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Community engagement approaches for Indigenous health research: recommendations based on an integrative review

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ABSTRACT

Objective Community engagement practices in Indigenous health research are promoted as a means of decolonising research, but there is no comprehensive synthesis of approaches in the literature. Our aim was to assemble and qualitatively synthesise a comprehensive list of actionable recommendations to enhance community engagement practices with Indigenous peoples in Canada, the USA, Australia and New Zealand.

Design Integrative review of the literature in medical (Medline, Cumulative Index to Nursing and Allied Health Literature and Embase) and Google and WHO databases (search cut-off date 21 July 2020).

Article selection 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.

Analysis Recommendations for community engagement approaches were extracted and thematically synthesised through content analysis.

Results A total of 63 studies were included in the review, with 1345 individual recommendations extracted. These were synthesised into a list of 37 recommendations for community engagement approaches in Indigenous health research, categorised 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 on their practices, encouraging changes in research processes that are strengths based.

Strengths and limitations of this study

► The integrative review design, which is a literature synthesis method, permitted us to systematically review and produce qualitative syntheses from the existing literature.

► Both academic-based literature and grey literature sources were searched to include diverse research approaches and audiences.

► Our synthesis of principles was completed through a thematic analysis that produced a comprehensive list of practical, action-oriented recommendations for researchers to appropriately engage with Indigenous peoples.

► Recommended actions reflect descriptions made by primary authors of included articles, and may unintentionally exclude necessary strategies.

► We restricted studies to those involving Indigenous populations of Canada, Australia, New Zealand and the USA and health-specific research only.

INTRODUCTION

Indigenous populations of Canada, Australia, New Zealand and the USA share common histories of colonisation, with persistent and ongoing disempowerment to maintain the status quo, and with significant impacts on health and wellness outcomes. Research provides the opportunity to understand and resolve disparities, yet 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] 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,[6] enactment of the Ownership, Control, Access and Possession principles for research involving First Nations People of Canada,[7] and institutional review boards by various tribal regions in the USA.[8] Despite these measures, a recent systematic review surveying patterns of community engagement in arthritis studies in the

USA, 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 communities[1] throughout the research process, including stages of identifying and addressing relevant health concerns, to data collection, interpretation of results and utilisation of results together with those that are impacted by it. This represents an entry point to 'decolonising methodologies',[10] which requires a shift of typical power from the researcher to the community, and prioritising 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 Indigenous and non-Indigenous researchers to learn how to enact these principles, yet with a general uncertainty on how to do so. This is supported by recent literature contributions across different disciplines and methodological approaches that provide ideas for improved research and engagement practices with Indigenous communities.[11 12] There is however a 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 minimising risks of unintended harms and consequences for Indigenous communities.

METHODS
Identification of the existing literature
We used an 'integrative review' methodology, a well-established method to systematically review and produce qualitative syntheses from the existing literature.[13] We summarised principles, existing recommendations and strategies for community engagement with Indigenous peoples in Canada, the USA, Australia and New Zealand, 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 WHO database. All searches were performed from each database inception (Medline: 1946; CINAHL: 1937; Embase: 1974) up to 21 July 2020. There were no restrictions on study type, publication status or publication year. Selection was restricted to English language studies. A summary of terms used during our literature search strategy to identify manuscripts on community engagement (and related concepts of community-based research and participatory action research), guidelines/recommendations and Indigenous peoples are listed in table 1. The full search strategy is available in online supplemental file 1, and the 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 AL-S) 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 coauthorship 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

Table 1 Search strategy		
Medline, CINAHL and Embase	**Google**	**WHO database**
"Community Engagement" OR "Action Research" OR "Community-Based Participatory Research" OR "Participatory Research" OR "Community-Based Research" AND "Guideline" OR "Overview" OR "Principles" OR "Framework" OR "Recommendation" AND "Indigenous" OR "Aborigin*" OR "First Nation" OR "Inuit" OR "Metis"	"Aboriginal engagement strategy health" OR "Indigenous community engagement health" OR "Indigenous community engagement health university"	"Indigenous action research" OR "Indigenous Community Engagement"

CINAHL, Cumulative Index to Nursing and Allied Health Literature.

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 recommendations 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, the USA, New Zealand or Australia
	Non-English publications

EB) through a piloted form on Microsoft Word (Washington, 2018), and consensus was reached without the involvement of a third party. As the intent of our review was to identify community engagement recommendations employed in different research studies, the quality of the studies in relation to their primary objective was not assessed.

Qualitative synthesis of community engagement recommendations

The extracted recommendations for community engagement approaches were synthesised thematically using Dedoose qualitative software (Los Angeles, 2018). Initially, two researchers (CYL and AL-S) conducted a thematic analysis of five randomly selected manuscripts,[14–18] which represented studies conducted in different conditions, with variations in research activities, years of study and countries of research. Using a categorisation method,[19] the researchers generated a list of themes based on the stage of research for which recommendations were most relevant. Subsequently, all extracted actions were assigned to themes by the same two researchers independently. 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. Throughout the process, each set of actions assigned to 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, using an Excel spreadsheet (Washington, 2018). The researchers then converged their analysis; once this synthesis strategy was completed, an expert Indigenous scholar (CB) reviewed all initial extracted actions, confirmed the identified themes and categorisation procedures and undertook a final synthesis to generate a concise list of recommendations to be enacted within Indigenous health research.

RESULTS
Study selection

A total of 393 manuscripts were screened for title and abstract relevancy and 263 were removed as they did not fulfil the inclusion criteria. A total of 130 full texts were further reviewed and 67 were removed as they fulfilled the exclusion criteria. A total of 63 studies were included in the qualitative synthesis (figure 1).

Process of qualitative synthesis of the recommendations

From the 63 included studies,[11 14–18 20–75] a total of 1345 actionable community engagement recommendations were extracted, with an average of 21 statements extracted per study. Study characteristics are found in table 3. Following the first thematic analysis, the 1345 recommendations were synthesised into 213 recommendations. The final synthesis step resulted in 37 main recommendations, categorised by the research stage and topic related to community engagement, which is summarised 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 colonisation 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 the 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. One notable example in this phase of the research is to be careful with the use of language and terminologies when communicating, avoiding terms that might be viewed as colonising (eg, terms such as 'occupation' to describe jobs/careers may trigger negative responses).[65] This requires researcher education and sensitivity training.[61]

'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. One way to establish genuine relationships with communities is by honouring welcoming practices which might include hosting a meal in the researchers' home, sharing meals and providing appropriate gifts as initial friendly gestures.[23] Additionally, individual nations will
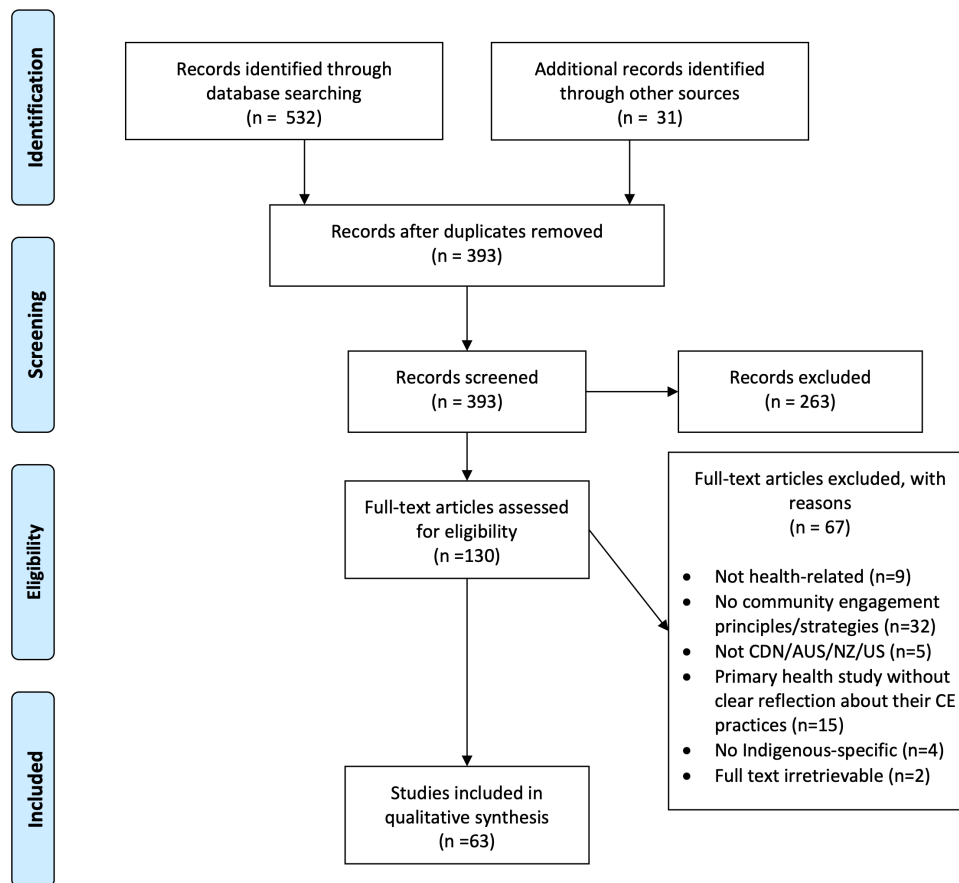
Figure 1 Study selection. Adapted from: Moher *et al.*[77] AUS, Australia; CDN, Canada; CE, community engagement; NZ, New Zealand; US, the USA.

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 prioritised, 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 formalisation 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 minimise fatigue. Any instruments used for the research should

be user friendly, and are devoid of jargon. In one health promotion project, researchers designed locally relevant pamphlets relating to influenza prevention, which were easily relatable to community members. Several years later, these pamphlets were still circulating in the community.[34] 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. This is particularly important for projects involving biospecimens of Indigenous communities, and will require iterative feedback sessions through community workshops, tribal meetings and presentations to communities.[26]

'Analysis and interpretation': Community representatives and leadership remain involved in knowledge exchange dynamics in the process of analysing and interpreting data. The researcher should privilege Indigenous knowledge and views, and identify emergent community benefits of the research. This can be done by directly holding community meetings and workshops that aim to elicit feedback, or by directly inviting community input on data generated by the research.[69] One author had recommended that researchers develop personal responsibility for the long-term implications of the generated data.[57] It might be irresponsible to represent an entire community when only a small number of individuals are impacted by a medical condition. In addition, secondary analysis

Table 3 Characteristics of included studies

Study	Area of research	Indigenous coauthorship	Indigenous population	Country	Framework or guideline	Methodology
Assembly of First Nations Environmental Stewardship Unit[20]	General research	Yes	First Nations	Canada	Ethics in First Nations research	Guidelines
Bailey et al[21]	General research	Unclear	Aboriginal and Torres Strait Islander health workers	Australia	Research capacity building framework	Report
Baird[22]	General research	Unclear	Aboriginal peoples in the HNHB LIHN	Canada	Community engagement	Report
Ball and Janyst[23]	Youth health	Yes	Indigenous people in Canada participating in and/or impacted by research.	Canada	Memorandum of understanding/research ethics	Group reflection
Bandler[24]	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
Bartlett et al[25]	Chronic disease	Yes	Métis and First Nations people with diabetes in Winnipeg, Manitoba (urban)	Canada	Decolonising research	Report
Beaton et al[26]	Genomics	No	Maori	New Zealand	'He Tangata Kei Tua' — a relationship model for biobanks	Literature review and mixed methods
Beaton et al[26]	Genomics	Yes	Maori	New Zealand	He Tangata Kei Tua/engaging communities	Guidelines
Bell et al[27]	Chronic disease	Yes	Maori/New Zealand Indigenous community	New Zealand	CBPR	Report
Bharadwaj[28]	Toxicology	No	First Nations communities in Saskatchewan	Canada	CBPR/OCAP	Literature review
Bingham[29]	General research	Yes	Aboriginal communities in the Fraser region	Canada	Community Driven Primary Health Care Research with Aboriginal People	Report
Brown and Whiteside[30]	Addictions	Unclear	Indigenous Australian and Torres Strait Islander people in far North Queensland	Australia	A process of feedback	Literature review
Brunger[31]	General research	Unclear	Aboriginal communities in Newfoundland and Labrador	Canada	Research ethics/process for review of health research involving Aboriginal communities	Guidelines
Brunger and Wall[32]	General research	Yes	NunatuKavut communities	Canada	Community engagement	Individual reflection
Christopher et al[33]	General research	Yes	Non-specific	USA	CBPR	Guidelines
Cooper et al[34]	Health promotion	No	First Nations and Metis living in Manitoba	Canada	Knowledge translation/implementation	Report

Continued

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Table 3 Continued

Study	Area of research	Indigenous coauthorship	Indigenous population	Country	Framework or guideline	Methodology
Couzos et al[35]	Otorhino	Yes	Indigenous Australians	Australia	Aboriginal Community-Controlled Health Research	Report
Crooks et al[36]	Youth health	Yes	First Nations, Metis and Inuit	Canada	CBPR/culturally sensitive interventions	Group reflection
Duff et al[37]	Chronic disease	Unclear	Aboriginal and Torres Strait Islander	Australia	Consultation strategies	Guidelines
Duffy et al[38]	General research	Yes	Mount Isa Indigenous community in North Queensland	Australia	PAR	Report
Esler[39]	Mental health	Unclear	Indigenous Australians in the Danila Dilba community, Darwin (northern territory)	Australia	PAR	Individual reflection
First Nations Health Council Communications Advisory Committee and Communications Department[18]	General research	Yes	First Nations communities in BC	Canada	Community Engagement Hub Toolkit	Guidelines
Funnell et al[40]	End of life	Yes	Indigenous peoples in Canada	Canada	Research partnerships	Primary study
Glass et al[41]	General research	No	Indigenous communities in North America	Canada	Developing community sensitive research ethics review processes, collective rights	Literature review
Harding et al[42]	General research	Yes	Native American tribal nations	USA	CBPR	Group reflection
Harfield et al[43]	Quality appraisal tool	Unclear	Aboriginal and Torres Strait Islander	Australia	Tool development	Review
Haswell-Elkins et al[14]	Mental health	Yes	Aboriginal Australians in two communities in North Queensland, Hope Vale and Yarrabah	Australia	Priority-driven research	Literature review
Haynes et al[44]	Chronic disease	Yes	Australian Aboriginal	Australia	CBPR	Primary study
Hedges et al[45]	Cancer	Yes	Indigenous Australians	Australia	CONSIDER[76] statement trial	Primary study
Heffernan et al[46]	Chronic disease	Yes	Village of Skidegate, Haida Gwaii	Canada	CBPR	Report
Hyett[11]	Healthcare	Unclear	Indigenous people in Canada participating in and/or impacted by research.	Canada	Not described	Literature review
Jaworsky[47]	Epidemiology	No	Canadian Indigenous population	Canada	CBPR	Reflection
Johnston Research Inc[48]	Healthcare	Unsure	Aboriginal people accessing the Waterloo Wellington LHIN	Canada	Community engagement	Report

Continued

Table 3 Continued

Study	Area of research	Indigenous coauthorship	Indigenous population	Country	Framework or guideline	Methodology
Kassi et al[49]	Nutrition	Yes	Indigenous communities in Yukon territories	Canada	Community engagement	Not reported
Kerr et al[50]	Chronic disease	Unclear	Maori	New Zealand	Kaupapa Maori research	Literature review
Khayyat Kholghi et al[51]	Chronic disease	Yes	Iroquoian and Mohawk	Canada	CBPR with deliberative democratic theory	Group reflection
Liaw et al[52]	Chronic disease	Unclear	Aboriginal Australians and Torres Strait Islanders	Australia	Cultural competence/respect framework	Literature review
Maar et al[53]	General research	Yes	Rural and urban communities in north-eastern and south-western Ontario	Canada	Community engagement	Qualitative research
Mitchell et al[15]	Cancer	Yes	Canadian Aboriginal and Native American women with breast and gynaecological cancer	Canada	PAR and OCAP	Group reflection
Morton Ninomiya et al[16]	FASD	No	Sheshatshiu Innu First Nation, an Indigenous community in Labrador	Canada	CBPR	Group reflection
Morton Ninomiya et al[54]	FASD	Yes	Sheshatshiu Innu First Nation	Canada	Institutional ethnography as a decolonising research methodology	Group reflection
Naqshbandi Hayward et al[55]	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
Oneha et al[56]	Cancer	Yes	Pacific Islander communities	USA	CBPR	Group reflection
Oneha et al[57]	Women's health	Yes	Pacific Islanders. Women from communities from Ewa Beach to Wai'anae	USA	CBPR	Qualitative research
Packer et al[58]	Traditional medicine	Yes	Mbabaram Community, Yirralka Rangers	Australia	PAR	Case study
Peake et al[59]	Chronic disease	Unclear	Aboriginal and Torres Strait Islander	Australia	PAR	Primary study
Priscilla et al[60]	General research	Yes	Aboriginal and Torres Strait Islander peoples	Australia	CBPR	Guidelines
Quigley[61]	Public health	Unclear	Native American and Pacific Islander communities	USA	CBPR	Case studies

Continued

Table 3 Continued

Study	Area of research	Indigenous coauthorship	Indigenous population	Country	Framework or guideline	Methodology
Relationship Building with First Nations and Public Health Research Team[62]	Public Health	Yes	First Nations in Ontario	Canada	Indigenous engagement	Literature review
Ritchie et al[63]	Youth health	Yes	Indigenous communities in Northern Ontario	Canada	CBPR	Group reflection
Singer et al[64]	Mental health	Unclear	Indigenous Australian and Torres Strait Islander peoples	Australia	CBPR	Individual reflection
Spencer[17]	Social work	Yes	Native Hawaiians, Pacific Islander people	USA	CBPR	Individual reflection
Thomas et al[65]	Homelessness	Unclear	Aboriginal and Torres Strait Islander Australians	Australia	Reflective practice 'closing the gap'	Group reflection
Tremblay et al[66]	Chronic disease	No	Mohawk	Canada	CBPR with social movement theory	Qualitative research
University of Calgary[67]	General research	Yes	Indigenous communities	Canada	Cultural protocol engagement	Guidelines
University of Manitoba[68]	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
Voyle and Simmons[69]	Health promotion	Unclear	An urban Maori community in New Zealand, Whaiora Marae	New Zealand	Community development partnership	Literature review
Wahbe et al[70]	Food security	Yes	Musqueam (Coast Salish, Canada) and Totoras (Quichua, Ecuador)	Canada and Ecuador	CBPR	Group reflection
Walker et al[71]	Chronic disease	No	First Nations in Ontario	Canada	Ethical code of contact	Individual reflection
Wilson[72]	Health	Unclear	First Nations	Canada	Circle of engagement	Report
Wright et al[73]	Mental health	Unclear	Torres Strait Islander	Australia	PAR	Primary study
Young and Wabano[74]	Youth health	Yes	Wiikwemkoong Unceded Territory	Canada	Not described	Individual reflection
Zemits et al[75]	Health promotion	Yes	Australian Aboriginal (Yolngu) communities in northeast Arnhem Land	Australia	Actor–network theory (Latour)	Group reflection

AB, Alberta; BC, British Columbia; CBPR, community-based participatory research; CONSIDER, CONSolIDated critERia for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement; FASD, Fetal Alcohol Spectrum Disorder; MB, Manitoba; NL, Newfoundland; OCAP, Ownership, Control, Access and Possession; ON, Ontario; PAR, participatory–action research; QC, Quebec.

Table 4 Community engagement approaches in Indigenous health research

Stage	Topic	Statement
Preparation and learning	Knowledge of Indigenous peoples	► 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	► Learn the history of disempowerment of Indigenous peoples and communities through research. ► Explore the history of Indigenous-driven research, recognising that Indigenous peoples have always conducted research to seek understanding and knowledge.
	Research ethics	► Gain knowledge of the ethical principles developed by Indigenous. organisations 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	► Recognise 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	► 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	► 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	► Engage with the broader community. ► Formalise participation of community members.
Research activities	Research approach	► Use a strength-based research lens when developing research goals and objectives. ► Select research methods congruent with Indigenous knowledge and approaches.
	Budgetary considerations	► Appropriately estimate costs of conducting community-based research. ► Transfer funds to the community to support the research process.
	Ethical research processes	► 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	► Hire community members and support capacity-building and self-determination activities.
	Participant recruitment and data collection	► Use strategies to facilitate participation in research. ► Be efficient in research activities to minimise burden to individuals and the community.
	Evaluating the research process	► 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.

Continued

Stage	Topic	Statement
Analysis and interpretation	Collective interpretation	▶ 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	▶ Seek feedback from community leadership about the results and their implications and provide space for two-way knowledge transfer.
Dissemination and utilisation of results	Community approval	▶ Pursue dissemination of results only if leadership and communities approve, and according to their terms and conditions.
	Communication of results	▶ 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 coauthorship, 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	▶ Ensure accurate presentation of the research process.
	Attribution of benefits of research	▶ Be transparent and share benefits of any commercialisation that came about as a result of Indigenous data.

Table 4 Continued

of data should occur only if explicit permission has been provided by the community on a case-by-case basis.

'Dissemination and utilisation 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. A Canadian study examining diabetes in Indigenous populations deployed a transparent framework, whereby the study would not be published beyond what is required by the funding agency, if any of the community members had rejected the results.[46]

Approach to community engagement and list of recommendations

Two overarching 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 recognise individual preconceptions 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
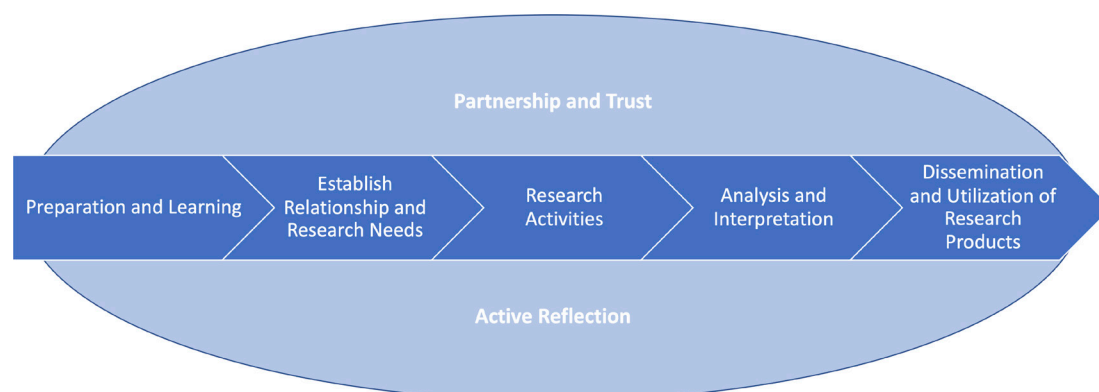

Figure 2 Synthesised model of Indigenous community engagement.

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 synthesise 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 overarching concepts were identified: the critical components of building partnership and trust, and pursing active reflection of one's interactions and approaches with community. Through the recommendations suggested in this work, we endeavour to provide direction to researchers in decolonising 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.[42] In addition to understanding the historical context, it is equally important to understand that the current health inequities are rooted in colonialism,[16] 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.[32] Nevertheless, it is important to recognise that it is the researcher's responsibility to invest significant amounts of time and energy in ongoing relationship building.[28] It is worth investing in relationships as these will enable meaningful dialogues that will help define what is important within the community's self-determined health agenda.[36] Only after determining community needs should the plan for research be considered and developed. In addition, formalising terms of reference or memorandums of understanding between researchers and community are fundamental to ensure the researcher commitment to the community's benefit.[33]

Details of the research plan need to reflect community strengths,[28] and must be realistic, feasible and transparent, especially relating to the costs[35] and timelines of the project.[32] 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.[53] Moreover, throughout the research process it is important to iteratively obtain feedback from communities, relating to data collection processes and research progress.[27]

Any collected data should belong to the communities which they are derived from,[20] and any intellectual property rights generated from the research need to reflect this.[39] 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.[60]

The dissemination and utilisation 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 honour requests for correcting misinterpretations.[61] Shared authorship with communities is one step in ensuring that research results are interpreted at least in part with communities.[61] Benefits of the research must be transparent, and shared with communities, especially relating to any commercialisation that results.[26]

The recommendations produced in this work represent one approach to engage Indigenous communities in research, and put 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 honouring 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 'decolonising methodologies' predominate, and power paradigms shift back to communities that experience the impact of the research.

Funding agencies also have a role in upholding and enacting these recommendations at all stages of the grant cycle. Initial awarding of funds should be on demonstration of appropriate Indigenous community engagement, as vetted by Indigenous researchers and community representatives. This is already in progress at the Canadian Institutes of Health Research, which has increasingly engaged Indigenous elders and community members in peer-review committees. We encourage funding agencies to also consider policies and activities that can ensure ongoing appropriate engagement throughout

the research process, a mechanism by which Indigenous community representatives and research participants can provide feedback on research engagement practices, and also confirming upholding of the recommendations through end-of-grant reporting requirements. These steps may be seen to be onerous or complex, dissuading Indigenous health research topics, but would be easy to demonstrate if true engagement and reflexivity was occurring.

One limitation of our study is that the methodology of qualitative synthesis may inevitably miss some of the recommendations currently in the literature. Search terms used in our strategy may have excluded key articles. Further, authors may not have detailed their community engagement approaches in their manuscript, as this is not mandated historically by journal editors and publishers. The new CONSIDER statement[76] for Indigenous health research provides an advance by structuring reporting requirements in manuscripts, yet still does not address fully the longitudinal commitment required when engaging with an Indigenous community. Researchers who abided by Indigenous health research ethics and who did not proceed with publishing their work as requested by community would result in their approaches not being included in our review. Despite this, we believe that our review is comprehensive, and is also informed by our experience within our own research programmes. 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 synthesise 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.

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