

Community Engagement Approaches for Indigenous Health Research: an Integrative Review

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Abstract

Background

Community engagement practices in Indigenous Health research are promoted as a means of decolonizing research, but there is no comprehensive synthesis of approaches in the literature. Our aim was to assemble and qualitatively synthesize a comprehensive list of actionable recommendations to enhance community engagement practices with Indigenous Peoples.

Methods

We performed an integrative review of literature in medical (Medline, CINAHL and Embase), as well as Google and World Health Organization databases (search cutoff date November 17, 2018). Studies that contained details regarding Indigenous community engagement frameworks, principles or practices in the field of health were included, with exclusion of non-English publications. Two reviewers independently screened the articles in duplicate and reviewed full text articles. Recommendations for community engagement approaches were extracted and thematically synthesized through content analysis.

Results

A total of 52 studies were included in the review, with 1268 individual recommendations extracted. These were synthesized into a list of 37 recommendations for community engagement approaches in Indigenous health research, categorized by stage of research. In addition, activities applicable to all phases of research were identified: partnership and trust building, and active reflection.

Conclusions

We provide a comprehensive list of recommendations for Indigenous community engagement approaches in health research. A limitation of this review is that it may not address all aspects applicable to specific Indigenous community settings and contexts. We encourage anyone who does research with Indigenous communities to reflect upon their practices, encouraging changes in research processes that are strengths-based.

Background

Research involving Indigenous communities has been linked to research fatigue,¹ the misuse of genetic samples from Indigenous peoples,² and an approach that is rooted in community deficits rather than strengths.³ Perhaps it is for these reasons that many communities have developed a fear of the term 'research',⁴ and have viewed this process as an extension of colonialism.⁵ Reports in health research frequently characterize disparities in outcomes between Indigenous and non-Indigenous people and offer an explanation that is rooted in socioeconomic differences.⁶ Less frequent is the consideration that these so-called disparities are attributed to forced attempts of assimilation and removal of Indigenous language, culture and knowledge from the research process. Negative examples of research being conducted in Indigenous communities overshadow positive ones, and have prompted the establishment of guidelines for Indigenous Health research by the tri-council research bodies in Canada,⁷ enactment of the Ownership, Control, Access and Possession (OCAPTM) principles for research involving First Nations People of Canada,⁸ and institutional review boards by various tribal regions in the United States.⁶ Despite these measures, a recent systematic review surveying patterns of community engagement in arthritis studies in the United States, Canada, Australia and New Zealand produced by our research group found that the majority of research processes continue to nominally involve Indigenous Peoples at meaningful levels,⁹ leading to minimal benefit for the participants and communities involved.

One way to move forward is to engage in meaningful collaborations with communities¹ throughout the research process, including stages of identifying and addressing relevant health concerns, to data collection, interpretation of results, and utilization of results together with those that are impacted by it. This represents an entry point to 'decolonizing methodologies',¹⁰ which requires a shift of typical power from the researcher to the community, and prioritizing community needs rather than researcher interests. In our experiences in facilitating Indigenous Health research in our local environment, we have observed that there is interest from researchers to learn how to enact these principles, yet with a general uncertainty on how to do so. It is likely that this is linked to the

paucity of comprehensive recommendations for community engagement approaches with Indigenous Peoples in the existing literature, and an inconsistent reporting requirement for community engagement practices among journal publishers.

The purpose of this integrative review was to produce a comprehensive list of recommendations for the engagement of Indigenous communities in health research, through a systematic search of the literature and subsequent qualitative synthesis. This would support paradigm-shifting research practices that value community input while minimizing risks of unintended harms and consequences for Indigenous communities.

Methods

Identification of Existing Literature

We utilized an “integrative review” methodology, a well-established method to systematically review and produce qualitative syntheses from the existing literature.¹¹ We summarized principles, existing recommendations and strategies for community engagement with Indigenous Peoples, in order to generate a comprehensive list of recommendations for researchers. The literature search was conducted in Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Embase databases, devised with the help of a medical librarian. A grey literature search was performed through Google search engine and the World Health Organization database. All searches were performed from each database inception up to November 17, 2018. There were no restrictions on study type, publication status, or publication year. Selection was restricted to English language studies. The terms utilized during our literature search strategy to identify manuscripts on community engagement, guidelines/recommendations and Indigenous Peoples are listed in Table 1. A review protocol is available by contacting the corresponding author.

Study Selection

The titles and abstracts of retrieved studies were screened in duplicate by two members of our research team (CYL and ALS) following specific inclusion and exclusion criteria (Table 2). These same two researchers independently conducted a full-text review of the manuscripts that fulfilled our inclusion criteria.

Data Collection Process

Full-text manuscripts meeting the inclusion criteria and not excluded were reviewed and general information on the study was extracted, including author, year of publication, journal, Indigenous co-authorship or endorsement, methodology, Indigenous population involved, country of origin, name of guideline or framework, and health area. We then extracted statements about strategies and recommendations for community engagement, only if they were actionable, implying that purely theoretical statements were not considered. Data collection was completed independently and in duplicate by two reviewers (CYL and EB) through a piloted form on Microsoft Word (Washington, 2018), and consensus was reached without the involvement of a third party.

Qualitative Synthesis of Community Engagement Recommendations

The extracted recommendations for community engagement approaches were synthesized under identified relevant themes, using Dedoose Qualitative Software (Los Angeles, 2018). Initially, two researchers (CYL and ALS) conducted a preliminary analysis of five manuscripts and generated a list of themes based on the stage of research for which recommendations were most relevant. Subsequently, all extracted recommendations were assigned to the identified themes by the same two researchers. Revisions to the initial themes were constantly performed throughout the thematic analysis as new insights emerged and to accommodate for all of the recommendations identified.

Each set of recommendations assigned to their respective themes were further condensed into single statements according to their similarity and complementarity in order to produce a concise yet comprehensive list of recommendations for community engagement with Indigenous Peoples, utilizing an Excel spreadsheet (Washington, 2018). Once this synthesis strategy was

completed, an expert Indigenous scholar (CB) further synthesized the statements, producing a final concise list of recommendations to be enacted within Indigenous Health research.

Role of the Funding Source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

Study Selection

Two-hundred and ninety-five manuscripts were screened for title and abstract relevancy and 181 were removed as they did not fulfill the inclusion criteria. One-hundred and fourteen full-texts were further reviewed and 62 were removed as they fulfilled the exclusion criteria. A total of 52 studies were included in the qualitative synthesis (Figure 1).

Process of Qualitative Synthesis of the Recommendations

From the fifty-two included studies,¹²⁻⁶³ a total of 1268 actionable community engagement recommendations were extracted, an average of twenty-four statements per manuscript. Study characteristics are found in Table 3. Following the first thematic analysis, the 1268 recommendations were synthesized into 213 recommendations. The final synthesis step resulted in 37 main recommendations, categorized by the research stage and topic related to community engagement, summarized below (Table 4).

Recommendations by Stage of Research

'Preparation and Learning': This stage includes recommendations for the researcher to gain knowledge about the history of colonization with its' negative impact on Indigenous Peoples' health, as well as the local customs and history of the Indigenous communities to be engaged. The researcher should also understand the tensions of research in Indigenous communities, and be accepting of Indigenous ways of learning and knowing. It is also critical for the researcher to have in-depth knowledge of relevant research ethics, at the institutional and community levels.

'Establish Relationship and Research Needs': Recommendations in this stage stress the importance of appropriately establishing relationships with the community and its' leadership. These relationships should be entered with a longitudinal commitment, and with the intention of being an ally rather than with a 'saviour' ethos. Individual nations will have protocols and expectations for beginning and establishing the relationship, and expertise from others should be sought. If there is acceptance of the researcher by the community and its leadership, then discussions to learn about community needs is prioritized, rather than the researcher determining the topic or a preset research agenda. Formal approval processes to proceed with research will be determined by the community. The researcher may then proceed with broader community engagement, and formalization of the research team.

'Research Activities': This stage includes determining the research approach, agreeing to budgets, conducting research with ethical processes, and addresses employment of community members, recruitment of research participants, and data collection. It is critical to conduct the research within a clear ethical framework, including approaches to research that are congruent with the specific Indigenous communities' values and culture and that consider Indigenous Peoples' strengths. In addition, the recommendations promote the importance of considering the costs of initiating and maintaining community participation, especially to facilitate individual participation in research and hiring community members to do different research activities. Research can be burdensome to participants, and it is important to keep the data collection process efficient to minimize fatigue. Finally, it is critical to monitor the process of research, respond to concerns and feedback expressed by leadership and the community, and communicate throughout the project.

'Analysis and Interpretation': Community representatives and leadership remain involved in knowledge exchange dynamics in the process of analyzing and interpreting data. The researcher should privilege Indigenous knowledge and views, and identify emergent community benefits of the research.

'Dissemination and Utilization of Results': Here, a fundamental guiding principle that empowers Indigenous communities is that they hold the final voice to approve research results in any form before they are disseminated and used. We stress the importance of having clear and transparent processes to communicate the research results to communities, under an ethics framework of community ownership.

Approach to Community Engagement and List of Recommendations

Two over-arching themes for community engagement with Indigenous Peoples were identified, which include recommendations that are pertinent to enact at all stages of a research project: "partnership and trust" and "active reflection" (Figure 2). Every stage of a research project includes the potential to increase Indigenous communities' capacity to address their health issues, strengthen the relationships between community and researchers, and to equilibrate power and knowledge between these two parts. Consequently, it is recommended under the theme of "Partnership and trust" to always aim to build partnerships with community members aiming for mutual benefit and trust, based on principles of Indigenous autonomy, community participation, capacity building, respect, reciprocity, responsibility, advocacy and power redistribution during decision making. In addition, it is essential for researchers to engage in a continuous process of self –reflection throughout all research stages, in order to recognize individual pre-conceptions and worldviews, and transcend these to collaborate with community members to produce knowledge that can be shared and accepted by all. Therefore, under the theme of "active reflection" it is recommended that researchers actively reflect on their personal motivations and on power differentials between them and communities as a way to embrace learning and move forward with true collaborative actions.

Discussion

These recommendations synthesize and promote actionable recommendations for community engagement approaches with Indigenous Peoples when engaging in health research. While detailing practices throughout the different stages of the research process, two over-arching concepts were identified: the critical components of building partnership and trust, and pursuing active reflection of one's interactions and approaches with community. Through the recommendations suggested in this work, we endeavor to provide direction to researchers in decolonizing methodologies—a much needed impetus for avoiding a 'researcher-knows-best' and 'deficit-based' approach to research involving any Indigenous community as has been occurring in the scientific community.

The process of community engagement begins far before data collection—it begins with preparation and learning on behalf of the researchers, and this sets the tone for subsequent stages of the research. Important questions to consider before initiating a research project in an Indigenous community are: a) Why is it that some communities oppose research?, and b) for what reasons did some communities distance themselves from research? Researchers can begin by understanding the history of the relationship between research and Indigenous communities, and the experiences of oppression and assimilation Indigenous communities have faced historically and continue to experience.³⁵ In addition to understanding the historical context, it is equally important to understand that the current health inequities are rooted in colonialism,⁴⁶ a legacy propagated to this day. It is crucial that researchers do not move ahead with a research idea until they obtain a solid understanding of historical implications of research and colonialism.

Following this preparatory step, researchers need to establish relationships and earn their trust in local communities. One way to create a path for creating new connections is through seeking introductions from individuals who already have an established connection with the community.²⁶ Nevertheless, it is important to recognize that it is the researcher's responsibility to invest significant amounts of time and energy in ongoing relationship-building.²² It is worth to invest in relationships as these will enable meaningful dialogues that will help define what is important within the community's self-determined health agenda.³⁰ Only after determining community needs should the plan for research be considered and developed. In addition, formalizing Terms of

Reference or Memorandums of Understanding between researchers and community are fundamental to ensure the researcher commitment to the community's benefit.²⁷

Details of the research plan need to reflect community strengths,²² and must be realistic, feasible and transparent, especially relating to the costs²⁹ and timelines of the project.²⁶ Researchers must also delineate which data are to be collected and agree on the limits for data collection. One way to increase community capacity and increase data collection appropriateness is through hiring local community members.⁴⁴ Moreover, throughout the research process it is important to iteratively obtain feedback from communities, relating to data collection processes and research progress.²¹

Any collected data should belong to the communities which they are derived from,¹⁴ and any intellectual property rights generated from the research need to reflect this.³² Community members need to be consulted for interpreting findings, through creating a safe space for knowledge exchange between Indigenous knowledge and researcher views. No result should be deemed final unless approved by the community. Discussions for implications of the results should be also facilitated.⁴⁹

The dissemination and utilization of research results should reflect the objectives of the research project, that is, it should address the needs of the communities. Dissemination of any results relating to research in any format will require approval from communities, and researchers should honor requests for correcting misinterpretations.⁵⁰ Shared authorship with communities is one step in ensuring that research results are interpreted at least in part with communities.⁵⁰ Benefits of the research must be transparent, and shared with communities, especially relating to any commercialization that results.²⁰

The recommendations produced in this work represent one approach to engaging Indigenous communities in research, and puts a great emphasis on partnership and trust building practices, as well as in the important role of researchers' active reflection. This set of recommendations is different from others in that they overarch all stages of the research process and are focused on the actions that researchers should take in order to be mindful of their intentions, as well as respecting and honoring community interests. These recommendations are intended to bridge the gaps for researchers who want to forge a new beginning to go forward, in collaboration with Indigenous communities. Historical shortcomings cannot be forgotten—but they will help shape what the future of research can look like—a future where 'decolonizing methodologies' predominate, and power paradigms shift back to communities that experience the impact of the research.

One limitation of our study is that the methodology of qualitative synthesis may inevitably miss some of the recommendations currently in the literature. Despite this, we believe that our review is comprehensive, and is also informed by our experience within our own research programs. Another limitation is that the review is limited by what is available in the literature and may not address all questions that readers may encounter during the research process. We direct researchers to the local community to continuously seek feedback on desired community engagement processes that best fit to their individual cultural practices; being transparent about wanting to improve the researcher-community relationship is an important gesture to communities. Additionally, our review does not reflect the issue of sustainability of research projects as well as its results. We encourage readers to ensure proper community engagement, as well as an appropriate allocation of funds, in order to sustain projects and their positive results.

Conclusions

These recommendations synthesize and promote 37 actionable recommendations for community engagement approaches with Indigenous Peoples when engaging in health research, while reinforcing the critical elements of partnership and building trust, and active reflection by the researcher.

Declarations

Ethics approval and consent to participate—Not applicable

Consent for publication—Not applicable

Availability of data and materials—Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

Competing interests—The authors declare that they have no competing interests.

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Authors' contributions—Study conception and design: ALS and CB; Data collection: CYL, ALS, EB; Analysis: CYL, ALS, EB, CB; Manuscript drafts and approval of final version: All authors

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List Of Abbreviations

Ownership, Control, Access and Possession (OCAP™)

Cumulative Index to Nursing and Allied Health Literature (CINAHL)

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Tables

Table 1. Search Strategy

Medline, CINAHL, Embase	Google	World Health Organization Database
<p>"Community Engagement" OR "Action Research" OR "Community-Based Participatory Research" OR "Participatory Research" OR "Community-Based Research"</p> <p>AND</p> <p>"Guideline" OR "Overview" OR "Principles" OR "Framework" OR "Recommendation"</p> <p>AND</p> <p>"Indigenous" OR "Aborigin*" OR "First Nation" OR "Inuit" OR "Metis"</p>	<p>"Aboriginal engagement strategy health pdf" OR "Indigenous community engagement health pdf" OR "Indigenous community engagement health university pdf"</p>	<p>"Indigenous action research" OR "Indigenous Community Engagement"</p>

Table 2. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Publications detailing community engagement frameworks and/or principles	Primary health studies that did not have actionable strategies as <i>recommendations</i> after reflecting on their experience of applying community engagement strategies
Publications concerning Indigenous communities	Any other type of publication without specific, actionable strategy/principles/guidelines
Publications on health	Publications outside the health field
	Publications not including Canada (CA), The United States of America (USA), New Zealand (NZ) or Australia (AUS)
	Non-English publications

Table 3. Characteristics of Included Studies

Study	Area of Research	Indigenous Coauthorship	Indigenous population	Country	Framework or Guideline	Methodology
Christopher 2011 ²⁷	General research	Yes	Non-specific	USA	CBPR	Guidelines
Harding 2012 ³⁵	General research	Yes	Native American tribal nations	USA	CBPR	Group reflection
Tremblay 2018 ⁵⁶	Chronic disease	No	Mohawk	Canada	CBPR with social movement theory	Qualitative research
Baird 2015 ⁵²	General research	Unclear	Aboriginal peoples in the HNHB LIHN	Canada	Community Engagement	Report
Cooper 2018 ²⁸	Health promotion	No	First Nations and Metis living in Manitoba	Canada	Knowledge translation/implementation	Report
Bandler 2015 ¹⁷	General research	No	Aboriginal and Torres Strait Islander Australians	Australia	Chapter 4.7 of the National Statement on Ethical Conduct in Human Research	Individual reflection
University of Manitoba ⁵⁸	General research	Yes	Manitoba First Nations, Inuit and Métis	Canada	Framework for Research Engagement between the University and First Nation, Métis and Inuit Peoples	Guidelines
Thomas 2011 ⁵⁵	Homelessness	Unclear	Aboriginal and Torres Strait Islander Australians	Australia	Reflective practice "closing the gap"	Group reflection
Johnston Research Inc 2011 ⁴⁰	Healthcare	unsure	Aboriginal people accessing the Waterloo Wellington LHIN	Canada	Community Engagement	Report
Voyle 1999 ⁵⁹	Health promotion	Unclear	An urban Maori community in New Zealand, Whaiora Marae	New Zealand	Community Development Partnership	Literature review
Crooks 2013 ³⁰	Youth health	Yes	First Nations, Metis and Inuit	Canada	CBPR/culturally sensitive interventions	Group reflection
Singer 2015 ⁵³	Mental health	Unclear	Indigenous Australian and Torres Strait Islander Peoples	Australia	CBPR	Individual reflection
Kerr 2010 ⁴¹	Chronic disease	Unclear	Maori	New Zealand	Kaupapa Maori Research	Literature review
Wahbe 2007 ⁶⁰	Food security	Yes	Musqueam (Coast Salis, Canada) and Totoras (Quichua, Ecuador)	Canada and Ecuador	CBPR	Group reflection
Esler 2008 ³²	Mental health	Unclear	Indigenous Australians in the Danila Dilba	Australia	PAR	Individual reflection

			community, Darwin (Northern Territory)			
Oneha 2004 ⁴⁷	Cancer	Yes	Pacific Islander communities	USA	CBPR	Group reflection
Ball 2008 ¹⁶	Youth health	Yes	Indigenous people in Canada participating in and/or impacted by research.	Canada	Memorandum of Understanding/research ethics	Group reflection
Liaw 2011 ⁴³	Chronic disease	Unclear	Aboriginal Australians and Torres Strait Islanders	Australia	Cultural Competence/Respect Framework	Literature review
Naqshbandi ³⁷	Chronic disease	Unclear	11 First Nations communities across six provinces (BC, AB, MB, ON, QC, NL)	Canada	TransFORmation of IndiGENous PrimAry HEALTHcare Delivery (FORGE AHEAD): Community-driven Innovations and Strategic Scale-up Toolkit	Report
Walker 2018 ⁶¹	Chronic disease	No	First Nations in Ontario	Canada	Ethical code of contact	Individual reflection
Bharadwaj 2014 ²²	Toxicology	No	First Nations communities in Saskatchewan	Canada	CBPR/OCAP	Literature review
Bell 2016 ²¹	Chronic disease	Yes	Maori/ New Zealand Indigenous community	New Zealand	CBPR	Report
Couzos 2005 ²⁹	Otorhino	Yes	Indigenous Australians	Australia	Aboriginal Community- Controlled Health Research	Report
Community Engagement Hubs, First Nations Health Council 2011 ³³	General research	Yes	First Nations communities in BC	Canada	Community Engagement Hub Toolkit	Guidelines
Kassi 2015 ¹³	Nutrition	Yes	Indigenous communities in Yukon Territories	Canada	Community Engagement	Not reported
Assembly of First Nations Environmental Stewardship Unit 2009 ¹⁴	General research	Yes	First Nations	Canada	Ethics in First Nations Research	Guidelines
Duffy 2013 ³¹	General research	Yes	Mount Isa Indigenous community in North Queensland	Australia	PAR	Report
Ninomiya 2017 ⁴⁶	FASD	No	Sheshatshiu Innu First Nation, an Indigenous	Canada	CBPR	Group reflection

			community in Labrador			
University of Calgary 2016 ⁵⁷	General research	Yes	Indigenous communities	Canada	Cultural Protocol Engagement	Guidelines
Heffernan 1999 ³⁸	Chronic disease	Yes	Village of Skidegate, Haida Gwaii	Canada	CBPR	Report
Quigley 2006 ⁵⁰	Public health	Unclear	Native American and Pacific Islander communities	USA	CBPR	Case studies
Maar 2011 ⁴⁴	General research	Yes	Rural and urban communities in north-eastern and south-western Ontario	Canada	Community Engagement	Qualitative research
Young 2018 ⁶²	Youth health	Yes	Wiikwemkoong Unceded Territory	Canada	Not described	Individual reflection
Pyett 2002 ⁴⁹	General research	Yes	Aboriginal and Torres Strait Islander peoples	Australia	CBPR	Guidelines
Kholghi 2017 ⁴²	Chronic disease	Yes	Iroquoian and Mohawk	Canada	CBPR with deliberative democratic theory	Group reflection
Anticona 2013 ¹²	Toxicology	Unclear	Peruvian Amazon Indigenous Communities	Peru	PAR/ Ecohealth Framework	Individual reflection
Mitchell 2005 ⁴⁵	Cancer	Yes	Canadian Aboriginal and Native American women with breast and gynecological cancer	Canada	PAR and OCAP	Group reflection
Spencer 2015 ⁵⁴	Social work	Yes	Native Hawaiians, Pacific Islander people	USA	CBPR	Individual reflection
Ritchie 2013 ⁵¹	Youth health	Yes	Indigenous Communities in Northern Ontario	Canada	CBPR	Group reflection
Brunger 2013 ²⁵	General research	Unclear	Aboriginal communities in Newfoundland and Labrador	Canada	Research Ethics/ Process for Review of Health Research Involving Aboriginal Communities	Guidelines
Brunger 2016	General research	Yes	NunatuKavut communities	Canada	Community Engagement	Individual reflection
Hyett 2018 ³⁹	Healthcare	Unclear	Indigenous people in Canada participating in and/or	Canada	Not described	Literature review

			impacted by research.			
Beaton 2017 ²⁰	Genomics	Yes	Maori	New Zealand	He Tangata Kei Tua/ Engaging Communities	Guidelines
Brown 2002 ²⁴	Addictions	Unclear	Indigenous Australian and Torres Strait Islander people in Far North Queensland	Australia	A Process of Feedback	Literature review
Glass 2007 ³⁴	General research	No	Indigenous communities in North America	Canada	Developing community sensitive research ethics review processes, collective rights	Literature review
Bailey 2006 ¹⁵	General research	Unclear	Aboriginal and Torres Strait Islander health workers	Australia	Research capacity building framework	Report
Bingham 2013 ²³	General research	Yes	Aboriginal communities in the Fraser region	Canada	Community Driven Primary Health Care Research with Aboriginal People	Report
Beaton 2016 ¹⁹	Genomics	No	Maori	New Zealand	"He Tangata Kei Tua" – a relationship model for biobanks	Literature review and mixed methods
Oneha 2004 ⁴⁸	Women's health	Yes	Pacific Islanders. Women from communities from Ewa Beach to Wai'anae.	USA	CBPR	Qualitative research
Bartlett 2007 ¹⁸	Chronic disease	Yes	Métis and First Nations people with diabetes in Winnipeg, Manitoba (urban)	Canada	Decolonizing research	Report
Haswell-Elkins 2009 ³⁶	Mental health	Yes	Aboriginal Australians in two communities in North Queensland, Hope Vale and Yarrabah.	Australia	Priority Driven Research	Literature review
Zemits 2015 ⁶³	Health promotion	Yes	Australian Aboriginal (Yolngu) communities in northeast Amhem Land	Australia	Actor Network Theory (Latour)	Group reflection

Legend: USA United States of America; CBPR community-based participatory research; HNHB LIHN; PAR participatory-action research; BC British Columbia; AB Alberta; MB Manitoba; ON Ontario; QC Quebec; NL Newfoundland

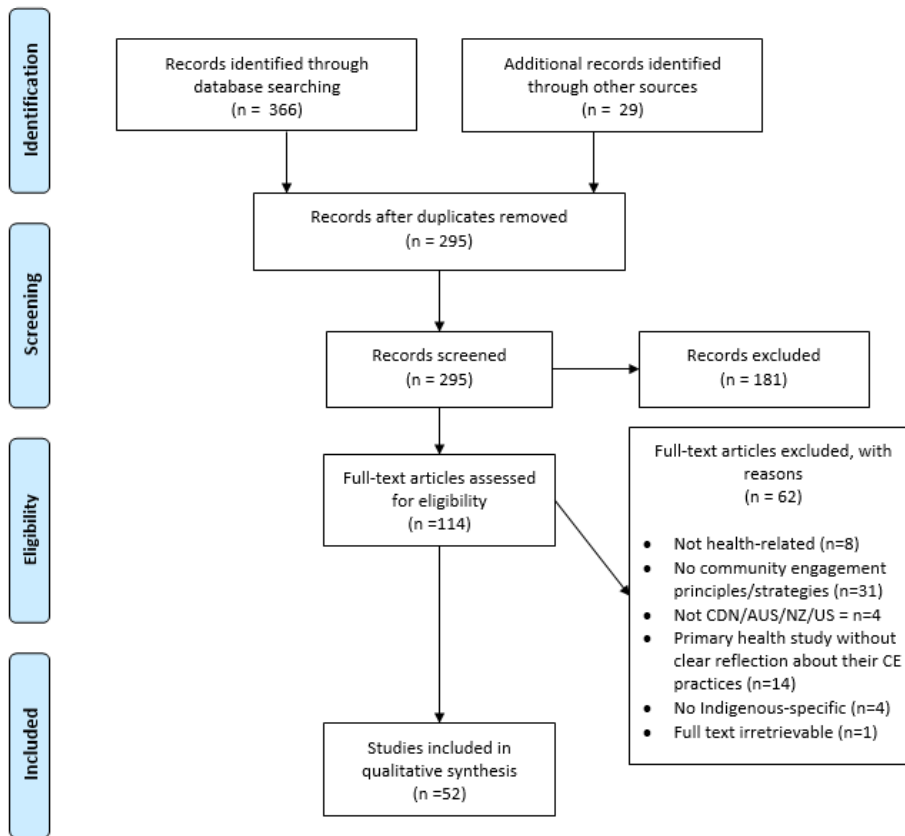
Table 4. Community Engagement Approaches in Indigenous Health Research

Stage	Topic	Statement
Preparation and Learning	Knowledge of Indigenous Peoples	<ul style="list-style-type: none"> • Seek opportunities to participate in cultural sensitivity and competency training to gain knowledge in Indigenous Peoples' history. • Understand the relationship between colonialism and the health of Indigenous populations, including the effects of intergenerational trauma, power differentials and identity loss. • Become familiar with local Indigenous communities' contexts and protocols.
	History of Research and Indigenous Peoples	<ul style="list-style-type: none"> • Learn the history of disempowerment of Indigenous Peoples and Communities through research. • Explore the history of Indigenous-driven research, recognizing that all Indigenous people have always conducted research to seek understanding and knowledge.
	Research Ethics	<ul style="list-style-type: none"> • Gain knowledge of the ethical principles developed by Indigenous organizations and funding bodies • Determine ethical approval processes and requirements at both at the institutional and local community level.
Establish Relationship and Research Needs	Introduction to the Community	<ul style="list-style-type: none"> • Recognize that engaging and establishing a relationship with community requires a significant time investment and longitudinal commitment. • Seek advice and introductions from individuals and partners who have strong relationships with Indigenous communities. • Engage with community councils and leadership.
	Determine Needs and Role for Research	<ul style="list-style-type: none"> • Hear from leadership and community what is needed to meet their determined health agenda. • Identify if there is leadership and community interest in research activities to meet their health agenda.
	Leadership Approval	<ul style="list-style-type: none"> • Secure approval from community leadership entrusted with the authority to confirm engagement in research. • Develop Terms of Reference or a Memorandum of Understanding for all aspects of the proposed research. This document should be refined through an iterative process and focused on mutual agreement for all outcomes and benefits.
	Community Engagement	<ul style="list-style-type: none"> • Engage with the broader community. • Formalize participation of community members.
Research Activities	Research Approach	<ul style="list-style-type: none"> • Use a strengths-based research lens when developing research goals and objectives. • Select research methods congruent with Indigenous knowledge and approaches.
	Budgetary Considerations	<ul style="list-style-type: none"> • Appropriately estimate costs of conducting community-based research. • Transfer funds to the community to support the research process.
	Ethical Research Processes	<ul style="list-style-type: none"> • Clarify what data can be collected. • Be honest in disclosing risks of research. • Protect the privacy of participants, and respect wishes for individual and community identification.
	Employment of Community Members	<ul style="list-style-type: none"> • Hire community members and support capacity-building and self-determination activities.
	Participant Recruitment and Data Collection	<ul style="list-style-type: none"> • Use strategies to facilitate participation in research. • Be efficient in research activities to minimize burden to individuals and the community.

	Evaluating the Research Process	<ul style="list-style-type: none"> • Continuously monitor the research process and respond to feedback from leadership and the community. • Ensure ongoing relationship building. • Reassess the appropriateness of continuing the research project.
Analysis and Interpretation	Collective Interpretation	<ul style="list-style-type: none"> • Interpret findings and results along with community members, privileging Indigenous knowledge and views. • Identify benefits and outcomes of the research, and potential implications of the findings.
	Leadership Review and Interpretation	<ul style="list-style-type: none"> • Seek feedback from community leadership about the results and their implications and provide space for two-way knowledge transfer.
Dissemination and Utilization of Results	Community Approval	<ul style="list-style-type: none"> • Pursue dissemination of results only if leadership and communities approve, and according to their terms and conditions.
	Communication of Results	<ul style="list-style-type: none"> • If approved to disseminate results in academic and public settings, ensure all products have been reviewed and approved by community leadership and members, with opportunity for co-authorship, and that ownership of data remains with communities. • If approved to disseminate results to community, ensure all products are accessible and use methods of communication appropriate to the community.
	Ethical Considerations	<ul style="list-style-type: none"> • Ensure accurate presentation of the research process.
	Attribution of Benefits of Research	<ul style="list-style-type: none"> • Be transparent and share benefits of any commercialization that came about as a result of Indigenous data.

Figures

Study Selection Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Figure 1

Study Selection

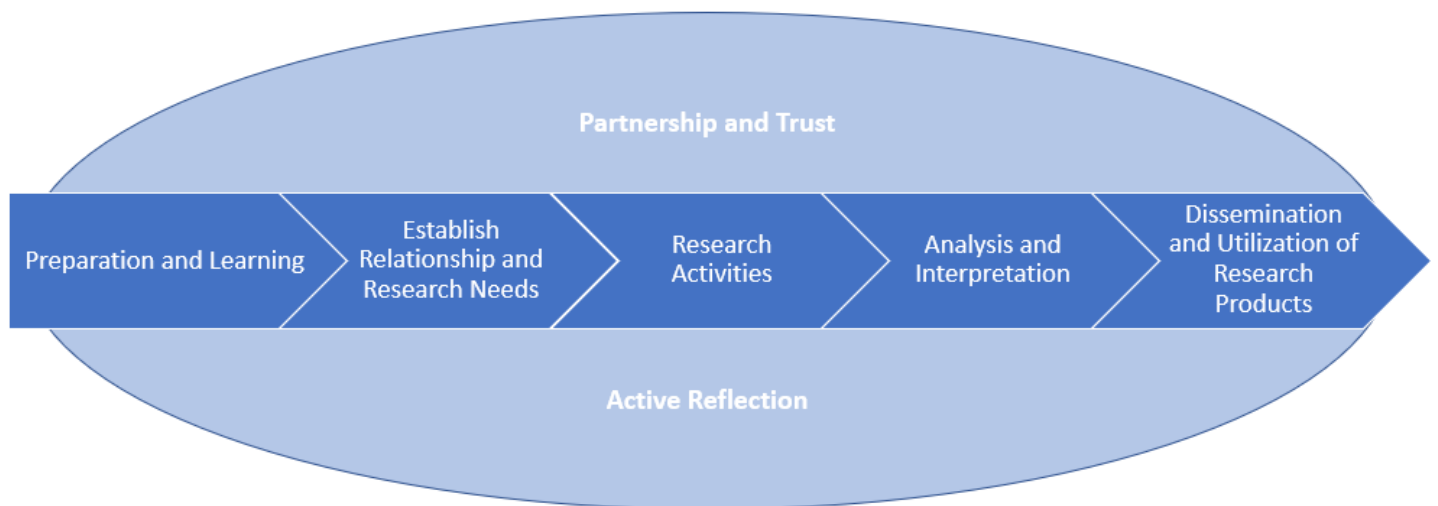


Figure 2

Synthesized model of Indigenous community engagement

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [PRISMA2009checklist.doc](#)