

# BMJ Open Integrative review protocol for Indigenous youth participation in health equity promotion

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## ABSTRACT

**Introduction** Indigenous youth participation in decision-making is internationally recognised as a pathway to promote health equity, decolonisation and social inclusion. Hearing Indigenous youth voices and actively involving them in decisions that affect their lives and their communities has the potential to address disproportionate health and social challenges they encounter. Yet the existing evidence-base on participatory approaches remains fragmented and vast leading to a lack of integration.

**Methods and analysis** An integrative review methodology will be used to conduct a comprehensive, multidisciplinary review of the literature about Indigenous youth participation in health equity promotion. The literature search is anticipated to be carried out in July–August 2022. We will search online databases Scopus, Ovid MEDLINE, Embase and PsycINFO along with several interdisciplinary databases indexed in EBSCOhost and ProQuest. Key Indigenous research journals not consistently indexed in the online databases will be examined to identify additional journal articles. We will employ a blinded, dual-reviewer two-step selection process with established inclusion/exclusion criteria and limit data to English-language publications related to Indigenous populations in Canada, USA, Aotearoa New Zealand and Australia. Focusing on qualitative empirical and theoretical studies, they will undergo quality appraisal and Covidence software will be used to manage the review. Data will be sorted, extracted and analysed. We will codify data for descriptive reporting and conduct a narrative synthesis to identify a common conceptualisation for Indigenous youth participatory approaches across disciplines, its barriers and facilitators, and knowledge gaps.

**Ethics and dissemination** Ethical review is not required for the integrative review. The review will be shared through various publication and non-academic platforms as well as our university and community research networks. Findings will have broad relevance for those seeking to involve Indigenous youth to be active decision-makers across a range of fields, but with specific implications for health equity.

## INTRODUCTION

In the last two decades, health and social policy has paid increasing attention to

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first review of any kind to synthesise literatures on Indigenous youth participatory approaches with implications for health equity promotion.
- ⇒ An integrative review has the potential to capture the extensive, multidisciplinary, and cross-cultural conceptual and operational definitions of Indigenous youth participatory approaches.
- ⇒ A blinded dual-reviewer process will be used to search, select and extract data sources to limit potential selection bias and ensure review comprehensiveness.
- ⇒ The inclusion of a select number of Indigenous populations through English-language publications may under-represent unique conceptual aspects of Indigenous youth participation globally.
- ⇒ The review will exclude popular and social media sources where young people typically self-author and report on their own participatory work.

consulting youth (We define youth as those aged 15–29 years old for the purposes of this review to ensure we capture the breadth of evidence pertaining to young people and distinguish them from children. Youthhood is often defined using chronological age and based on the United Nations Convention on the Rights of the Child, it refers to young people up to the age of 18 years old. Considering the cultural bias inherent in universal human rights approaches, age is both biologically and socially constructed based on cultural, developmental and geographical specificities. Given our experience working within Indigenous contexts, youthhood has typically included older youth (or young adults) that self-identify in this way and are accepted within initiatives targeting young people.) and including them in decision-making processes.<sup>1–4</sup> Based on rationales underpinned by children's rights, citizenship and intergenerational equity, as well as instrumental motivations of involvement reasoned to lead to improved outcomes, youth are increasingly understood to have the capacities

to inform the development of health interventions and influence the distribution of the social determinants of health.<sup>5–8</sup>

Among Indigenous peoples in colonised states (eg, Canada, USA, Aotearoa New Zealand, Australia), urgent calls have been mobilised internationally through the United Nations Permanent Forum on Indigenous Issues and Global Indigenous Youth Caucus to foster Indigenous youth participation on issues and decisions affecting their lives.<sup>9</sup> Young people have intimately encountered the historical and contemporary effects of colonisation, racism and marginalisation frequently leading to poorer health and social outcomes.<sup>9–11</sup> Examining youth participation follows broader contemporary social justice movements among Indigenous and racialised communities such as the *Idle No More*,<sup>12</sup> *Land Back*<sup>13</sup> and *Black Lives Matter*<sup>14</sup> movements in North America, which have captivated and mobilised many Indigenous and racialised peoples in countries globally. These diverse movements have also begun to operate and intensify within the shared global context of the COVID-19 pandemic.

Deliberations on Indigenous health equity in colonised state contexts tend to not only focus on ameliorating unfair and avoidable health disparities, but ensure communities affected by poorer health and social well-being are democratically represented in the identification, definition, governance, implementation, delivery and evaluation of solutions.<sup>15–19</sup> These considerations on health equity have occurred within and alongside broader decolonising interventions to uphold Indigenous and land rights, revitalise Indigenous institutions and cultural lifeways and promote planetary health.<sup>15 20–22</sup> Although such aspirations globally resonate with Indigenous peoples across various regions and jurisdictions experiencing settler colonisation, pathways to achieving health equity vary depending on local cultures, histories and geographies.<sup>23</sup> As many Indigenous peoples worldwide have younger populations compared with their non-Indigenous counterparts,<sup>24</sup> the impetus to include Indigenous youth is both a matter of democratic representation and responsibility as well as centred within conversations on decolonisation, cultural continuity and supporting younger generations to promote and sustain healthy Indigenous futures.<sup>25–29</sup>

Despite various efforts to conceptualise and operationalise Indigenous youth participation in health equity promotion,<sup>6</sup> there remains important questions on how to articulate participation that extends across disciplinary, cultural and geographical boundaries. No comprehensive review exists to unify conceptual definitions of Indigenous youth participation in the broader domain of health equity and detail pathways toward inclusion, decolonisation and improving health outcomes. Accordingly, this integrative review (IR) protocol aims to share an approach to integrate and synthesise diverse theoretical and empirical literatures on Indigenous youth participation. It advances shared conceptualisations and best practices focused on health equity promotion.

## Indigenous youth participation

Youth participation generally refers to a process of young people partaking directly (eg, youth councils) and indirectly (eg, youth consultations) in decision-making processes.<sup>30</sup> Recognising youth as agents of social and political action became largely acceptable through the ratification of the United Nations Convention on the Rights of the Child (1990) and popularised by Roger Hart's 'Ladder of Children's Participation'—a heuristic model to elucidate different levels of participation as children and youth share power and influence with adults.<sup>31 32</sup> This youth involvement approach to participation has been distinguished from the more popular youth development approach.<sup>33</sup> Here youth are viewed as able to contribute to decision-making processes related to systems change, political action, community development and programme design that can facilitate their ability to affect positive change in their own lives as well as their communities.<sup>34 35</sup>

Developmental perspectives, however, have ordinarily conceptualised youth participation as individualised activities outside the public sphere and limited the study of participation to pathophysiological and psychosocial outcomes without considerations on young people's agency to transform broader socioecological contexts.<sup>36</sup> Youth are typically conceptualised as sick, deviant and apathetic recipients of adult intervention.<sup>2 37–39</sup> Indeed, developmental theory has produced discourses of 'at-risk youth' that can mire youth participation through notions of paternalism and state intervention.<sup>40</sup> Even in instances where youth participation in decision-making is considered, participation may seek to facilitate the development of youth into well-adjusted adults through various forms of social control.<sup>41 42</sup> This depoliticised, deficit and adultist approach problematically positions youth as 'incomplete' adults transitioning toward a normative expectation of desired adulthood, and assumes that adulthood is an endpoint where development concludes, and civic participation and citizenship thus become possible and permissible.<sup>37 43</sup> In the daily lives of Indigenous youth, these problematic Western approaches to 'participation' have negatively shaped Indigenous youthhood in particular and justified their continued marginalisation and disempowerment.<sup>29 44–46</sup> Although having held responsibilities and playing an active leadership role in community and family governance, the roles of Indigenous youth have shifted over time and in many ways are negatively impacted by colonisation that introduced external forms of democracy.<sup>28 47 48</sup>

As some recent applications of developmental approaches within Indigenous health should be commended for their attention to strengths, agency, wellness and community/cultural context, they remain limited in their conceptualisation of participation as a means to prevent illness and promote health.<sup>49–52</sup> In many ways, health literatures can be skewed towards a *youth development* focus as opposed to an explicitly *youth involvement* one. As various disciplines such as education,

youth studies, human geography and environmental studies have approached empirical questions of Indigenous youth participation, health researchers are only recently taking these questions more seriously.

There is an ever-expanding base of individual health studies reporting on the challenges and benefits of Indigenous youth participatory approaches, especially the use of Youth Participatory Action Research (YPAR). Current literature only includes one published systematic review on health promotion delivery,<sup>53</sup> one published scoping review protocol on programme design and evaluation,<sup>54</sup> and one unpublished scoping review on YPAR.<sup>55</sup> While important, such studies generally report on participatory approaches within structured interventionist contexts compared with the plethora of natural settings in which youth can participate. Few researchers have differentiated Indigenous youth populations, local geographies and cultural backgrounds in broader reviews of the literature about participatory approaches. Moreover, such reviews have not focused on the implications of such research as it relates to health equity and wellness.<sup>33 56</sup>

Youth participation literatures are also often characterised by several terms to describe participation, including, but not limited to: ‘youth engagement,’ ‘youth involvement,’ ‘youth voice,’ ‘youth leadership,’ ‘youth civic engagement,’ ‘youth empowerment’ and ‘youth citizenship.’ These terms tend to conceptually flatten the multiplicity of different youth participatory approaches.<sup>6</sup> In a recent international-based IR of youth participatory approaches promoting health equity, for example, Ozer and colleagues<sup>6</sup> address this conceptual issue by outlining a typology of six participatory approaches, including: (1) youth-led participatory action research; (2) youth organising; (3) youth-led planning; (4) human-centred design; (5) participatory arts; and (6) youth advisory boards and councils. They also observed that literatures on youth participation generally focus on high-income countries, older youth, urban areas and youth from more privileged backgrounds. Reviewing these literatures pose significant challenges apart from categorising its breadth, such as discerning multidisciplinary perspectives,<sup>57</sup> interpreting cross-cultural (non-Western) conceptualisations of youthhood and participation,<sup>58</sup> identifying undocumented and ill-defined participatory outcomes<sup>34</sup> and teasing out polarising theoretical frameworks of participation that range from conservatively managerial and dutiful to the other extreme of being described as overtly political and creative.<sup>35</sup>

Given the fragmented and extensive literature-base on Indigenous youth participation, this IR will synthesise research and explore approaches supportive of Indigenous youth voices, leadership, participation and agency with the goal of more equitable health for youth by youth. The IR will focus on three primary objectives to guide and inform our research questions, search strategy, analysis and reporting, including: (1) to explore how Indigenous youth participation has been conceptualised and to what extent a common

### Box 1 Integrative review questions

- ⇒ What disciplines and subject areas have investigated Indigenous youth participation in decision-making?
- ⇒ How are concepts of youth participation, decision-making and health equity conceptualised within these literatures and what are their theoretical or empirical underpinnings?
- ⇒ What motivations and contexts encourage Indigenous youth to participate in decision-making?
- ⇒ Where and when does Indigenous youth participation in decision-making take place?
- ⇒ What modes of participation and participatory outcomes are measured for Indigenous youth participation in decisions?
- ⇒ How do various structural or sociocultural barriers, facilitators and characteristics operate during Indigenous youth participation in decision-making?

conceptualisation can be conceived for addressing health equity; (2) to describe facilitators and barriers of Indigenous youth participation; and (3) to identify knowledge gaps related to Indigenous youth participation that can inform a research agenda addressing the social determinants of health and health equity. To achieve these objectives, six review questions have been identified (see [box 1](#)).

Establishing an evidence-base of best practices on Indigenous youth participation will enhance the theoretical and empirical understandings for communities, researchers, policymakers, practitioners and activists working toward the promotion of health equity, decolonisation and youth inclusion. By outlining this IR protocol, we hope to demonstrate review methods for investigating multidisciplinary phenomena in health research as well as to encourage more critical and constructive dialogue about youth participation that enhances culturally sensitive research and engagement with Indigenous youth populations globally. This IR will also inform the ongoing work on a national YPAR project focusing on Indigenous youth, social action and health and resilience within urban Indigenous contexts in Canada.<sup>59–63</sup>

## METHODS AND ANALYSIS

### Integrative review methodology

An IR is a broad approach used to systematically sample and review diverse literatures of a specific phenomenon to provide a more holistic understanding.<sup>64 65</sup> An IR should not be confused with systematic and scoping reviews whereby the former aims to collate and assess empirical literature from a small number of studies with clearly bounded research questions and the latter to provide a descriptive overview of a topic, including the state of knowledge, potential research questions and existing knowledge gaps.<sup>66</sup> The IR serves to not only describe states of knowledge but integrate diverse evidence sources, approaches, designs, methodologies and various forms of rigour and validity.<sup>66</sup>



An IR can also generate and refine conceptual definitions of obscure concepts by combining empirical and theoretical reports.<sup>65 66</sup> Although less attention has been given to the methodological challenges of enrolling both empirical and theoretical literatures in IRs, it is suggested that reviews of theory in particular must clearly define the term ‘theory’ (eg, grand theory, mid-range theory), remain resistant to rigid inclusion criteria and determine whether causality or criticality are the primary goals of theory identification. They also require subjective appraisal and expert knowledge to identify theoretical literatures directly and indirectly related to the review topic.<sup>67</sup> Given the fragmented, extensive and multidisciplinary literature on Indigenous youth participation in health equity promotion, an IR will offer the analytical power to manage heterogeneity in the literature yet provide explanatory potential to reconceptualise and synthesise participatory approaches.

### Search strategy and data sources

An academic health sciences librarian (second author) with over 20 years’ experience specialising in Indigenous health and knowledge synthesis has designed the search strategy and carried out test searches in several databases using keywords and subject headings (see online supplemental file 1). Additionally, the tables of contents from a selection of Indigenous research journals will be checked to identify possible articles for inclusion. These publications are often inconsistently indexed in major commercial and scholarly databases. The identification and inclusion of these community-informed, scholarly Indigenous journals will enhance comprehensiveness and ensure Indigenous researchers are not overlooked. Journal articles will be retrieved from interdisciplinary and major biomedical databases including Scopus, EBSCOhost and ProQuest, as well as MEDLINE, Embase and PsycINFO using Ovid. A detailed list of the various databases, structured searches for Scopus and MEDLINE and a list of Indigenous journals to be examined for relevant articles are listed (see online supplemental file 2). Database searches will be limited to English language publications from January 2000 to July 2022 about Indigenous youth from Canada, USA, Australia and Aotearoa New Zealand. Publications by prominent authors investigating Indigenous youth participatory approaches will be identified and reference lists will be checked for additional relevant items. References to books, book chapters, and theses and dissertations will be retrieved through searches of the commercial databases identified above, from reference lists and additional searching of academic bibliographic databases. The IR will include evidence of a qualitative nature that reports on theoretical and empirical findings, case studies and insights. We have chosen to exclude literature using quantitative and mixed-method methodologies as they

are limited and are not well suited to our research objectives.

### Inclusion and exclusion criteria

#### Participant demographics and settings

We will include studies where participants self-identify as Indigenous (including various nation-based identifiers) between the ages of 15–29 years old or are stakeholders/communities seeking to include and hear the voices of Indigenous youth through various participatory approaches. They will be drawn from examples in Canada, USA, Aotearoa New Zealand and Australia, which all have distinctive Indigenous populations living in similar settler-colonial contexts while socially and politically identifying with the term ‘Indigenous.’

#### Participatory approaches and outcomes

The concept of youth participation is broad, multidisciplinary and cross-cultural in nature even when considering the specificity of health equity. Comparing cross-cultural conceptualisations of participation within various Indigenous contexts may be challenging and bounding the concept of participation a priori may inadvertently exclude unique perspectives on how participatory approaches have been conceptualised and operationalised within health contexts. Nevertheless, we have determined a few criteria to focus these searches in ways that are manageable yet not overly restrictive.

Drawing from heuristic frameworks of *youth involvement*<sup>33</sup> and *Indigenous determinants of health*<sup>20 22</sup> to guide our interpretations, participatory approaches will include data sources where the primary variable is participation in diverse forms of collective action and the primary outcome is broader political, civic, community or social engagement. In instances where the primary or only outcome is therapeutic or developmental (eg, youth development-oriented studies, mentorship, support groups, life skills development), these sources will be excluded. The IR will further exclude data sources focusing on individual-level and private modes of decision-making (eg, medical and judicial decision-making, educational decision-making, extracurricular activities); individual forms of institutionalised political participation (eg, petitions, online surveys, donations, electoral voting); participation that involves one-off events or discussion groups; job or employment participation; and consumer participation (which differs from participation in human-centred design/planning approaches that also use user experiences).

#### Data management

We will use EndNote and Covidence review management software to manage the different stages of the review process. EndNote will enable the importation of citations from online databases<sup>68</sup> while Covidence will ensure rigour and efficient processes for study selection, data extraction, methodological appraisal and analysis.<sup>69</sup>

### Study screening, selection and sorting

The selection of studies to be included will be performed through a blinded dual-reviewer process. First, a partial screening process will consist of removing duplicate citations and two reviewers (first and third authors) will screen titles and abstracts for relevancy based on inclusion/exclusion criteria. Following this stage, full screening will involve a full-text scan. These stages will classify articles as 'relevant,' 'irrelevant' and 'undetermined,' for which decisions will be finalised by checking inter-reviewer consistency and resolving discrepancies through in-depth discussion and consensus. A minimum of 10 articles will be checked once both reviewers select articles to identify any challenges earlier in the selection process.

### Quality appraisal and scoring

The IR will adapt the Joanna Briggs Institute (JBI) critical evaluation tool to evaluate primary qualitative studies while a six-step procedure proposed by Walker and Avant will be used for appraising theoretical concepts. The premise of the JBI tool focuses on ensuring congruity between stated aims and methods and operational outputs of research, and the six-step procedure interrogates theoretical assumptions, structure and application.<sup>70 71</sup> Studies will be scored by two reviewers to determine studies to be included/excluded for analysis while keeping in mind general principles for evaluating qualitative studies such as transferability, credibility, dependability and confirmability. In the case that there is a discrepancy between two reviewers or a study is rated poorly but is considered relevant and important, the study will be further discussed to reach consensus and determine eligibility.

### Data extraction, analysis and synthesis

Data extraction by the first author and verified by the third author will begin simultaneously with study selection after agreement on each data source. We will create a review matrix to support the writing of narrative summaries. Using Covidence and included in the matrix will be descriptive information pertaining to authorship, study title, date of publication, location of article, field of study, type of study, publication objectives, study design, population demographics, participatory approach type, key results and outcomes, quality rating and strengths and limitations.<sup>72</sup> Alternatively, theoretical studies will extract data related to paradigm, concepts and statements, assumptions, structure, utility, generalisability/transferability, testability and application, and strengths and limitations.<sup>71</sup> Extracted information will be closely guided by the IR research questions to ensure the review remains focused and multiple matrices will be constructed to respond to the different questions. When inconsistent or incomplete findings are reported, the corresponding authors of their respective articles will be contacted.

The purpose of data analysis and synthesis during IRs entails the integration of diverse literature to reconstruct a new understanding of a phenomenon. It does not merely consist of documenting the plethora of extant data or

listing summaries of the available literature.<sup>73</sup> Following a hybrid inductive and deductive process, codes and (sub) categories will be generated based on existing conceptual categories and emerging ones. Initially, 10 articles will be randomly sampled and coded to construct a code book which reviewers will use and revise over time. Constant comparison methods of data reduction, data display and thematic analysis will follow this step to finally expose emerging patterns and generate themes forming the basis of our review findings.<sup>74</sup> Data sources reporting on theoretical insights will follow a similar thematic analysis. However, they will also be read and analysed in relation to empirical data sources to understand how theorising Indigenous youth participation converges and diverges from the operationalisation of concepts within primary studies. The first author will direct the analysis with the support of the third author. To ensure a comprehensive and accurate interpretation of review findings, collaborating researchers and youth partners on a larger national YPAR project we are engaged in will be consulted.

### Patient and public involvement

Indigenous youth and community members will not be directly involved in the design, implementation, reporting and dissemination of the IR. It was reasoned among the research team that the extent and nature of this IR would not be suitable given the time and resources Indigenous communities and youth we work with would need to dedicate. However, the focus of this IR emerged from several years of health research and community engagement with First Nations and Métis youth and youth-serving organisations in Canada's prairie regions by the first and third author. Through shared observations, discussions and collaborative work the authors have continuously asked questions about youth participation as they collaborate on research projects, community initiatives and advocacy campaigns with youth as both research partners and participants.

### ETHICS AND DISSEMINATION

The IR does not require ethical review and approval nor is it subject to the same registration and reporting requirements of systematic reviews. We will disseminate findings through various local and international public networks we have established over the years and through the YPAR project we are actively engaged in at a national level in Canada and globally with various researchers, youth-serving organisations, Indigenous communities, activists, and youth and elders. In addition to reports, academic publications and conference presentations, we will leverage non-traditional spaces of knowledge exchange, translation and action such as community gatherings and events, youth committees and councils, and social media and online platforms among researchers and youth. The IR has the potential to guide global mobilisations in a variety of fields working to operationalise Indigenous youth participation in decision-making processes. As part



of the national YPAR project the first and third author are leading, these findings will directly support the ongoing development and application of Indigenous youth participatory approaches as well as a smaller study currently underway in Winnipeg, Manitoba, Canada that focuses on contemporary Indigenous youth participation in youth organising, community development, and activism with implications for health equity.

## DISCUSSION

The purpose of outlining this review protocol prior to the IR is to highlight our unique and purposefully designed methodology to address the multifaceted aspects of reviewing Indigenous youth participation in health equity. The literatures on Indigenous youth participation in decision-making and various forms of collective action remain fragmented and extensive, leading to a lack of integration and shared conceptual understanding. To date, no review clearly reports on this broader topic in a systematic and explicit way. A growing number of studies and a small selection of reviews exist in cases of youth involvement in health promotion and participatory health research. However, in the broader context of health equity, knowledge gaps are particularly pronounced and persist despite concerted efforts in recent years to hear the voices of and include Indigenous youth in decisions over the lives of their nations, communities and themselves. Such decisions reflect wider forms of self-determination and collective healing as a result of trauma and oppression caused by settler colonisation, social exclusion and land dispossession within Indigenous communities.<sup>20</sup> Although the following IR will document Indigenous youth participation with implications for health equity, these findings will be unique in that they will be multidisciplinary, cross-cultural, and focus on formal and informal modes of participation, which may have potential benefits for others living and working in broader contexts of decolonisation, youth inclusion and planetary health promotion.

While we anticipate the scope of this IR to cover a wide range of literature which may pose challenges with reconciling the heterogeneity and plurality of participatory approaches, it will provide an evidence-base to begin articulating concepts to interrogate, operationalise and holistically understand Indigenous youth participatory approaches. Given that youth participation has sometimes been mobilised as a panacea toward dealing with the unfair treatment and disproportionate health and social outcomes of youth populations,<sup>9</sup> there remains challenging instances of operationalising these concepts in practice and diverse contexts, for which many members of our research team have witnessed and experienced. Although youth voice and participation may be necessary, the literature clearly demonstrates that simply including and hearing the voices of youth is not sufficient to mobilise the type of transformative changes needed in areas such as research, governance, policy, service,

community development and activism. Rather, further understanding the ways in which youth participation operates through various historical, geographical and sociocultural contexts will provide a more nuanced and productive understanding of participatory approaches. These circumstances are particularly important within Indigenous contexts that must not only contend with youth-adult power relations, but those between Indigenous and non-Indigenous communities and across other axes of social difference. The multidisciplinary insights this IR will uncover can inform and shape conversations on health equity promotion as we transition to a post-pandemic era that has equally witnessed calls toward racial and environmental justice, decolonisation and sustainable economic equality.

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