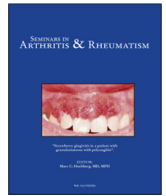




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Characterization of indigenous community engagement in arthritis studies conducted in Canada, United States of America, Australia and New Zealand

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ABSTRACT

Background: Research adhering to community engagement processes leads to improved outcomes. The level of Indigenous communities' engagement in rheumatology research is unknown.

Objective: To characterize the frequency and level of community engagement reporting in arthritis studies conducted in Australia (AUS), Canada (CAN), New Zealand (NZ) and the United States of America (USA).

Methods: Studies identified through systematic reviews on topics of arthritis epidemiology, disease phenotypes and outcomes, health service utilization and mortality in Indigenous populations of AUS, CAN, NZ and USA, were evaluated for their descriptions of community engagement. The level of community engagement during inception, data collection and results interpretation/dissemination stages of research was evaluated using a custom-made instrument, which ranked studies along the community engagement spectrum (i.e. inform–consult–involve–collaborate–empower). Meaningful community engagement was defined as involving, collaborating or empowering communities. Descriptive analyses for community engagement were performed and secondary non-parametric inferential analyses were conducted to evaluate the possible associations between year of publication, origin of the research idea, publication type and region of study; and meaningful community engagement.

Results: Only 34% ($n=69$) of the 205 studies identified reported community engagement at ≥ 1 stage of research. Nearly all studies that engaged communities (99% ($n=68$)) did so during data collection, while only 10% ($n=7$) did so at the inception of research and 16% ($n=11$) described community engagement at the results' interpretation/dissemination stage. Most studies provided community engagement descriptions that were assessed to be at the lower end of the spectrum. At the inception of research stage, 3 studies reported consulting communities, while 42 studies reported community consultation at data collection stage and 4 studies reported informing or consulting communities at the interpretation/dissemination of results stage. Only 4 studies described meaningful community engagement through all stages of the research. Inferential statistics identified that studies with research ideas that originated from the Indigenous communities involved were significantly more associated with achieving meaningful community engagement.

Conclusions: The reporting of Indigenous community engagement in published arthritis studies is limited in frequency and is most frequently described at the lower end of the community engagement spectrum. Processes that support meaningful community engagement are to be promoted.

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Introduction

The “Indigenous health gap” is a common conclusion of studies that draw comparisons between the health status of Indigenous

and non-Indigenous populations [1–3]. In rheumatology, this gap has been described in the domains of epidemiology [4], disease phenotypes and outcomes [5], including mortality [6] and health service utilization [7]. Description of the “Indigenous health gap” without moving towards solutions to resolve it can further stigmatize populations and reinforce deficit models. Community engagement practices in research could help to avoid this stigma,

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as these practices are demonstrated to yield sustainable solutions based on the strengths of communities, as has been seen in health promotion research engaging Canadian Indigenous youths [8], as well as cancer awareness research engaging Native Hawaiians [9].

Community engagement, as an approach to conducting research, stems from a need for meaningful ways to construct a relationship between researchers and communities, with the goal of addressing and understanding the priorities of the community [10]. Several guiding documents for research with Indigenous communities have been created in Canada (e.g. Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans [11], Ownership, Control, Access, and Possession (OCAP®) [12,13], which invoke community engagement in the conduct of research. This has been further reinforced through the requirement of active engagement of Indigenous members in research teams to access health research funding streams [14]. Not all community engagement practices are equally meaningful to the community. According to the Edinburgh Beltane - Beacon for Public Engagement [15], a spectrum for engaging communities exist and includes: informing, consulting, involving, collaborating with, and empowering communities of interest.

With that in mind, our primary objective was to characterize the stage and level of community engagement in arthritis research with respect to the Indigenous peoples of Australia (AUS), Canada (CAN), New Zealand (NZ) and the United States of America (USA). With a common history of colonialism [16], Indigenous peoples' mistreatment in research [17] and inequities in health status [16], research in these countries is susceptible to low levels of community engagement patterns with respect to their respective Indigenous populations. Our secondary objective was to examine characteristics of studies

assessed to have meaningful community engagement to identify actionable predictors to inform future studies involving Indigenous communities.

Methods

This is a secondary analysis of a previously conducted and published systematic review. Our group previously conducted the review to describe outcomes of arthritis epidemiology including estimates of incidence or prevalence [4]; disease phenotypes and outcomes including disease characteristics and activity measures [5]; mortality estimates [6]; and reports on health service utilization including hospitalization and medication use [7] in Indigenous populations of AUS, CAN, NZ, and USA. Detailed descriptions of literature identification, selection and inclusion criteria are described elsewhere [4–7]. Briefly, keywords and Medical Subject Headings for the terms 'arthritis' and 'indigenous populations' from the four countries of interest were selected with the assistance of a medical librarian (Appendix A). Medical literature databases searched included Medline (1946–June 2015), EMBASE (1980–June 2015) and CINAHL (1996–June 2015). Searches of these databases was updated in September 2018. Indigenous specific online indexes and organization websites searched (until June 2015) were the Circumpolar Health Database, Health Info Net, Metis Health Database, Native Health Database, Native Indigenous Studies Portal and The First Nations Periodical Index. In addition, a literature search within each country's government websites was performed to identify relevant publications. References of relevant identified studies were reviewed for additional

Table 1
Assessment toolkit for indigenous community engagement.^a

		Stage of research		
		Inception of research	Data collection	Results interpretation and dissemination
Spectrum of engagement	<i>Inform</i>	Community was provided with information about the research idea (e.g. dialogue with leadership, participants) [15].	Researchers notified the community about the research plan and the data collection process [15,19].	Researchers shared interpretation of data/ results with the community [15,21].
	<i>Consult</i>	Researchers consulted the community to better understand the culture and needs (i.e. to refine or generate the research idea) [15,22].	Acceptance of research plan through completion of consent forms or another method to endorse the project [1,2], or a process for the community to report and address concerns about the data collection process [15,18].	Feedback was obtained from the community with regards to the interpretation and dissemination of the results [15].
	<i>Involve</i>	Workshops, town halls, community meeting, dialogues, debates, or other methods were employed to obtain community input to ensure that the research would be beneficial to the community [10,15].	The community provided input during the definition of the research plan and data collection [15,19], or community members were directly involved in collecting data.	The community provided input which was incorporated into the interpretation and the dissemination of results [15,19].
	<i>Collaborate</i>	Power and responsibility for finalizing the research ideas is shared between community and the researchers [10,15], and solidified through research agreements or memorandum of understanding, ceremony, or group meeting.	Power and responsibility for finalizing the research plan, including data collection, was shared between community and the researchers [10,15].	Power and responsibility for interpreting and disseminating data was shared between community and the researchers [10,15].
	<i>Empower</i>	Only community members constituted the decision-making body for the research idea [15].	Only community members constituted the decision-making body for the research plan, including data collection [15].	Only community members constituted the decision-making body for the interpretation and dissemination of the results [15].

^a Community Engagement Spectrum adapted from Faulkner and Beltane [15], with ethical goals identified through a literature review conducted by MacQueen et al. [20].

primary references. No language or publication date restrictions were imposed during the electronic search.

Data collection process and data items

For the purposes of this review, we developed an Assessment Toolkit for Indigenous Community Engagement (ATICE) (Table 1). The design of this toolkit was informed by an established model for public engagement developed by the Beacon for Public Engagement in the UK which considers community engagement as a spectrum, from *Informing, Consulting, Involving, Collaborating* to *Empowering* communities [15]. In addition, community engagement criteria [10,15,18–22] specific to each stage of research were included in the ATICE, as adapted from a literature review on the ethical goals of community engagement [20]. Consequently, the ATICE tool reflects an evaluation of the extent of decision-making power transfer from researchers to Indigenous communities, as well as the relevance of the research conducted for the communities of interest, within an ethical research framework. [23]

Using the ATICE toolkit, we evaluated community engagement descriptions in studies across the various stages of research: inception of research, data collection, and the interpretation and dissemination of data. The described methodologies at each stage of the research for each included study were assessed and located within the community engagement spectrum contained in the ATICE. In addition, some study characteristics, which were defined *a priori* as potentially related to the existence of meaningful community engagement, were extracted separately from the assessments for community engagement. These characteristics included: a) year of publication, b) origin of the research idea (i.e. idea generated from community vs. idea generated from literature gaps), c) publication type (i.e. full publication vs. abstract) and d) region of study (i.e. North America vs. Oceania).

Ahmed and Palermo reported that the sharing of power and responsibility with communities is one of the ethical goals of community engagement [10]. Consequently, we attributed “meaningful” community engagement to the studies reviewed if the community engagement was clearly assessed to be at *Involving, Collaborating* or *Empowering* levels. This judgment for “meaningful” community engagement was further characterized at each of the three main research stages.

Data extraction was conducted in duplicate and independently by two reviewers (CL and ALS) using Google Forms (Google, California US). The results of data extraction were discussed by the two reviewers, who reached consensus without the need to involve a third party.

Analyses

Descriptive analyses were conducted to characterize the extent of community engagement reported in each included study, as well as the frequency of studies that reported meaningful community engagement at each stage of research. Contingency tables were constructed and chi-squared tests were applied, where applicable, to identify studies’ characteristics that were likely related to the determination of meaningful community engagement. The year of publication was used to create a dichotomized category for the period of publication (i.e. prior to 1980, or 1980 and after), based on the date of the first revision of the Helsinki Declaration in 1975 [23]. This revision clarified that research should be submitted to independent research review boards and be “diagnostic or therapeutic” in nature. Consequently, the period of publication might have an influence on the practice of community engagement. *P* values lesser than 0.05 were considered as significant. Statistical software (STATA 12.1, StataCorp, Texas USA) was used to estimate descriptive and inferential statistics.

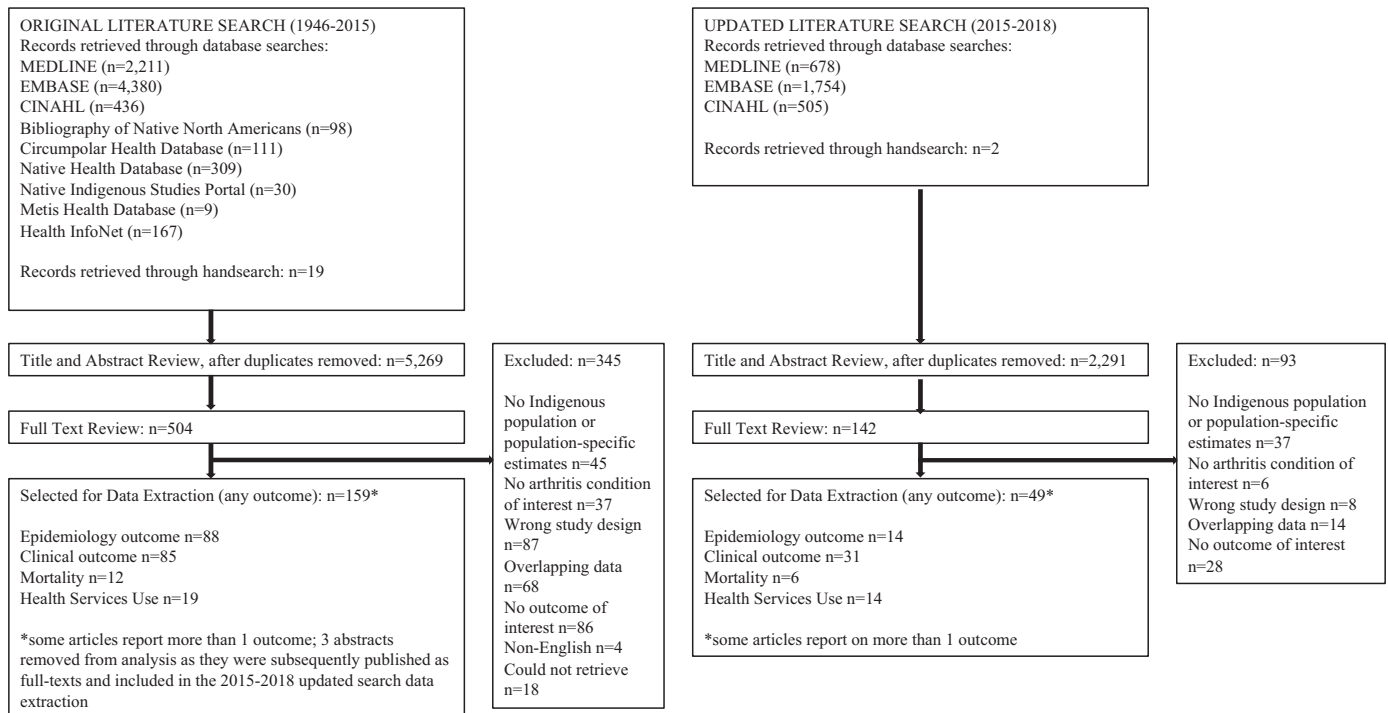


Fig. 1. Article identification and selection.

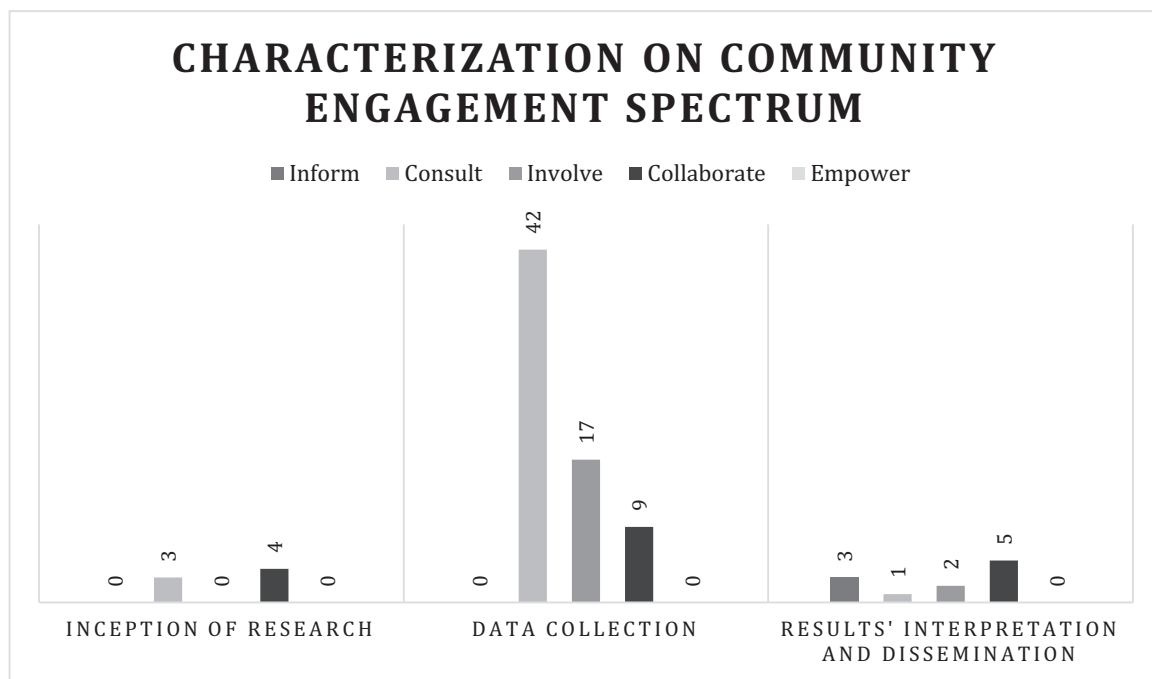


Fig. 2. Type of community engagement described in the manuscripts that reported community engagement ($n = 69$).

Results

In total, 205 studies were included (Fig. 1). These studies primarily reported the epidemiologic, phenotypic, and health services utilization aspects of arthritis in Indigenous populations [24–228]. Twenty-two studies (11%) were published prior to 1980. Seventy-nine percent of the studies were conducted in North America (see Appendix B).

Only 34% (69/205) of the included studies reported some level of community engagement at ≥ 1 stage of the research, with 5% (11/205) of studies reporting this at > 1 stage of research. Sixty-two of the 69 (90%) studies which described community engagement were published on or after 1980. Fewer studies reported community engagement at inception of research ($n = 7$) and results interpretation/dissemination ($n = 11$) stages in comparison to the data collection stage ($n = 68$).

At the inception of research stage, three studies reported below *Involvement*, while four studies reported at or above *Involvement* level. Specifically, three studies reported community engagement at the *Consultation* level, and four reported community engagement at the *Collaboration* level (Fig. 2). At the data collection stage, 42 studies reported below *Involvement*, while 26 studies reported at or above *Involvement* level. Specifically, 42 studies reported community engagement at the *Consultation* level, 17 studies reported at *Involvement* level, and 9 studies reported at *Collaboration* level. (Fig. 2). At the results interpretation/dissemination stage, 4 studies reported community engagement below the *Involve* level, whereas 7 studies reported at or above this above that level (Fig. 2). Specifically, 3 studies reported *Informing* communities, 1 study reported *Consultation*, 2 studies reported *Involve*ment and 5 studies reported community *Collaboration*.

Meaningful community engagement (i.e. community engagement greater than the *Consultation* level at any stage, excluding recruiting community members for data collection) was observed in a small

proportion of studies across the various stages of the research. Specifically, four studies reported meaningful community engagement during the inception stage of research (2%). Sixteen studies reported meaningful community engagement during the data collection stage (8%). Finally, 7 studies reported meaningful community engagement during the results' interpretation and dissemination stage (3%).

The origin of the research idea was significantly associated with an assessment of meaningful community engagement. At the data collection stage, 4 of the 10 studies that reported the research idea had been generated from the community were assessed as having meaningful community engagement, while only 12 of the 195 studies which reported that research ideas were originated from the literature were assessed to have meaningful community engagement. Similarly, at the results interpretation/dissemination stage, 4 of the 10 studies with the research ideas originating from the community were assessed to have meaningful community engagement compared to just 3 of the 195 studies where the research idea originated from the literature. These differences were statistically significant with p values < 0.001 .

Only North American studies were assessed to have meaningful community engagement at the inception of research and results interpretation/dissemination stages, with no studies conducted in Oceania determined to meet the meaningful community engagement definition. Similarly, at the data collection stage, 13 of 161 North American studies were assessed to have meaningful community engagement compared to just 3 of the 44 studies conducted in Oceania. Only full-text studies described meaningful community engagement. Finally, all studies with meaningful community engagement at any stage were published on or after 1980. Nevertheless, statistical tests to confirm the significance of all these differences were not significant.

There were only four studies that were assessed to have meaningful community engagement at the three main stages of research. These four studies either had Indigenous co-authorship or had a

formal academic-Indigenous research partnership. In addition, they were either community-driven or community-based research initiatives [135,186,229,230]. Furthermore, these 4 studies were all North American in origin and were published after 1980.

Discussion

Our study has quantified and qualified the reporting of community engagement in rheumatology studies conducted with Indigenous peoples, identifying significant gaps in the reporting and conduct of ideal processes. Only 34% ($n=69$) of the identified studies from our search reported community engagement at some research stage, mostly at the data collection stage, which could reflect the process of having obtained individual informed consent for the research, and not a more significant community engaged process. Fewer than 5% of studies reported community engagement at the inception of research ($n=7$), and results' interpretation/dissemination stages ($n=11$), respectively. Only 4 studies were deemed to have "meaningful" community engagement, or *Involvement*, *Collaboration* or *Empowerment* of Indigenous communities, in all three stages of the research process. More meaningful community engagement research practices were described when the research idea was clearly originating from communities involved. Effects of location of research (North America compared to Oceania) and time also impacted this determination. Our findings of low levels of community engagement reporting are similar to a previous literature review recently conducted in the Circumpolar North [231], which indicates that only 19% of studies have included discussions on Indigenous community engagement.

Research that does not engage Indigenous communities is at increased risk of misrepresenting community values, and this has occurred historically and repeatedly with Indigenous health research [12]. Considering that arthritis is one of the most common chronic illnesses that Indigenous populations face [232] and that community engaged research has been linked to positive outcomes in health [233], there is a clear need for guidelines and promotion of community engagement when conducting arthritis research in Indigenous communities that aim to identify and resolve care gaps.

Historically, patient engagement in research is poor. In Canadian arthritis research however, patient engagement for non-Indigenous populations has a strong track record. Patient-driven research is supported through a national funding stream of the Canadian Institutes of Health Research [234] and promoted by dedicated organizations such as the Arthritis Patient Advisory Board of Arthritis Research Canada [235] and the Canadian Arthritis Patients Association (CAPA). In the US, similar organizations exist, such as the Patient-Centered Outcomes Research Institute (PCORI). Similarly, there is an ongoing strategy for national patient engagement in health research in Australia (e.g. Sydney Health Partners) [236]. Yet, none of these strategies are specifically crafted for Indigenous populations. Given the historical legacy of research that is inconsistent with Indigenous community values, and the prevalence of deficit-based research hypotheses, engagement of Indigenous communities in arthritis research remain a distinct area of need.

The enactment of Indigenous-specific research guidelines and principles reflect a shift in research that stems from academia to one that reflects community values, a core aspect of community engagement in research. Additionally, methods of community engagement in research are gaining the spotlight as a means of best-practice and as a way to address Indigenous health disparities. A recent review of cancer control studies demonstrates that when Indigenous members assume genuine roles in guiding research, they tend to have successful outcomes [237]. Models for community engagement have been proposed, such as the community-based participatory research

strategy [238], the participatory action research [239] or the participatory rapid appraisals [240]. Although these models vary in their specific strategy for engaging communities, they share a common understanding of the need to improve current approaches to health research involving vulnerable and/or disadvantaged populations.

The fact that the majority of studies reporting community engagement described engaging people at the *Consultation* level during data collection is an indication that a gap in meaningful community engagement exists within arthritis research. Consultation is defined as obtaining feedback from communities, but does not accompany a promise to incorporate the feedback into decision-making [15]. One metric for reaching consultation at data collection is evidence for gathering informed consent. As a result, many of the included studies were identified to have some level of community engagement simply because they included an individual informed-consent process. Informed consent, despite satisfying ethical requirements for the protection of individuals from harm by doing research [241], fails to recognize community-based values in light of their social and historical context [242], and represents Western notions of private ownership rather than collective values of consensus, which are essential for many Indigenous communities worldwide [243].

This lack of meaningful community engagement in health research has been documented in non-Indigenous populations as well. For example, in the United States the Patient Centered Research Institute (PCORI) was created in 2010 to support research that engages patients in the definition and aims of health research endeavors [244]. Furthermore, PCORI promoted the formation of Patient Powered Research Networks (PPRN) in Rheumatology, which are changing the trajectory of governance and research in the US, including more patient involvement [245]. Nevertheless, this strategy does not clearly identify Indigenous communities, as unique populations with specific engagement needs.

The majority of studies that reported community engagement in at least one stage of the research were published on or after 1980. This observation may be attributable to the improvements in the rigor of research ethical guidelines throughout the 20th century. Research guidelines have gradually improved in scope, with particular focus on participant safety and research intent, as demonstrated in the transition from the Nuremberg Code in 1947 [246] to the National Statement on Ethical Conduct in Research Involving Humans in 1999 [247]. These early guidelines focused on the protection of participants, but more recent guidelines, such as the Canadian Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans, reflect community engagement principles [248].

Community engagement during the inception of research and data usage (i.e. interpretation and dissemination of results) is rare. This indicates that communities are rarely involved in the definition of arthritis research questions and objectives or the dissemination of arthritis research findings in Indigenous communities. Conducting community engagement at the inception of research helps to ensure the relevance of the research to the community of interest, rather than imposing researchers or the healthcare systems' interests in the definition of a research proposal. Further, the incorporation of Indigenous insight and lived-experiences enrich research beyond the limitations of Western knowledge systems. The institution of oral histories and Indigenous ways of knowing, as an aggregation of knowledge from multiple generations, can contribute to research by making it more meaningful and holistic [249]. Consequently, community engaged arthritis research with Indigenous communities should be promoted.

The need for research that involves communities in decision-making from inception is clear. Our results suggest that power differentials between researchers and communities continue to exist, leaving Indigenous communities with little to no negotiating

power concerning decisions that impact their health and wellbeing. Partnering with and engaging Indigenous communities to define the research plan is a way to address power inequities, as it is exemplified in the results of this review, where meaningful community engagement was significantly associated with the research idea coming from the communities in which research was conducted.

Systemic changes in arthritis research are necessary to increase the feasibility of community engagement, particularly with respect to short research funding timelines that limit researchers' extent of commitment to relationship building with communities. Recently, Canadian government agencies have stressed the importance to engage communities to do research, through capacity-building strategies [250]. We recommend that research funding agencies consider community engagement during the definition of the research problem and questions as an essential point to increase capacity in community-based research.

Interestingly, in this review there was little evidence for the application of the OCAP™ principles across the included studies, which is reflected in the small number of studies that reported meaningful community engagement at the results interpretation/dissemination stage. The Institute of Indigenous Peoples' Health, which is part of the Canadian Institutes for Health Research, stresses the importance of conducting appropriate knowledge translation strategies in Indigenous communities as a way to create positive change [251]. Creating social positive change should be the goal of any health research with Indigenous populations and one essential step to do this is to respect the well-defined OCAP™ principles as not doing so puts communities at risk for the mismanagement and misuse of data [13].

Community engagement reporting appears to be more frequent in the North American arthritis literature. This may be attributable to the differences in research funding policies across the continents (North America vs. Oceania), as well as legal and legislative framework differences with respect to government-Indigenous community relations. For example, whereas Canadian government-Indigenous relations are rooted in historic treaties that are recognized by the Constitution Act of 1982 [252], Australian government-Indigenous engagement processes are not rooted in comprehensive frameworks or treaties [253]. For clarity on issues regarding these differences, we call for a comprehensive review of government-Indigenous relations across the four countries included in our systematic review.

One main limitation of this review is its exclusive focus on the assessment of published studies, rather than study protocols or survey of authors. We based our judgments about the existence and appropriateness of community engagement solely on what has been reported and included in the published literature. Our extraction criteria required clear descriptions of community engagement in order for inclusion during data extraction. It is possible that community engagement practices could have been different than what was reported in the manuscripts. For example, it may be possible for studies to include Indigenous co-authors without specifically mentioning their affiliation/association with the Indigenous communities involved. In some cases, tribal approval was obtained and mentioned in the published manuscript, but the details of such approval were not specified in the manuscript. As a result, we interpreted tribal approval under the data collection stage only. Should this be the case, we call for improved reporting of community engagement within the arthritis literature, for there exists a need for consensus and elucidation of clearer Indigenous community engagement guidelines specific to arthritis research. Currently, journals do not request authors to state their community engagement practices in their submitted manuscripts.

Another limitation of this review is that since this a secondary analysis of an original systematic review, some of the included studies were not Indigenous-specific, but instead had population-wide parameters. This can inflate the proportion of studies that were deemed to not have engaged communities. However, we think community engagement should still be required whenever Indigenous data is utilized, as to prevent its misuse. Because so few studies reported community engagement, we were unable to assess temporal patterns. Lastly, studies were included based on publication, and it is likely that some large-scale studies produced multiple publications, which could over-represent studies that do not report community engagement.

Conclusions

This review highlights that the reporting of community engagement in Indigenous arthritis studies in AUS, CAN, NZ and USA is limited and heavily skewed towards the lower end of the spectrum (i.e. informing and consulting individuals and the community). Community engagement was most frequently reported during the data collection stage at the community consultation level, which can be reached by merely obtaining individual informed consent. This reflects researchers' adherence to ethical guidelines rather than authentic efforts to meaningfully engage Indigenous communities in the research process. Processes to involve community representatives in the identification of the research problem and the definition of the research question, while adhering to principles of community-based and community-driven research throughout the research activities are to be promoted.

Declarations

Ethics approval and consent to participate- not applicable

Consent for publication- not applicable

Availability of data and material- the datasets used during the current study are available from the corresponding author on reasonable request.

Competing interests- the authors declare that they have no competing interests.

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Authors' contributions- CYL and ALS participated in the conception & design of the review, the analysis and interpretation of data and the drafting and revising of the manuscript. KH and CB participated in the acquisition, analysis and interpretation of data as well as in the drafting and revising of the manuscript. LC and BH participated in the analysis and interpretation of data as well as in the drafting and revising of the manuscript.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.semarthrit.2018.11.009](https://doi.org/10.1016/j.semarthrit.2018.11.009).

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