellectual property and knowledge. - The CRA contained provisions around publications arising from the project that allowed DWECHS to publish following review by Deakin University to ensure it did not disclose confidential information or prejudices the value of Deakin's intellectual property, or any opportunity to pursue commercialisation of project intellectual property. - The project had little scope for commercial benefit. - The National Health and Medical Research Council Human Research Ethics Application submitted to DUHREC was much more focused on how cultural knowledge would be managed through the project. As the ethics submission was reviewed by investigators from DWECHS, it was this process that was used to build in issues around Indigenous intellectual property and knowledge (See 5. <i>Relationships</i> for further detail).
Prioritisation	
4. Explain how the research aims emerged from priorities identified by either Indigenous stakeholders, governing bodies, funders, non-government organisation(s), stakeholders, consumers, and empirical evidence.	- The project was designed in conjunction with local health leaders who were also community members. - The systematic scoping review acknowledges their input into the research process [9]. - The education component (tertiary study), clinical skills workshop, and CBSD methods employed at the community lunches were mutually agreed as areas of need.
	- The PAR approach (in particular, the pre-lunch meetings) was key for adaptive project management and making key decisions. An example of this was the redirection of project funds from the original clinical skills focus to leadership and relevant contemporary standards at the request of the CEO and Practice Manager due to changing priorities. This aspect of the project evolved into a series of staff development days covering a variety of topics. - In addition to strengthening leadership and mentoring within the organisation, all staff were upskilled in the new Royal Australian College of General Practitioners and Aged Care standards to ensure services are delivered within scope of practice.
Relationships (Indigenous stakeholders/participants and Research team)	
5. Specify measures that adhere and honour Indigenous ethical guidelines, processes, and approvals for all relevant Indigenous stakeholders, recognising that multiple Indigenous partners may be involved, eg Indigenous ethics committee approval, regional/national ethics approval processes.	- In Victoria there is currently no formal process for having research projects involving Aboriginal people reviewed by an Indigenous ethics committee. - Local processes were used to ensure the cultural appropriateness and safety of the research project. Prior to submitting a formal ethics application to DUHREC, a meeting was held at DWECHS to discuss ethical approaches for working together, including the need to adhere to local cultural protocols. Local stakeholders from DWECHS who participated in the meeting included the CEO and SPO. Also present were Aboriginal academics from Deakin University. - The formal ethics application was then reviewed by the same group.
6. Report how Indigenous stakeholders were involved in the research processes (i.e., research design, funding, implementation, analysis, dissemination/recruitment).	- Project design was agreed upon by DWECHS and DRH, with input from Aboriginal academics from School of Medicine and Institute of Koori Education. - The funding submission had input from DWECHS staff members, and the main study activity (CBSD workshops) were planned to coincide with scheduled fortnightly community lunches. - The SPO received training in quantitative methods and undertook the retrospective audit and was directly involved with recruitment at the community lunches.
7. Describe the expertise of the research team in Indigenous health and research.	- Involvement of DWECHS as partner from project conception ensured the research team had demonstrated skills in Indigenous health – key input at all project stages was provided from the CEO through to the Practice Manager and numerous health service staff. - The Deakin University research team included public health and clinical experience in Aboriginal health, as well as Indigenous staff members from the School of Medicine and Institute of Koori Education. - Other relevant experience in the team includes a partnership involving a mobile clinic to deliver Aboriginal health outreach services in the Grampians region of Victoria (located in Outer Regional Australia) – this project is multifaceted and involves medical, nursing, and allied health training, in addition to research and evaluation [17,18].
Methodologies	
8. Describe the methodological approach of the research including a rationale of methods used and implication for Indigenous stakeholders, eg privacy and confidentiality (individual and collective).	- A PAR framework was chosen for the project's design and implementation. - Active community engagement aspect of the research was the CBSD. Chosen in consultation with DWECHS, it was preferred as it leveraged off existing gatherings, and was a transparent way for the community to exchange ideas. - The resultant causal loop diagram was entirely de-identified (Figure 2). - Complementing the causal loop diagram was an action planning table to assist DWECHS to implement ideas identified by the community to record some thoughts around how these ideas might be progressed (eg timeframe, resources required). - Feedback from DWECHS management was this method was viewed favourably as community members were able to identify their ideas that had been captured verbatim (manuscript detailing the CBSD is in preparation).
9. Describe how the research methodology incorporated consideration of the physical, social, economic and cultural environment of the participants and prospective participants. (eg impacts of colonisation, racism, and social justice). As well as Indigenous worldviews.	- There was direct engagement with local stakeholders and community members in the study design, data collection, and analysis phases. - The design of the study ensured engagement was ongoing and allowed for some flexibility in adapting the research activities to meet local needs. - This resulted in modifications to the research plan, and multiple amendments submitted to DUHREC. Some examples of this include the recruitment of additional investigators from the local Aboriginal community and changes to the dates of CBSD lunches due to unforeseen circumstances. - In the data collection phase, capturing the experiences and perspectives of local Aboriginal community members was imperative to achieving the objectives of the research (eg developing community-driven strategies to improving the management of chronic disease). By engaging community members through lunches at DWECHS, it became clear that there were many factors influencing the health of Aboriginal people which were not limited to clinical factors (Figure 2).
Participation	
10. Specify how individual and collective consent was sought to conduct future analysis on collected samples and data (eg additional secondary analyses; third-parties accessing samples (genetic, tissue, blood) for further analyses).	- The systematic scoping review and retrospective audit of de-identified data did not require specific consent – although a letter of support was provided by the Practice Manager and was submitted to DUHREC with the initial application. - At the beginning of each community lunch, consent forms with plain language statements were circulated (contents of the consent forms were agreed to by DWECHS). Indigenous academic leads were central to the facilitation of such information to maintain trust, respect, and transparency during this process.
11. Describe how the resource demands (current and future) placed on Indigenous participants and	- A conscious effort was made at the beginning of the partnership to remove barriers that the researchers had direct control over. The resource demands were described in the project

research process on Indigenous participants and communities involved in the research were identified and agreed upon including any resourcing for participation, knowledge, and expertise.	- Researchers had strict control over the research activities that occurred in the project plan, and where possible, these were funded (eg scheduled community lunches and travel). The in-kind contribution of DWECHS staff was not accounted for in the project plan. Once the project was established much of the in-kind work was undertaken by the funded SPO.
12. Specify how biological tissue and other samples including data were stored, explaining the processes of removal from traditional lands, if done, and of disposal.	Not applicable to this study.
Capacity	
13. Explain how the research supported the development and maintenance of Indigenous research capacity (eg specific funding of Indigenous researchers).	- The project was initiated with funding secured through DRH to employ the SPO at DWECHS. Further funding was secured through the Western Alliance Academic Health Science Centre and covered Graduate Diploma of Indigenous Research for the SPO delivered through the Institute of Koori Education, including travel costs.
14. Discuss how the research team undertook professional development opportunities to develop the capacity to partner with Indigenous stakeholders?	- This was an organic process that took place through regular project meetings with DWECHS – particularly prior to community luncheons. Several Aboriginal colleagues from both Deakin University and DWECHS undertook training in CBSD – this was an opportunity for staff from the Global Obesity Centre to develop skills in culturally safe research training, and for the CBSD method to be adapted so it was appropriate for the local community.
Analysis and interpretation	
15. Specify how the research analysis and reporting supported critical inquiry and a strength-based approach that was inclusive of Indigenous values.	- Data collection and analysis for the CBSD component occurred concurrently throughout the project and involved the contributions of local Aboriginal stakeholders, community members and Aboriginal academics. - Findings were provided to community members for discussion prior to formal reporting. This was considered essential to ensuring the knowledge shared by Aboriginal community members was respected and interpreted in a culturally appropriate manner.
Dissemination	
16. Describe the dissemination of the research findings to relevant Indigenous governing bodies and peoples.	- The systematic scoping review [12] was rapidly circulated to local Indigenous health services with an example of suggested text for future grant applications that highlights the need for investment in Inner and Outer regions of Australia (August 19th 2019). It was also widely circulated via the Lowitja ebulletin on the same day (Lowitja Institute, 2019). The same approach will be used for future research outputs arising from the project.
17. Discuss the process for knowledge translation and implementation to support Indigenous advancement (eg research capacity, policy, investment).	- Findings from the CBSD luncheons and scoping review are available for use by local Aboriginal stakeholders. The systematic scoping review is open access and provides recommendations for policy – with explicit reference to the geographical regions where investment would have a public health benefit. - The publication process across the project actively involved the local community in the capacity of author (the scoping review [12], this manuscript, and the publication plan), and as acknowledgement of intellectual property that developed the review question [9]. - The CBSD lunches led to locally informed responses to chronic disease management with translation and timelines of these actions to be determined by the community (to be detailed in a future publication). - Research capacity and capability was built with non-Indigenous researchers – ongoing and close interaction with the local community (eg attending community lunches) enhanced their cultural knowledge, and has provided a solid base for future Aboriginal health research endeavours.

^ Huria T, Palmer SC, Pitama S, Beckert L, Lacey C, Ewen S, Smith LT. Consolidated criteria for strengthening reporting of health research involving Indigenous peoples: the CONSIDER statement. *BMC medical research methodology*. 2019;19(1):173.

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