Addressing the need for indigenous and decolonized quantitative research methods in Canada

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ABSTRACT

Though qualitative methods are often an appropriate Indigenous methodology and have dominated the literature on Indigenous research methods, they are not the only methods available for health research. There is a need for decolonizing and Indigenizing quantitative research methods, particularly in the discipline of epidemiology, to better address the public health needs of Indigenous populations who continue to face health inequities because of colonial systems, as well as inaccurate and incomplete data collection about themselves. For the last two decades, researchers in colonized countries have been calling for a specifically Indigenous approach to epidemiology that recognizes the limits of Western epidemiological methods, incorporates more Indigenous research methodologies and community-based participatory research methods, builds capacity by training more Indigenous epidemiologists, and supports Indigenous self-determination. Indigenous epidemiology can include a variety of approaches, including: shifting standards, such as age standardization, according to Indigenous communities; changing recruitment methods to fulfill statistical standards for stratification; acting as a bridge between Indigenous and Western technoscientific perspectives; developing culturally appropriate data collection tools; and developing distinct epidemiological methods based on Indigenous knowledge systems. This paper explores how decolonization and Indigenization of epidemiology has been operationalized in recent Canadian studies and projects, including the First Nations Regional Longitudinal Health Survey and how this decolonization and Indigenization might be augmented with the capacity-building of the future Our Health Counts Applied Indigenous Epidemiology, Health Information, and Health Services and Program Evaluation Training and Mentorship Program in Canada.

1. Introduction

Despite acknowledging health disparities faced by racialized groups, data is seldomly collected based on ethnicity or race in Canada. Non-Indigenous governments’ use of defined ‘standards’ for quantitative methods and infrastructures are rooted in colonial approaches that lack the capacity to properly articulate and acknowledge Indigenous histories and experiences (Lane, 2020; Power et al., 2020), including the collection of first nations health status in Canada, the lack of adequate health data, and the need for Indigenous-led research methods.

Abbreviations: CBPR, community-based participatory research; CIHR, Canadian Institutes of Health Research; FNIGC, First Nations Information Governance Centre; FNIM, First Nations Inuit and Métis; ISC, Indigenous Services of Canada; NEIHR, Network Environments for Indigenous Health Research; OHC-NET, Our Health Counts Applied Indigenous Epidemiology; Health Information and Health Services and Program Evaluation Training and Mentorship Program; PAHO, Pan American Health Organization; RHS, The First Nations Regional Longitudinal Health Survey; TEC, Tribal Epidemiology Centers.

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and interpretation of health data. Often Indigenous research is relegated to the qualitative collection of data, rather than exploring the quantitative potential of Indigenous health research and its ability to predict health outcomes that contribute to solutions to improve the health and well-being for Indigenous Peoples in Canada. For these reasons, it is imperative to decolonize and Indigenize quantitative research methods and ensure that Indigenous Peoples are determining these methods for themselves. Though decolonization originally referred to a devolution of empire and the granting of independence to colonial countries throughout the 1930s through the 1970s (Setts, 2012), for the purposes of this paper, we are defining decolonization as “work toward disassembling (especially White) settler supremacy by de-centering and dismantling colonial institutions, modalities, systems, structures, and ways of knowing and being that continue to dispossess Indigenous peoples of their lands, families, homes, languages, and rights” (de Leeuw & Greenwood, 2017). Similarly, Indigenization has its roots in the postcolonial context of third-worldism (Yunong & Xiong, 2008) and can be defined in multiple ways, but we are defining it as a process that “centers a politics of indigenous identity and indigenous cultural action,” and “privileges indigenous voices” (Tubalwi Smith, 2012, p. 245).¹ We see these processes as working in tandem, the former decentering and dismantling Eurocentric views and methods, the latter centering and strengthening Indigenous views and methods. In this paper, we, as a team of Métis and First Nations scholars along with our allied colleagues, demonstrate the need and methods for decolonizing and Indigenizing quantitative research methods, particularly in the discipline of epidemiology, and how these initiatives might be augmented with the capacity-building provided by the future Our Health Counts Applied Indigenous Epidemiology, Health Information, and Health Services and Program Evaluation Training and Mentorship (OHC-NET) Program.

2. Gaps and issues in Indigenous quantitative data collection

Part of the reluctance and difficulty in engaging in Indigenous quantitative health data begins with the issues in how the data is collected and identified in Canada. Although the Constitution Act, 1982 refers to the Aboriginal Peoples of Canada as inclusive of three groups—“Indians,” Métis, and Inuit—the reality is that these groups have different social, political, and legal contexts. In particular, “Indians” and those registered as such are defined in the federal Indian Act. This strictly defined version of who is an “Indian” imposes a non-Indigenous definition and excludes other Indigenous Peoples, including Métis, non-status First Nations, disenfranchised status First Nations (those attending school off reserve, women choosing to marry off reserve, or those who purchase property off reserve), and Inuit living outside of their traditional territories (Coates, 2004; Cornett, 2003; Government of Canada, 2021; Joseph & Joseph, 2019; Lavoie, 2013). Notably, the Indian Register, which is the basis for First Nations demographics, is a continuous statutory administrative file based on the registration of status “Indians,” predetermined by qualifications and provisions outlined in the Indian Act. The Indian Register is maintained by Indigenous Services of Canada (ISC), and for an individual to be included on the Indian Register, they must successfully apply for “Indian” status and be eligible under the provisions of the Indian Act. However, this system of registry has been employed as a tactic to disenfranchise Indigenous Peoples in Canada because of the gendered and discriminatory nature of the colonial system of exclusion perpetuated by the Indian Act that is widely recognized for its discriminatory aspects (see Bonnassa, McKay, & Hampton, 2005; Hartley, 2007; Jobin & Kappo, 2017; Joseph, 2018; McCallum & Perry, 2018; National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019). Further, these imposed definitions of “Indian” have shifted over time “reflecting values and assumptions embedded in the Canadian body-politic, rather than Indigenous beliefs, practices and self-definitions” (Lavoie & Forget, 2011, p. 26).

The Indian Register only records enfranchised “Indians” and consequently complicates statistical applications by not capturing a folsome picture of First Nations and Inuit populations. For example, non-status First Nations are excluded from the federal definition of “Indian” and will not be counted within those datasets. That said, this is one of few mechanisms currently available to provide baseline data.

Moreover, these enacted definitions create inaccuracies in data because they are not reflective of how the sub-population (e.g., different language or dialect groups) identify themselves collectively. These gaps are further perpetuated in data collection as definitions fail to “respectfully, systematically, comprehensively and consistently recognize self-identified First Nations, Métis or Inuit ethnicity” (Smiley & Anderson, 2006, p. 603). As Smiley notes about health status and determinants among Indigenous Peoples, the “inequities... facing First Nations, Inuit, and Métis people, while variable, are not limited to a particular geographic region or Indian Act-defined sub-population” Smiley (2009, p. 2). She goes on to argue that because of these issues, “it is very important that health information can be separated out or ‘dis-aggregated’ in data subsets that are specific to First Nations, Inuit, or Métis subgroups” Smiley (2009, p. 2), but also that these datasets are made available in various levels of geographic aggregation for more granular analysis according to region and community. Obtaining accurate Nation-specific data is imperative to identify appropriate and relevant health indicators used to establish self-determined health services and policies that best serve the needs of the population and ultimately improve Indigenous health outcomes. For example, in Canada, provinces and territories have different requirements for birth registration with some not requiring or requesting racial or ethnic information, which then affects the type of data that is available because of the reliance on self-identification for Indigenous populations. The incomplete nature of this data requires data users to review such information critically. Most recently, the Government of Canada’s Epidemiological summary of COVID-19 cases in First Nations communities reveals through a critical lens the difficulty in understanding who has been counted and who has been left out (Health Council of Canada, 2005; Government of Canada, 2021; Mashford-Pringle, Ring, Al-Yaman, Waldeon, & Chino, 2019). The Pan American Health Organization (PAHO) argues that current health data collection methods, particularly those used in emergency situations allow for specific populations to remain invisible because they are excluded from governmental registries, and these absences in the data are compounded in emergency situations, resulting in deficits when advocating for the adequate distribution of critical resources (Del Pino & Camacho, 2020).

One such emergency situation is the COVID-19 pandemic, which continues to highlight the substantial healthcare gaps in society that greatly affect marginalized people’s access to quality care (Gostin, Friedman, & Wetter, 2020). It is essential to consider not only how the data is collected but also the methodologies underpinning the data that is collected during the COVID-19 pandemic, as these factors will inform how we respond to the disease as well as direct how we prepare and respond to any future pandemics. In order to make future data projections, it is important to have accurate, inclusive baseline data. Nation-specific disaggregated data collected in previous pandemics have been notably absent, collected without community input, or used to perpetuate racial stereotypes or inequities (Spence and White, 2010; Wong, 2020; Wyton, 2020). For example, administrative decisions to delay sending alcohol-based gel sanitizer during the 2009 H1N1 pandemic to First Nations communities was based on paternalistic approaches and the unfounded assumption that the gel may be ingested by individuals (Spence and White, 2010). These administrative decisions were made without informed data on substance use being reviewed or accounted for. The hope is that Indigenous epidemiological data that is

¹ Though space prohibits a full discussion of these terms, we acknowledge that there is much literature and debate on definitions of these concepts (Siun, Desai, & Ritzkes, 2012), including Eve Tuck and K. Wayne Yang’s ground-breaking “Decolonization is Not a Metaphor” (2012).
collected and interpreted from the COVID-19 pandemic will incorporate decolonized and Indigenous research methodologies and recognize the need for more Indigenous epidemiologists. In the end, this will inform future emergency response, service delivery, and policies for Indigenous health. Before we discuss the need for decolonized and Indigenous quantitative research methodologies, we turn to discussion of Indigenous research methodologies to outline their focus on qualitative methodologies.

3. Indigenous research methodologies and the dominance of qualitative methodologies

In today’s research environment, Indigenous methodologies, including the research structure and process, as well as the data and analysis, have been linked to self-determination broadly, and Indigenous communities are voicing their need for relevant and ethical engagement (Absolon & Willett, 2005). There are ongoing adaptations of methodologies that better incorporate Indigenous values, beliefs, and ways of knowing, which ultimately lead to respectful, collaborative research that affirms community benefits and strengths and is relevant, relational, and responsive to community-driven priorities (Dawson, Toombs, & Mushquash, 2017; Kovach, 2009; Simonds & Christopher, 2013; Wilson, 2001).

It is important to recognize that Indigenous Peoples are diverse in knowledge systems, histories, beliefs, languages, protocols or customs, and identities (Brant-Castellano, 2000, pp. 21–36; Giesbrecht, Crooks, & Morgan, 2016, pp. 1–13; Hankivsky & Cormier, 2009; Lavallée, 2009). From this diversity, we must recognize that there is not one single Indigenous research methodology (or Pan-Indigenous approach); rather there are multiple Indigenous methodologies and methods that are based on shared histories of colonization and contemporary realities (Paradies, 2016). Indigenous Peoples have always conducted research using their own epistemologies and ontologies, thus, describing the various ways in which Indigenous Peoples conduct research is a step towards asserting Indigenous knowledges in the Western academic system. This is not to imply that there are binary ways to approach research (i.e., Indigenous/Traditional versus Western “ways of knowing”) (Simonds & Christopher, 2013); often these different systems and methodologies are used in tandem and are complementary.

Some scholars believe Indigenous research methods must privilege research participants’ agency and expert knowledge about themselves (Tuhiiwi Smith, 2012). Other scholars discuss the importance of respect, relevance, reciprocity, responsibility, and relationships within the research methods (Craft, 2017; Kirkness & Barnhardt, 1991; Restoule, 2008; Simonds & Christopher, 2013), or the involvement of spiritual and intuitive learning (Copenace, Cidro, Johnson, & Anderson, 2021, pp. 189–202; Craft, 2014; Lavallée, 2009; Wilson, 2001). As such, Indigenous research methodologies have largely been focused on qualitative approaches (Walter & Suina, 2019), which can be defined as:

- studied use and collection of a variety of empirical materials – case study; personal experience; introspection; life story; interview; artifacts; cultural texts and productions; observational, historical, interactional, and visual texts – that describe routine and problematic moments and meanings in individuals’ lives. (Denzin & Lincoln, 2005, p. 3, p. 3)

Notably, a recent systematic review conducted on Indigenous research methods (Dawson et al., 2017) does not include quantitative methods as an individual Indigenous research method, but only in combination with qualitative methods as “mixed methods.” The dominance of qualitative methods in Indigenous research can be attributed to the nature of Indigenous epistemologies, which often rely on traditional knowledge that has been handed down through generations (Brant-Castellano, 2000, p. 23), revealed knowledge that is “acquired through dreams, visions, and intuitions that are understood to be spiritual in origin” (Brant-Castellano, 2000, p. 23), and an empirical knowledge that is “not based on quantitative analysis of repeated observations in a controlled setting,” but is instead based on “a convergence of perspectives from different vantage points, accumulated over time” (Brant-Castellano, 2000, p. 24). Indigenous quantitative researcher Maggie Walter (2005) argues that there has been limited engagement with quantitative methods in Indigenous research due to the fraught history of Indigenous Peoples’ involvement with Western scientific paradigms, the limited number of Indigenous researchers engaged in quantitative methods, and the dearth of relevant Indigenous data sets. Put differently, quantitative methods are often perceived as having a Eurocentric, non-Indigenous face, and therefore, of little benefit and relevance to Indigenous communities. Nevertheless, as demonstrated in our next section, when quantitative methodologies are decolonized and Indigenousized, they can serve to benefit Indigenous communities and their health.

4. Decolonizing and indigenizing quantitative research methodologies

Numerical data collected through quantitative methods have often been positioned as neutral facts used to support Western scientific claims as long as variables are controlled (Kovach, 2009; Open North & British Columbia First Nations Data Governance Initiative, 2017). Current non-Indigenous approaches primarily locate the collection and validation of empirical evidence within the paradigm of positivism without explicitly describing underlying assumptions (i.e., knowledge inquiry is value-free and is generated through scientific methods that are reproducible and verifiable) (Botha, 2011; Creswell & Creswell, 2018; Ravitch & Mittenfelscher Carl, 2020). Though “quantitative avoidance can be linked to Indigenous Peoples’ longstanding (and largely justified) suspicions around research using positivist methodologies,” it is important to note that “Indigenous [P]eoples are, and have always been, highly numerate in how we understand our worlds” (Walter & Suina, 2019, p. 233). Blackstock corroborates this argument by challenging the view that qualitative research methods are “almost inherently, more ‘Indigenous’ in nature than quantitative methods” and the assumption that “Indigenous [P]eoples were (and are) more concerned about storytelling and ceremony than scientific and numeric endeavour” (Blackstock, 2009, p. 135). She goes on to argue that numerical data is often more persuasive in knowledge translation to policymakers within the Western system, and thus, often has more potential for agendas of social justice, which is echoed by other researchers working in Indigenous health (Jaworsky, 2019; Prussing, 2018, 2019).

Though numerical data is often presented as true, verifiable, and more accurate than other qualitative forms of data collection, we must be careful to examine what the data signifies and who benefits from the results that are “drawn from the dominant social norms, values and racial hierarchy of the society in which they are created” (Walter, 2016, p. 79). This bias is especially true for inferential statistics, which are used within health-related applied statistics like epidemiology, the study of the distribution of illness across a population used to assess probable causes. Inferential statistics can be used to make generalizations about larger groups of populations from data gathered from a smaller sample of the larger group and can determine the probability that any differences found between groups was caused by chance (Dodge, 2017; Urdan, 2005). Inferential statistics are used more frequently than population-based studies since the latter take considerable resources (time and money) to execute (Dodge, 2017). Nevertheless, researchers such as Roy (2014) contend that there is a “possibility of deconstructing and decolonizing Western quantitative methods to meet the approaches and needs of Aboriginal communities—in the same way that Western critical theory and constructivism have been successfully deconstructed and decolonized for Aboriginal use” (p. 122). Equally, there is an opportunity to Indigenize quantitative research methods to “incorporate [Indigenous] cosmology, worldview, epistemology and ethical beliefs”.
As part of this approach, we propose the following methods to decolonize and Indigenize quantitative research methods: (1) strengths-based approach; (2) positionality; (3) community-based participatory research; and (4) Indigenous data sovereignty.

4.1. Strengths-based approach

Similar to many qualitative methods, a decolonized approach to quantitative research is contextual and temporal, meaning it exists within a certain period of time politically, socially, historically, and organizationally (Ravitch & Mittenfelner Carl, 2020). The data is then interpreted using a strengths-based lens which is “consistent with community values and principles” and supports “a more positive story to be told [using the data], without altering statistical rigour” (Thurber et al., 2020, p. 1). Community members are involved from the initiation of the research idea to ensure relevance, assist with study design, and implement data collection, analysis, and dissemination (Woodbury, Beans, Hiratsuka, & Burke, 2019). This meaningful involvement ensures that the research is not only useful and accurate in the conclusions, but also respectful to the participants and community. Further, community involvement empowers a Nation by affirming their identity and pride thereby increasing the relevance and value of the data for that specific community. This engagement, in turn, leads to an increase in use of the data by the community because it emerged from their priorities and understandings.

A prominent example of an Indigenous approach to quantitative methods is a Canadian health survey of First Nations Peoples called The First Nations Regional Longitudinal Health Survey (RHS) (Gray, 2005). This national health survey, which was developed over two years, was the first health survey created, conducted, and carried out by First Nations People for First Nations People (First Nations Information Governance Centre [FNIGC], 2018b). As stated by Prussing (2019), “for and by marks research that departs from long histories of research about Indigenous Peoples, little of which engaged communities or substantively incorporated their perspectives (Solomon & Randall, 2014; Tuhiwai Smith, 2012). The RHS is a holistic survey that gathers data from both traditional and Western understandings of health and well-being from First Nations reserves and northern communities across Canada. Importantly, regional community definitions were utilized in the development of the survey; for example, in one region, adults were defined as fifteen years of age and older, whereas elsewhere adults were defined as eighteen years of age and older (First Nations Information Governance Centre, 2006). The ability of the community to define their own terms within the data collection is imperative in representing community priorities and expressing their concerns in health discussions at the national level. The RHS emphasizes the importance of study design to the interpretation of data by using both Western and traditional understandings of health and well-being to collect data that supports policy and programming at the community, regional, and national levels.

4.2. Positionality

In addition to collaborative, co-created research, decolonized and Indigenous methodologies encourage researchers to be their subjective selves, removing the false assumption that researchers can present neutral or unbiased data while also being “engaged actively as participants in the research process” (Weber-Pillwax, 2004, p. 174). Similarly, Cameron and colleagues describe Indigenous research methodology as one in which the researcher works “alongside Indigenous experience rather than framing the Indigenous world-view from a distance” (Cameron, Del Pilar Carmargo Plazas, Salas Santos, Bourque Bearskin, & Hungler, 2014, p. E5). In their systematic review of Indigenous research methodologies, Drawson et al. (2017) conclude that there are three standards across Indigenous research methods: contextual reflection (positionality), inclusion of Indigenous Peoples in respectful and reciprocal ways, and prioritizing Indigenous ways of knowing (p. 15). This contextualization and positionality place:

- the research within the context of the data course(s). This means that the data collection, analysis, and interpretation may vary... compared to typically Western methods that are often highly standardized and where removing context from the research is paramount. (Drawson et al., 2017, p. 13, p. 13)

Appropriately contextualizing numerical data can also be viewed as a step towards decolonizing quantitative methods because, as already stated, context provides information on who is (and is not) asking the questions and for what purpose.

A researcher’s positionality underpins their research as their societal position and worldview affect a series of conscious and unconscious choices made in the quantitative study design, which in turn, influences the results to be showcased (Jaworsky, 2019). Often, the findings of studies are then interpreted by a researcher for a particular purpose and presented as neutral data for a wider audience without addressing or accounting for positionality. In particular, epidemiology organizes numerical datasets to identify and explain health conditions in an ostensibly neutral manner, but like other research methods, it is affected by biases built into the study design and interpretation. The questions asked by the researchers are primarily deficit-based (Bailie & Paradies, 2005; Fontaine, 2018; Green & Haines, 2011; Jaworsky, 2019; Morgan & Zglio, 2007). Furthermore, epidemiological information has significant impact on studied populations as it is used to plan and evaluate health interventions or record health inequities compared to majority groups in national populations (Gracey & King, 2009; Smylie, Crengle, Free-mante, & Taualii, 2010). When epidemiological research negatively portrays Indigenous communities without historical contextualization, it can be used to “justify paternalism and threaten efforts of Indigenous self-determination” (Jaworsky, 2019, p. 2; see also O’Neill, Reading, & Leader, 1998).

Again, in Canada, The First Nations Regional Longitudinal Health Survey (RHS) is a significant example of contextualizing Indigenous health disparities rather than presenting the data as neutral. The RHS notably developed a Cultural Framework (FNIGC, 2018a, p. 7) to inform the research process and organize the interpretation of the data to account for the complexities embedded in First Nations conceptions of health. In using the Cultural Framework to collect and interpret the data, the researchers can provide “balance to previous research by drawing out the positive changes related to First Nations wellness” (FNIGC, 2018a, p. 9). For instance, the RHS uses connections to culture and language as an indicator of health, which can yield different, more strengths-based results within health data than are typically observed in Western-based epidemiological studies. This example can be compared with the Mayi Kuwayt National Study of Aboriginal and Torres Strait Islander Wellbeing in Australia, which also focuses on sociocultural determinants of health for Indigenous Peoples to provide context for the numerical statistics generated within the data and demonstrate an alternative narrative to the disparity/Indigenous problem model often used in epidemiology (Australian National University, nd; Bourke, 2020).

4.3. Community-based participatory research

Some scholars, such as Simonds and Christopher (20), believe the best approach for decolonized research is community-based participatory research (CBPR) because it challenges dominant power structures and relations that traditionally rely on a hierarchical or “expert” approach to generating knowledge to move to a power “with” approach which recognizes people’s lived experiences and traditions as knowledge (Darroch & Giles, 2014). Findings generated from CBPR are collaborative and therefore more culturally relevant to those involved (Atalay, 2012; Jacquez, Vaughn, & Wagner, 2013). This approach “emphasizes social relationships, joint decision-making, equitable
communication, mutual respect, and ethics” (Silliman, 2008, p. 7). Additionally, it “values experiential knowledge as scientific” (Bailie & Paradies, 2005, p. 27). Examples of the CBPR approach to Indigenizing epidemiology exist in Canada, including the Building Bridges project (Benoit et al., 2020), which collaborated with Indigenous community members in Toronto and Vancouver to conduct research and analysis on data for Indigenous people living with human immunodeficiency virus (HIV), and the Places of Death and Places of Care at End of Life for Indigenous People in Ontario project (Funnell, Tanuseputro, Letendre, Bourque Bearskin, & Walker, 2020), which developed a research partnership between academics and the Canadian Indigenous Nurses Association to interpret health administrative data held by the Institute for Clinical Evaluative Sciences on end-of-life care for Indigenous Peoples in Ontario.

Although CBPR is a collaborative process of co-learning that “involves all partners in the research process and recognizes the unique strengths that each brings” and “begins with a research topic of importance to the community with the aim of combining knowledge and action for social change” (Minkler & Wallerstein, 2003, p. 4), we recognize it is only one approach to partnership-based research. A more meaningful approach might include rooting the research methodology in the local context by closely following and respecting Indigenous laws and protocols of the Nation or community while facilitating research through a community-based researcher, rather than an academic. These approaches vary across communities, and therefore, exceed the scope of this paper.

### 4.4. Indigenous data sovereignty

Decolonizing data is crucial for the rights of Indigenous Peoples to strengthen and implement their data sovereignty (Espay, 2002; First Nations Information Governance Centre, 2019; Kukutai & Taylor, 2016; Schnarch, 2004; United Nations General Assembly [UNGA], 2007). The Global Indigenous Data Alliance developed the CARE—Collective benefit, Authority to control, Responsibility, and Ethics—Principles as a response to a movement towards FAIR—Findable, Accessible, Interoperable, Reusable—Principles, which are based on universalized access to data (Boeckhout, Zielhus, & Breedenoord, 2018; GO FAIR, n.d.). The CARE Principles were created with Indigenous data sovereignty in mind as a way to assert the rights of Indigenous Peoples and Nations to govern themselves and the data that is being collected about them. UNDRIP reaffirms Indigenous rights to Indigenous data, including data embedded in their culture such as languages, knowledge, practices, technologies, and land (UNGA, 2007). Further, the United Nations Permanent Forum on Indigenous Issues (UNPFII) held gatherings to discuss data collection, and Indigenous representatives raised concerns over statistical models and frameworks that do not adequately reflect their worldviews, ethnicity, and gendered dimensions (Kukutai & Taylor, 2016). UNPFII recommended that States:

- ensure that the collection of statistical data be disaggregated by sex and ethnicity; discourage monitoring that is focused only on national averages; ensure indigenous peoples’ and indigenous women’s effective participation in all stages of the preparation, coordination and implementation of data collection; develop a proper system of indicators in partnership with indigenous peoples and women; and enable a measurement of progress in the different areas. (Department of Economic and Social Affairs, 2010, p. 26)

These principles and rights are at the core of Indigenous epidemiology as a decolonized quantitative approach to data collection and interpretation that is aligned with Indigenous values and priorities.

### 5. Decolonizing and indigenizing epidemiology

As described in our introduction, decolonizing research is a process whereby Eurocentric views and methods are dismantled and reconfigured, thus, Indigenizing research can be viewed as a centring and strengthening of Indigenous views and methods. Indigenizing research is a process for conducting research with Indigenous communities that places Indigenous voices and epistemologies at the centre of the research process and deliberately works against colonial norms (Simonds & Christopher, 2013; Swadener & Mutua, 2008, pp. 31–43; Tuhisai Smith, 2012).

For the last two decades, researchers in colonized countries have been calling for a specifically Indigenous epidemiology that recognizes the limits of Western epidemiological methods, incorporates more Indigenous research methodologies and CBPR methods, builds capacity through training more Indigenous epidemiologists (both in and outside of academia), and supports Indigenous self-determination (Bailie & Paradies, 2005; Jaworsky, 2019; Prussing, 2018, 2019; Roy, 2014; Simmonds, Robson, Crum, & Purdie, 2008). Many of these researchers note that Indigenous epidemiology is building on growing trends in the broader discipline of epidemiology in “understanding the complex relationships between diverse and intersecting determinants of health” (Roy, 2014, p. 124) and using eco-social, multi-leveled frameworks, such as the Multiple Exposures – Multiple Effects Model developed by the World Health Organization (Bailie & Paradies, 2005; Roy, 2014). Based on her interviews with Indigenous epidemiologists, Prussing (2019) believes the emergent field of Indigenous epidemiology is useful in providing evidence-based data for advocacy and promotion of Indigenous health equity. This approach is in distinct contrast to deficit-based epidemiology that has traditionally shown Indigenous Peoples and communities through a lens of “disparity, deprivation, disadvantage, dysfunction, and difference” (Walter, 2016, p. 80; Walter & Suina, 2019).

The decolonization and/or Indigenization of epidemiology can appear in several guises, including community-based participatory epidemiology (Bach, Jordan, Hartung, Santos-Hövener, & Wright, 2017; Freifeld et al., 2010; Leung, Yen, & Minkler, 2004; Sapienza, Corbie-Smith, Keim, & Fleischman, 2007; Smith, 1998), community-driven epidemiology (Goodman et al., 2019), and culturally safe epidemiology (Cameron, Andersson, McDowell, & Ledogar, 2010).

All of these approaches have emerged in response to the growing recognition of the limitations of the modern epidemiology paradigm, including its focus on individual risk to the detriment of understanding community contexts, an inability to account for the interaction of different risk factors, and a dearth of engagement or influence on actual public health interventions. Community-based participatory epidemiology attempts to address these limitations by “extending the search for causes from the individual to the community and to sociopolitical systems,” “broadening the methodologies to include qualitative and participatory research methods,” and “integrating lay knowledge into scientific knowledge” (Leung et al., 2004, p. 499). In this approach, researchers apply multiple perspectives in data synthesis, including the use of mixed methods and data/investigator/theory/method triangulation; employ a “cyclical, iterative process of development, implementation, adaptation, and interpretation by academics, practitioners, and representatives of the researched population” (Bach et al., 2017, p. 9); and apply “dialogical methods for the co-production and dissemination of knowledge” to ensure relevance of the research for participants and communities (Bach et al., 2017, p. 9). Similarly, community-driven epidemiology ensures that the community is instrumental in developing the research question, engaging in knowledge exchange and dissemination, and contributing to a strengths-based approach to data

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2 Additional paradigms that may include or intersect with Indigenous epidemiology are lay epidemiology (Allmark & Tod, 2006; Davison, Smith, & Frankel, 1991; Olien & Banwell, 2013), popular epidemiology (Brown, 1993; San Sebastián & Hurtig, 2004), and cultural epidemiology (Brough, 2013; Trostle, 2005).
In Canada, there have been a number of community-driven and community-based epidemiological projects and studies, including the aforementioned Building Bridges project (Benoit et al., 2020) and the Places of Death and Places of Care at End of Life for Indigenous People in Ontario project (Funnell et al., 2020), as well as the Canadian North Helicobacter pylori (CanHelp) Working Group, which addresses community concerns about the prevalence of \textit{H. pylori} infections and stomach cancer in the Northwest Territories and Yukon Territory. Notably, this group developed their own set of guiding principles for stewardship and dissemination of collaboratively generated knowledge, including the process for review of research results and assignment of authorship and protocols that allow for all participants to contribute to data interpretation, even if consensus is not reached. These kinds of guidelines are used to mitigate one of the challenges raised within these community-based and community-driven studies: potential miscommunication and misunderstandings between Indigenous partners and academic researchers due to differences in use of language and definitions, expectations about timelines and process, and research purpose (Colquhoun, Geary, & Goodman, 2013; see also, Thompson, 1999).

Another of the limitations of these studies and other Indigenous epidemiological studies (Beals et al., 2003; Thompson, 1999) is the lack or limited number of Indigenous people trained in epidemiological methods and analysis and, relatedly, the time-consuming complexity of training so-called “lay interviewers” or data collectors, especially as attrition is common due to family responsibilities, community politics, or inadequate financial compensation.

An additional significant example of Canadian Indigenous community-based epidemiology research is Our Health Counts, a research initiative created by First Nations, Inuit, and Métis researchers and health service providers living in urban and related homelands, which meets community standards with the intention of addressing the near absence of population-based health assessment information for these populations (Our Health Counts, 2012; Rotondi et al., 2017; Smylie & Firestone, 2015). Our Health Counts research projects apply an Indigenous community partnership approach, delivered by and for local and regional Indigenous health service providers, and apply within-community social networks through their respondent-driven sampling frames. Health assessment surveys are constructed in partnership with local and regional Indigenous health service providers that reflect local community priorities. This model enforces self-determination and builds capacity for the community to conduct their own research in the future (Our Health Counts, 2012). To date, Our Health Counts has been successfully implemented by local Indigenous communities in five Ontario cities.

Our Health Counts is now expanding their work on Indigenous self-determination in health data by developing an Applied Indigenous Epidemiology, Health Information, and Health Services and Program Evaluation Training and Mentorship Program. This program would fill gaps identified by Indigenous communities in the province of Manitoba, in which First Nations political bodies have specifically expressed a need for Indigenous Peoples to have epidemiological training to work in Indigenous organizations and communities in the region. In 2012, the Assembly of Manitoba Chiefs and Manitoba First Nations Health and Wellness Strategy identified several key action areas, “including Key Action Area 14: The Pursuit of Health Information and Research as a priority for Manitoba First Nations’” (Assembly of Manitoba Chiefs [AMC], 2012, Resolution 12). Then Grand Chief of the Assembly of Manitoba Chiefs, Derek Nepinak, signed a resolution “to initiate discussions on the establishment of a Manitoba First Nations epidemiology research centre (Epi-Centre), which would be independent from academia and governments enabling First Nations independent research and studies with the focus on public health and prevention” (AMC, 2012, p. 6). Training in epidemiology is also identified as a priority in First Nations communities across the country with a national resolution motioned by Chief Elaine Johnston, Serpent River First Nation, Ontario, seconded by Chief Walter.
Spence, Fox Lake Cree Nation, Manitoba, and passed by consensus at the Assembly of First Nations Annual General Assembly (Assembly of First Nations [AFN], 2019, Resolution 20/2019, p. 57–58). This resolution calls on the Government of Canada to:

- support and direct Tri-Council agencies to support Indigenous communities and organizations to develop, implement, and evaluate a national Indigenous training and mentorship network to train and support a cadre of more than 100 Indigenous health information specialists, applied epidemiologists, and health service researchers who can lead the required transformation of Indigenous health and social information systems in Canada. (AFN, 2019, Resolution 20/2019, p. 2)

These calls for diversity and Indigenous representation in epidemiology training are consistent with calls and findings from other countries (Carter-Pokras et al., 2009; Durham & Plant, 2005; Jones et al., 2019), which often note that Indigenous representation in the field is among the lowest within different ethnicities. Because this decolonization of and capacity-building for Indigenous epidemiology are priorities for Indigenous health organizations and political bodies in the province of Manitoba, the Manitoba Network Environments for Indigenous Health Research (NEIHR) has decided to work with Our Health Counts on the development of their Applied Epidemiology program.

6. OHC-NET: a Canadian Indigenous applied epidemiology training program

The Network Environments for Indigenous Health Research (NEIHR) is a regional project funded by the Canadian Institutes of Health Research (CIHR). In Manitoba, the NEIHR is called Kishaadigh, which translates from Anishnaabemowin to “she who guards the lodge.” Part of the work of Kishaadigh is related to the development of an Indigenous epidemiology program that supports the development of the Our Health Counts Applied Indigenous Epidemiology, Health Information, and Health Services and Program Evaluation Training and Mentorship (OHC-NET) Program in principle and through funding contributions.

OHC-NET is a national initiative developed in response to significant human resource shortages in Indigenous health information specialists and leaders in Canada and to address the gaps and challenges in current Western-based epidemiology training models that primarily focus on ill health and discourage community-based participatory research. Due to the scarcity of existing Indigenous epidemiologists/health information specialists, most Indigenous organizations are required to hire non-Indigenous epidemiologists/health information specialists who lack an understanding of Indigenous worldviews, knowledge, and language systems, put in requests for data and/or data analysis through non-Indigenous organizations, such as the Institute of Clinical Evaluative Sciences (Funnell et al., 2020; Pyper et al., 2018), or alternatively, need to hire and train community members to support the research with short-term compensation and insufficient time (Beals et al., 2003; Thompson, 1999). OHC-NET will fill this gap by training the next generation of Indigenous epidemiologists/health information specialists and leaders to ensure that First Nations, Inuit, and Métis (FNIM) drive the planning, governance, implementation, analysis, and management of their own health information systems.

OHC-NET is a FNIM-led and -governed training initiative that aims to train 100 self-identified FNIM epidemiologists/health information specialists over fifteen years through the establishment of an Applied Indigenous Epidemiology Training Program. This program will provide supplementary Indigenous perspectives and be inclusive of the identities of more Nations, thereby being more reflective of Indigenous Peoples’ realities. In this way, Indigenous diversity is embraced and there is movement away from Pan-Indigenous approaches. To date, one Canadian university has committed to supporting this initiative, with the long-term goal of establishing a multi-university consortium to support and accredit the training program.

Initially, this program will begin with a two-year pilot training that is accessible to Indigenous researchers across Canada, with the long-term goal of developing an accredited graduate program. Trainees will conduct research primarily at local Indigenous and allied organizations, such as the First Nations Health and Social Secretariat of Manitoba, while they take a combination of distance/online courses and meet in person throughout the year for intensive courses taught by Indigenous public health leaders and scholars. This structure will make the training more accessible to Indigenous trainees who want or need to live in their communities, as well as those already working in healthcare in these communities. Working with Elders and Knowledge Keepers, engagement with place-based knowledge, practice, leadership, and training will be core components of the program and further supported by individualized learning plans. The program will culminate in an applied capstone or thesis project in partnership with a local Indigenous organization, in which the trainee will be immersed in local and Nation-based knowledge, practice, and research protocols. Customized coursework will build upon existing international curricula and will aim to balance practical and technical skills development while being rooted in Indigenous worldviews, knowledge, and languages. Curricula will be developed by the OHC-NET Program Coordinator in conjunction with a technical Strategic Council that includes participating regional NEIHRs across Canada, Indigenous leaders and scholars, and Elders and Knowledge Keepers. Trainees and alumni will be equipped to support Indigenous communities and organizations, drawing on their Indigenous worldviews, values, and languages, as they assume leadership roles in Indigenous health information system analysis and management.

In developing this program, OHC-NET will survey and analyze existing public health and epidemiology programs, with and without Indigenous specializations, and their core competencies, including the experiences of Indigenous students in these programs. The survey will encompass national and international programs, such as the University of British Columbia’s Indigenous Public Health Training Institutes and the Spirit of Eagles, a Special Populations Network in the United States that supports Indigenous community-based research, communication, and training for cancer control (Kaur, 2005; Kaur, Dignan, Burnhans-stipanov, Baukol, & Claus, 2006). Of particular note is the body of research on Australian experiences with developing and implementing graduate public health and applied epidemiology programs with Indigenous specializations and/or Indigenous cohorts (Anderson et al., 2004; Angus, Ewen, & Coombe, 2016; Coombe, Lee, & Robinson, 2017; Coombe, Lee, & Robinson, 2019; Davis, Patel, Fearnley, Viney, & Kirk, 2016; Deemal, 2001; Ewen, Ryan, & Platania-Phung, 2019; Genat, 2008; Guthrie et al., 2011; Lee, 2020; Maher, 2018; Patel & Phillips, 2009). In reviewing this review, it is apparent that there are considerations, opportunities, and challenges for various models, including effective Indigenous curriculum development/integration and relevant learning outcomes. In the Canadian context, there is not a national accrediting body for Master of Public Health (MPH) programs, and a recent study shows that Canadian MPH programs are focusing on quantitative methods while providing less training on diversity and inclusion (Apalu et al., 2021). Furthermore, unlike Australia (Genat, Robinson, & Parker, 2009, 2016), Canada’s core competencies for public health (Public Health Agency of Canada, 2008) do not explicitly include specific competencies that address Indigenous health, a point of critique from Indigenous health researchers in Canada (Baba & Reading, 2012; Hunt, 2015). In looking at the core competencies for epidemiologists, specifically, learning outcomes based on cultural competency and/or culturally appropriate methods for diverse populations are primarily located in competencies for applied epidemiology (Abraham, Gille, Puhan, ter Riet, & von Wyl, 2021; Council of State and Territorial Epidemiologists, Centers for Disease Control and Prevention, 2008; Bondy, Johnson, Cole, & Bercovitz, 2008; Moser, Ramiah, & Ibrahim, 2008), which demonstrates an opportunity to incorporate Indigenous methods and ways of knowing into both the quantitative competencies for general
epidemiology and the cultural competency domain for applied epidemiology. The OHC-NET applied epidemiology training program, which to our knowledge will be the first of its kind in Canada, will be closer in conception to the Institute of Koorie Education and Victorian Consortium of Public Health’s MPH program for community-based Indigenous cohorts, which uses Indigenous community-based pedagogies, mixed-mode delivery, and technology provision (Genet, Robinson, & Parker, 2016, p. 9). As such, this program is an applied example of a decolonized CBPR and Indigenous-partnered approach to quantitative research methods that empowers Indigenous Peoples with the tools to tell their own health stories based on their own priorities, knowledge, values, and languages within their own communities.

7. Conclusions

As modern medicine continues to promote more holistic understandings of health, including engagement with the social determinants of health, related disciplines such as epidemiology will also continue to shift their methods for measuring and impacting population health. It is pivotal that decolonization and Indigenousization of epidemiological methodologies be a cornerstone of these conversations, specifically as it pertains to Indigenous populations. In this paper, we make suggestions on how this objective could be attained in quantitative research through using strength-based approaches, foregrounding the researcher’s positionality, employing community-based participatory research, and upholding Indigenous data sovereignty, as well as addressing the need to increase the number of Indigenous epidemiologists to take on this work in a population health context and articulate Indigenous data inferences in culturally appropriate ways that improve the lives of Indigenous populations. In these suggestions there is an implicit imperative that colonial legacies and histories must be taken into consideration in epidemiological inquiry and interpretation, as well as in critically interpreting the flawed statistics and data collected by the state. These colonial ideologies are embedded in science and medicine, and they continue to perpetuate detrimental effects on Indigenous health. The call for the implementation of decolonized research methods is strongly rooted in the need to recognize that the current methodologies are not as objective nor hermeneutically sound as they purport to be.

In addition to the shift in understandings of health, there is also an opportunity to connect the OHC-NET applied epidemiology program to other Indigenous epidemiological training and research efforts internationally. For example, in the United States, there are several graduate programs, including Northern Arizona’s MPH Indigenous Health Track, University of North Dakota’s MPH with specialization in Indigenous Health and PhD in Indigenous Health, and University of Hawai‘i’s MPH with a specialization in Native Hawaiian and Indigenous Health, as well as professional training opportunities such as the Summer Research Training Institute for American Indian and Alaska Native Health Professionals offered by the Northwest Portland Area Indian Health Board and Oregon Health & Science University and Johns Hopkins University’s Public Health Training Certificate in American Indian Health. Additionally, there are opportunities to learn from the experiences and best practices (Tribal Epidemiology Centers, 2013) of the Tribal Epidemiology Centers (TEC), a collection of twelve distinct epidemiological centers that facilitates data collection at a community level. In New Zealand, the Nga Pae O Te Maramatanga (Māori Centre for Research Excellence) funded a project entitled “Kaupapa Māori Epidemiology in Health Research,” which “aimed to critique and refine standard statistical tools and their use, in order to better serve the interests of Indigenous Peoples” (Ngā Pae O Te Māramatanga, 2020) and builds upon earlier efforts to decolonize and Indigenize epidemiology (Cram, Keefe, Ormsby, & Ormsby, 1997; Keefe et al., 1999). Moreover, the University of Otago incorporates Kaupapa Māori epidemiology into their MPH courses, including Hauora Māori- Policy Practice and Research, and the University of Auckland includes a considerable group of Māori Health courses within their MPH. There is much to learn from comparing these programs and research projects to those that exist in Canada and incorporating relevant practices into the new OHC-NET program.

Despite the international acknowledgement of Indigenous health disparities across the globe, the problematic nature of colonial epidemiology, and the increasing implementation of graduate and non-graduate training in Indigenous public health, in Canada, there remains much work to do in terms of capacity-building solutions at a community level to address these issues and significantly increase the number of Indigenous epidemiologists nationally. It is our hope that this paper will highlight the ongoing need for decolonized quantitative methodologies in the study of epidemiology and provide concrete paths forward within Canada and beyond.

CRediT author statement

Hayward: Conceptualization; Writing - Original Draft; Writing - Review & Editing; Resources. Wodtke: Conceptualization; Writing - Original Draft; Writing - Review & Editing; Resources. Craft: Writing - Review & Editing; Resources. Robin: Writing - Review & Editing. Smylie: Writing - Review & Editing. McConkey: Writing - Review & Editing. Nychuk: Writing - Review & Editing. Healy: Writing - Review & Editing. Star: Writing - Review & Editing. Cidro: Conceptualization; Supervision; Funding acquisition.

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None declared.

Ethical statement

This manuscript represents the first public presentation of this work. The manuscript has been read and approved by all authors, the requirements for authorship have been met, and each author believes that the manuscript represents honest work. I have assumed responsibility for keeping my coauthors informed of our progress throughout the editorial review process, the content of the reviews, and any revisions made to the manuscript. I understand that, if accepted for publication, a certification of authorship form will be required that all coauthors will sign.

This work did not involve human subjects, as it is an analysis of public-facing documents.

Declaration of competing interest

None.

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3 In Canada, as in the United States and Australia, there are graduate public health programs with Indigenous specializations (MPH with Specialization in Indigenous and Northern Health at Lakehead University; MPH Indigenous Health at University of Toronto; pilot MSc in Indigenous Population Health at Simon Fraser University), but none with this accessible applied epidemiology focus.
