



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 populations to give appropriate weight to their experiences; carefully setting recruitment targets and using appropriate 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

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 (Betts, 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” (Tuhivai Smith, 2012, p. 245).¹ We see these processes as working in tandem, the former decentring and dismantling Eurocentric views and methods, the latter centring 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; Corntassel, 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 examples, see Bourrassa, McKay-McNabb, & Hampton, 2005; Hartley, 2007; Jobin & Kappo, 2017; Joseph, 2018; McCallum & Perry, 2018; National Inquiry into Missing and Murdered

¹ Though space prohibits a full discussion of these terms, we acknowledge that there is much literature and debate on definitions of these concepts (Sium, Desai, & Ritskes, 2012), including Eve Tuck and K. Wayne Yang’s groundbreaking “Decolonization is Not a Metaphor” (2012).

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 fulsome 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” (Smylie & Anderson, 2006, p. 603). As Smylie 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 subpopulation” (Smylie, 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” (Smylie, 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 nearly 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

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 (Drawson, 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 (Tuhiwai 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 spirituality 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 (Drawson 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 Indigenized, 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 & Mittenfelner 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”

(Wilson, 2008, p. 15) and privilege an Indigenous standpoint (Walter and Andersen, 2013). 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, Dawson 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. (Dawson 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 (Bailey & Paradies, 2005; Fontaine, 2018; Green & Haines, 2011; Jaworsky, 2019; Morgan & Ziglio, 2007). Furthermore, epidemiological information has significant impacts 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, Freemantle, & Taulii, 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’Neil, 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 Kuwayu 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” (Baillie & 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 (Espey, 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, Zielhuis, & Bredenoord, 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 decentred and dismantled, 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; Tuhiwai 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 by training more Indigenous epidemiologists (both in and outside of academia), and supports Indigenous self-determination (Baillie & Paradies, 2005; Jaworsky, 2019; Prussing, 2018, 2019; Roy, 2014; Simonds, Robson, Cram, & 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 (Baillie & 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-Hövenner, & 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).² 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 relevancy 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

² Additional paradigms that may include or intersect with Indigenous epidemiology are lay epidemiology (Allmark & Tod, 2006; Davison, Smith, & Frankel, 1991; Olsen & Banwell, 2013), popular epidemiology (Brown, 1993; San Sebastián & Hurtig, 2004), and cultural epidemiology (Brough, 2013; Trostle, 2005).

interpretation (Goodman et al., 2019); however, community-driven epidemiology can go further by engaging communities in “shared planning and oversight of biomedical epidemiologic research that addresses their priorities, incorporating local knowledge, approaches to knowledge-seeking, and values” (Goodman et al., 2019, p. 2). According to a group of Canadian epidemiology and public health researchers (Cameron et al., 2010), culturally safe epidemiology includes several “methodological moments” in which culturally safe approaches can be utilized: framing the issue, ethical review, funding, study design, review of existing knowledge, data analysis, interpretation of results, and communication and application of evidence. For example, using strengths-based approaches and methods such as cognitive mapping to encourage the self-voicing of research questions, priorities, and existing knowledge, separating analysis or “number crunching” from interpretation to integrate Western statistical methods with Indigenous knowledge, and drawing on “alternative methods—for example, universal coverage—to increase the size and representativeness of a sample and appreciate local expertise in the composition and distribution of the population to improve the scientific validity and cultural safety of the sampling and recruitment process” (Cameron et al., 2010, p. 15).

Indigenous epidemiology could use standard epidemiological or statistical methods with an Indigenous lens to track “health inequities as compared to majority groups in national populations” (Prussing, 2018, p. 99; also see; Gracey & King, 2009; Smylie et al., 2010). As colonialism has been recognized as a determinant of health (Commission on Social Determinants of Health, 2008; Czyzewski, 2011), Indigenous epidemiology would fully consider all of the determinants of health (Anderson, Smylie, Anderson, Sinclair, & Crengle, 2006; Jones, 2006; Paradies, 2016; Prussing, 2018). This approach can include multiple adjustments in an epidemiologist’s methods: shifting standards, such as age standardization, according to Indigenous populations to give appropriate weight to their experiences (Department of Economic and Social Affairs, 2010; Simmonds, Robson, & Purdie, 2006); “thoughtfully setting recruitment targets, and using appropriate recruitment methods to meet them, in order to fulfill well-recognized statistical standards for stratification” (Prussing, 2019, p. 1155); acting as a bridge between Indigenous and Western technoscientific perspectives (Beals, Manson, Mitchell, Spicer, & the AI-SUPERPPFP Team, 2003; Prussing, 2019); developing and/or co-developing culturally appropriate data collection tools with Indigenous communities and community organizations (Beals et al., 2003; First Nations Health Authority [FNHA], 2021; FNIGC, 2018a, 2018b; Gray, 2005; Thompson, 1999; Thompson & Thorpe, 1998); creating partnerships between Indigenous communities and organizations and non-Indigenous data organizations and holders to facilitate Indigenous-driven use of data (Pyper et al., 2018; Walker, Lovett, Kukutai, Jones, & Henry, 2017); or developing distinct epidemiological methods based on Indigenous knowledge systems such as those used in Canada by *The First Nations Regional Health Survey* (FNHA, 2021; First Nations Information Governance Centre, 2006) and *Our Health Counts* (Rotondi et al., 2017; Smylie, Firestone, & Spiller, 2018; Smylie, Lofters, Firestone, & O’Campo, 2012, pp. 67–92). Furthermore, in their qualitative study of Indigenous Peoples’ perspectives on and recommendations for conducting public health research in their communities, a group of Ontario researchers reveal potential points of discomfort and friction, including the perception of a project as “overwhelming and disjointed,” general research fatigue from community members, issues with standardized questionnaire development in terms of length and language used that can be perceived as being “bombarded with questions,” and the problematic nature of collecting biological specimens without a clear rationale (Maar et al., 2011). The respondents’ recommendations echo many of the suggestions provided by Indigenous scholars, including the need for direct involvement of community members in the design and implementation of the research, ethics approval sought at the community level, and the commitment to knowledge translation and development of shared understandings of the methods to support community health planning and intervention

creation (Maar et al., 2011).

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 *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 Kishaadigeh, which translates from Anishnawbemowin to “she who guards the lodge.” Part of the work of Kishaadigeh 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, Burhansstipanov, 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 work, 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 (Apatu 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,³ 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 (Genat, 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 Indigenization 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 Ngā Pae O Te Māramatanga (Māori Centre for Research Excellence) funded a project entitled "Kaupapa Māori Epidemiology in

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.

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.

References

- Abraham, A., Gille, D., Puhani, M. A., ter Riet, G., & von Wyl, V. (2021). Defining core competencies for epidemiologists in academic settings to tackle tomorrow's health research challenges: A structured, multinational effort. *American Journal of Epidemiology*, 190(3), 343–352.
- Absolon, K., & Willett, C. (2005). Putting oneself forward: Location in Aboriginal research. In L. Brown & S. Strega (Eds.), *Research as Resistance: Critical, Indigenous, and Anti-oppressive Approaches* (pp. 97–126). Canadian Scholars' Press.
- Allmark, P., & Tod, A. (2006). How should public health professionals engage with lay epidemiology? *Journal of Medical Ethics*, 32, 460–463.
- Anderson, I., Brabham, W., Genat, B., Keleher, H., Jessen, J., Fitzgerald, D., et al. (2004). *National indigenous public health curriculum audit & workshop project report October 2004*. VicHealth Koori Health Research & Community Development Unit.
- Anderson, M., Smylie, J., Anderson, I., Sinclair, R., & Crengle, S. (2006). *First nations, metsis, and Inuit health indicators in Canada: A background paper for the project "action oriented indicators of health and health systems development for indigenous peoples in Australia, Canada, and New Zealand."* University of Victoria.
- Angus, L., Ewen, S., & Coombe, L. (2016). Aboriginal and Torres Strait islander public health: Online and integrated into core master of public health subjects. *Journal of Public Health Research*, 5(675), 32–35.
- Apatu, E., Sinnott, W., Piggott, T., Butler-Jones, D., Anderson, L. N., Alvarez, E., et al. (2021). Where are we now? A content analysis of Canadian master of public health course descriptions and the public health agency of Canada's core competencies. *Journal of Public Health Management and Practice*, 27(2), 201–207. <https://doi.org/10.1097/PHH.0000000000001173>
- Assembly of First Nations. (2019). *Assembly of first nations 2019 annual general assembly: Final resolutions. Assembly of first nations*. Retrieved from <https://www.afn.ca/wp-content/uploads/2019/08/2019-AGA-Resolutions.pdf>. (Accessed 22 March 2021).
- Assembly of Manitoba Chiefs. (2012). Support to establish partnerships for the development of a first nations epidemiology centre (first nations epi-centre). *Assembly of Manitoba Chiefs 24th annual general assembly*. Retrieved from <https://mfnc.org/wp-content/uploads/2012/09/24th-aga-certified-resolutions.pdf>. (Accessed 22 March 2021).
- Atalay, S. (2012). *Community-based archaeology: Research with, by, and for indigenous and local communities*. University of California Press.
- Australian National University. (nd.). Mayi Kuwayu study. Retrieved from <http://mkstudy.com.au/>. (Accessed 19 July 2021).
- Baba, L. Y., & Reading, J. L. (2012). Core competencies for indigenous public health, evaluation and research (cipher): A health inequity mitigation Strategy. *Canadian Journal of Nursing Research*, 44(2), 123–128.
- Bach, M., Jordan, S., Hartung, S., Santos-Hövenner, C., & Wright, M. T. (2017). Participatory epidemiology: The contribution of participatory research to epidemiology. *Emerging Themes in Epidemiology*, 14(2).
- Baillie, R., & Paradies, Y. (2005). Adapt or die: Epidemiology and indigenous health research. *Australasian Epidemiologist*, 12(1), 24–30. <https://search.informit.org/doi/10.3316/informit.886779774867758>.
- Beals, J., Manson, S. M., Mitchell, C. M., Spicer, P., & the AI-SUPERPFP Team. (2003). Cultural specificity and comparison in psychiatric epidemiology: Walking the tightrope in American Indian research. *Culture, Medicine and Psychiatry*, 27, 259–289.
- Benoit, A. C., Jaworsky, D., Price, R., Whitebird, W., Benson, E., Nowgesic, E., et al. (2020). Building bridges: Describing a process for indigenous engagement in epidemiology. *Progress in Community Health Partnerships: Research, Education, and Action*, 14(4), 461–470.
- Betts, R. F. (2012). Decolonization: A brief history of the word. In E. Bogaerts, & R. Raben (Eds.), *Beyond empire and nation: The decolonization of african and asian societies* (pp. 1930s–1970s). Brill, 23–37.
- Blackstock, C. (2009). First nations children count: Enveloping quantitative research in an indigenous envelope. *First Peoples Child and Family Review*, 4(2), 135–143. <https://doi.org/10.7202/1069337ar>
- Boeckhout, M., Zielhuis, G. A., & Bredenoord, A. L. (2018). The FAIR guiding principles for data stewardship: Fair enough? *European Journal of Human Genetics*, 26(7), 931–936. <https://doi.org/10.1038/s41431-018-0160-0>
- Bondy, S. J., Johnson, I., Cole, D. C., & Bercovitz, K. (2008). Identifying core competencies for public health epidemiologists. *Canadian Journal of Public Health*, 99(4), 246–251. <https://doi.org/10.1007/BF03403748>
- Botha, L. (2011). Mixing methods as a process towards indigenous methodologies. *International Journal of Social Research Methodology*, 14(4), 313–325. <https://doi.org/10.1080/13645579.2010.516644>.
- Bourke, S. C. (2020). *Making cultures count: Transforming indigenous health Data in Australia*. Master's thesis, University of Oxford. Oxford University Research Archive.
- Bourrassa, C., McKay-McNabb, K., & Hampton, M. (2005). Racism, Sexism and Colonialism: The impact on the health of aboriginal women in Canada. *Canadian Woman Studies*, 24(1), 23–29. Retrieved from <https://cws.journals.yorku.ca/index.php/cws/article/view/6172/5360> (Accessed July 20, 2021).
- Brant-Castellano, M. (2000). Updating aboriginal traditions of knowledge. In B. H. G. Dei (Ed.), *Indigenous knowledges in global contexts*. University of Toronto Press.
- Brough, M. (2013). Toward cultural epidemiology: Beyond epistemological hegemony. In C. Banwell, et al. (Eds.), *When culture impacts health: Global lessons for effective health research* (pp. 33–42). Elsevier Science & Technology.
- Cameron, M., Andersson, N., McDowell, I., & Ledogar, R. J. (2010). Culturally safe epidemiology: Oxymoron or scientific imperative. *Pimatisiwin*, 8(2), 89–116.
- Cameron, B. L., Del Pilar Carmargo Plazas, M., Salas Santos, A., Bourque Bearsnik, R. L., & Hungler, K. (2014). Understanding inequalities in access to health care services for aboriginal people. *Advances in Nursing Science*, 37(3), E1–E16. <https://doi.org/10.1097/ans.0000000000000039>
- Carter-Pokras, O. D., Spirtas, R., Bethune, L., Mays, V., Freeman, V. L., & Cozier, Y. C. (2009). The training of epidemiologists and diversity in epidemiology: Findings from the 2006 congress of epidemiology survey. *Annals of Epidemiology*, 19(4), 268–275. <https://doi.org/10.1016/j.annepidem.2009.02.004>
- Coates, K. (2004). *A global history of indigenous peoples: Struggle and survival*. Palgrave.
- Colquhoun, A., Geary, J., & Goodman, K. J. (2013). Challenges in conducting community-driven research created by differing ways of talking and thinking about science: A researcher's perspective. *International Journal of Circumpolar Health*, 5(72), 21232.
- Commission on Social Determinants of Health. (2008). *Closing the gap in a generation: Health equity through action on the social determinants of health*. World Health Organization. Retrieved from <https://www.who.int/publications-detail-redirect/WHO-IER-CSDH-08.1> (Accessed July 19, 2021).
- Coombe, L., Lee, V., & Robinson, P. (2017). Integration models for indigenous public health curricula. *Higher Education Research and Development*, 36(4), 645–659.
- Coombe, L., Lee, V., & Robinson, P. (2019). Educating for Indigenous public health competence – how do we stack up in Australia? *Australian & New Zealand Journal of Public Health*, 43(2), 143–148.
- Copenace, S., Cidro, J., Johnson, A., & Anderson, K. (2021). Auntie's bundle: Conversation and research methodologies with knowledge gifter shery copenace. In B. Hokowhitu, A. Moreton-Robinson, L. Tuhiwai Smith, C. Andersen, & S. Larkin (Eds.), *Routledge handbook of critical indigenous studies*. Routledge.
- Corntassel, J. (2003). Who is indigenous? 'Peoplehood' and ethnonationalist approaches to rearticulating indigenous identity. *Nationalism & Ethnic Politics*, 9(1), 75–100. <https://doi.org/10.1080/13537110412331301365>.
- Council of State and Territorial Epidemiologists, & Centers for Disease Control and Prevention. (2008). Applied epidemiology competencies. Retrieved from <http://www.cste2.org/webpdfs/AppliedEpiCompwcover.pdf>. Accessed July 22, 2021.
- Craft, A. (2014). Living treaties, breathing research. *Canadian Journal of Women and the Law*, 26(1), 1–22. <https://doi.org/10.3138/cjwl.26.1.1>
- Craft, A. (2017). Giving and receiving life from anishinaabe nibi inaakonigewin (our water law) research. In J. Thorpe, S. Rutherford, & A. Sandberg (Eds.), *Methodological challenges in nature-culture and environmental history research* (pp. 105–119). Routledge.
- Cram, F., Keefe, V., Ormsby, C., & Ormsby, W. (1997). Memorywork and Māori health research: Discussion of a qualitative method. *He Pukenga Kōrero*, 3(1), 37–45.
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). Sage.
- Czyzewski, K. (2011). Colonialism as a broader social determinant of health. *The International Indigenous Policy Journal*, 2(1). <https://doi.org/10.18584/iipj.2011.2.1.5>
- Darroch, F., & Giles, A. (2014). Decolonizing health research: Community-based participatory research and postcolonial feminist theory. *Canadian Journal of Action Research*, 15(3), 22–36. <https://doi.org/10.33524/cjar.v15i3.155>
- Davis, S., Patel, M. S., Fearnley, E., Viney, K., & Kirk, M. D. (2016). The Australian master of applied epidemiology program: Looking back, moving forward. *Communicable Disease Intelligence Quarterly Report*, 40(3), E326–E333.
- Davison, C., Smith, G. D., & Frankel, S. (1991). Lay epidemiology and the prevention paradox: The implications of coronary candidacy for health education. *Sociology of Health & Illness*, 13(1), 1–19.
- de Leeuw, S., & Greenwood, M. (2017). Turning a new page: cultural safety, critical creative literary interventions, truth and reconciliation, and the crisis of child welfare. *AlterNative*, 13(3), 142–151.
- Deemal, A. (2001). From hopevale to the Australian national university, canberra: Reflections of an indigenous masters of applied epidemiology student. *Aboriginal and Islander Health Worker Journal*, 25(3), 17–22.
- Del Pino, S., & Camacho, A. (2020). *Considerations on indigenous peoples, afro-descendants, and other ethnic groups during the COVID-19 pandemic*. Pan American Health Organization. Retrieved from https://iris.paho.org/bitstream/handle/10665.2/52251/PAHOIMSPHECOVID-19200030_eng.pdf?sequence=1&isAllowed=y. (Accessed 22 March 2021).
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2005). *The SAGE handbook of qualitative research* (3rd ed.). Sage.
- Department of Economic, Affairs, S., & Peoples, I. (2010). *Permanent Forum on indigenous issues*. United Nations. Retrieved from <https://www.un.org/development/desa/indigenouspeoples/unpfii-sessions-2.html>. (Accessed 22 March 2021).
- Dodge, L. G. (2017). *Dr. Laurie's introduction to statistical methods*. Routledge.
- Drawson, A. S., Toombs, E., & Mushquash, C. J. (2017). Indigenous research methods: A systematic review. *The International Indigenous Policy Journal*, 8(2). <https://doi.org/10.18584/iipj.2017.8.2.5>
- Durham, G., & Plant, A. (2005). *Strengthening workforce capacity for population health (phase III PHERP review)*. Retrieved from [https://www1.health.gov.au/informat/mairn/publishing.nsf/Content/C66647AAB9871405CA257BF000209A71/\\$File/pherp_report.pdf](https://www1.health.gov.au/informat/mairn/publishing.nsf/Content/C66647AAB9871405CA257BF000209A71/$File/pherp_report.pdf). (Accessed 20 July 2021).
- Espey, J. (2002). *Stewardship and ocap: A discussion paper for the first nations statistical Institute*. First Nations Information Governance Centre. Retrieved from <https://fnigc.ca/sites/default/files/OCAP%20&%20Stewardship.pdf>. (Accessed 22 March 2021).
- Ewen, S. C., Ryan, T., & Platania-Phung, C. (2019). Capacity building of the Australian aboriginal and torres strate islander health researcher workforce: A narrative review. *Human Resources for Health*, 17(10).
- First Nations Health Authority. (2021). *Regional health survey*. First Nations Health Authority. Retrieved from <https://www.fnha.ca/what-we-do/research-knowledge-exchange-and-evaluation/regional-health-survey>. (Accessed 22 March 2021).

- First Nations Information Governance Centre. (2006). *The first nations regional longitudinal health survey (RHS) 2002/03: Report of process and methods*. First Nations Information Governance Centre. Retrieved from https://fnigc.ca/sites/default/files/ENpdf/RHS_2002-03-report_on_process_and_methods.pdf. (Accessed 22 March 2021).
- First Nations Information Governance Centre. (2018a). *National report of the first nations regional health survey; phase 3: Volume one*. Retrieved from https://fnigc.ca/wp-content/uploads/2020/09/713c8fd606a8eeb021deb927332938d_FNIGC-RHS-Phase-III-Report1-FINAL-VERSION-Dec.2018.pdf. (Accessed 22 March 2021).
- First Nations Information Governance Centre. (2018b). *Final volume of landmark report explores health care, language, culture*. Food Security in First Nations Communities. First Nations Information Governance Centre. Retrieved from <https://fnigc.ca/news/final-volume-landmark-report-explores-health-care-language-culture-food-security-first-nations>. (Accessed 22 March 2021).
- First Nations Information Governance Centre. (2019). *The first nations principles of OCAP®*. First Nations Information Governance Centre. Retrieved from https://fnigc.ca/wp-content/uploads/2020/09/5776c4ee9387f966e6771aa93a04f389_ocap_path_to_fn_information_governance_en_final.pdf. (Accessed 22 March 2021).
- Fontaine, R. E. (2018). *Describing epidemiologic data*. Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/eis/field-epi-manual/chapters/Describing-Epi-Data.html>. (Accessed 22 March 2021).
- Freifeld, C. C., Chunara, R., Mekaru, S. R., Chan, E. H., Kass-Hout, T., Iacucci, A. A., et al. (2010). Participatory epidemiology: Use of mobile phones for community-based health reporting. *PLoS Medicine*, 7(12), Article e1000376.
- Funnell, S., Tanuseputro, P., Letendre, A., Bourque Bearskin, L., & Walker, J. (2020). "Nothing about us, without us." how community-based participatory research methods were adapted in an indigenous end-of-life study using previously collected data. *Canadian Journal on Aging*, 39(2), 145–155.
- Genat, B. (2008). Feasibility study for a nationally accessible master of public health program specialising in indigenous health. In *Public health indigenous leadership in education (PHILE) network*. Retrieved from <http://www.phile.net.au/files/site/docs/Feasibility%20Study%20FINAL.pdf>. (Accessed 19 July 2021).
- Genat, B., Robinson, P., & Parker, E. (2009). *Foundation competencies for master of public health graduates in Australia*. Australian Network of Academic Public Health Institutions. Retrieved from <http://caphia.com.au/documents/Competencies-MPH-Graduates-Australia-ANAPHI-2009.pdf>. (Accessed 21 July 2021).
- Genat, B., Robinson, P., & Parker, E. (2016). *Foundation competencies for master of public health graduates in Australia* (2nd ed.). Council of Academic Public Health Institutions Australia. Retrieved from http://caphia.com.au/testsite/wp-content/uploads/2016/07/CAPHIA_document_DIGITAL_nov_22.pdf. (Accessed 21 July 2021).
- Giesbrecht, M. D., Crooks, V. A., & Morgan, J. (2016). Place, health, and diversity in Canada. In M. D. Giesbrecht, V. A. Crooks, & J. Morgan (Eds.), *Place, health, and diversity: Learning from the Canadian experience*. Routledge.
- GO FAIR. (n.d.). FAIR principles. GO FAIR. Retrieved from <https://www.go-fair.org/fair-principles/>. Accessed March 22, 2021.
- Goodman, K. J., Geary, J., Walker, E., Fagan-Garcia, K., Archie, B., Lennie, C., et al., CANHelpWorking Group. (2019). Community-driven epidemiologic research: Guiding principles. *Global Epidemiology*, 1(100013). <https://doi.org/10.1016/j.gloepi.2019.100013>
- Gostin, L., Friedman, E., & Wetter, S. (2020). Responding to covid-19: How to navigate a public health emergency legally and ethically. *Hastings Center Report*, 50(2), 8–12. <https://doi-org.uml.idm.oclc.org/10.1002/hast.1090>.
- Government of Canada. (2021). *Epidemiological summary of COVID-19 cases in first nations communities. Indigenous services*. Government of Canada. Retrieved from <https://www.sac-isc.gc.ca/eng/1589895506010/1589895527965>. (Accessed 22 March 2021).
- Gracey, M., & King, M. (2009). Indigenous health part 1: Determinants and disease patterns. *Lancet*, 374(9683), 65–75. [https://doi.org/10.1016/s0140-6736\(09\)60914-4](https://doi.org/10.1016/s0140-6736(09)60914-4)
- Gray, J. (2005). *First nations regional longitudinal health survey cultural framework*. First Nations Information Governance Centre. Retrieved from https://fnigc.ca/wp-content/uploads/2020/09/rhs_cultural_framework.pdf. (Accessed 22 March 2021).
- Green, G. P., & Haines, A. (2011). *Asset building & community development*. SAGE.
- Guthrie, J., Dance, P., Kelly, P. M., Lokuge, K., McPherson, M., & Faulkner, S. (2011). Public health capacity development through Indigenous involvement in the Master of Applied Epidemiology Program—celebrations and commiserations. *Australian Aboriginal Studies*, 2, 100–108.
- Hankivsky, O., & Cormier, R. (2009). *Intersectionality: Moving women's health research and policy forward*. Women's Health Research Network.
- Hartley, G. (2007). The Search for Consensus: A Legislative History of Bill C-31, 1969–1985. *Aboriginal Policy Research Consortium International (APRCI)*, 98, 5–34. Retrieved from <https://ir.lib.uwo.ca/cgi/viewcontent.cgi?article=1346&context=aprci> (Accessed July 20, 2021).
- Health Council of Canada. (2005). *The health status of Canada's first nations, Métis and Inuit peoples*. Health Council of Canada. Retrieved from <https://healthcouncilcanada.ca/files/2.03-BkgrdHealthyCdnsENG.pdf>. (Accessed 22 March 2021).
- Hunt, S. (2015). *Review of core competencies for public health: An aboriginal public health perspective*. National Collaborating Centre for Aboriginal Health. Retrieved from <https://www.cnsa-nccah.ca/docs/context/RPT-CoreCompetenciesHealth-Hunt-EN.pdf>. (Accessed 19 July 2021).
- Jacquez, F., Vaughn, L. M., & Wagner, E. (2013). Youth as partners, participants or passive recipients: A review of children and adolescents in community-based participatory research (CBPR). *American Journal of Community Psychology*, 51(1–2), 176–189. <https://doi.org/10.1007/s10464-012-9533-7>
- Jaworsky, D. (2019). An allied research paradigm for epidemiology research with Indigenous peoples. *Archives of Public Health*, 77, 22. <https://doi.org/10.1186/s13690-019-0353-1>
- Jobin, S., & Kappo, T. (2017). To Honour the Lives of Those Taken From Us: Restor(y)ing Resurgence and Survivance through Walking With Our Sisters. In K. L. Ladner, & M. J. Tait (Eds.), *Surviving Canada: Indigenous Peoples Celebrate 150 Years of Betrayal* (pp. 131–148). ARP Books.
- Jones, D. S. (2006). The persistence of American Indian health disparities. *American Journal of Public Health*, 96(12), 2122–2134. [10.2105/AJPH.2004.054262](https://doi.org/10.2105/AJPH.2004.054262).
- Jones, R., Crowshoe, L., Reid, P., Calam, B., Curtis, E., Green, M., et al. (2019). Educating for indigenous health equity: An international consensus statement. *Academic Medicine*, 94(4), 512–519.
- Joseph, B. (2018). *21 Things You May Not Know About The Indian Act: Helping Canadians Make Reconciliation With Indigenous Peoples A Reality*. Page Two Books.
- Joseph, R., & Joseph, C. (2019). *Indigenous relations: Insights, tips & suggestions to make reconciliation a reality*. Indigenous Relations Press.
- Kaur, J. S. (2005). The promise and the challenge of the Spirit of E.A.G.L.E.S. Program. *Journal of Cancer Education*, 20(Suppl), 2–6.
- Kaur, J. S., Dignan, M., Burhansstipanov, L., Baukol, P., & Claus, C. (2006). The "Spirit of Eagles" legacy. *Cancer*, 107(8 Suppl), 1987–1994.
- Keefe, V., Ormsby, C., Robson, B., Reid, P., Cram, F., Purdie, G., & Ngāti Kahungunu Iwi Authority Incorporated. (1999). Kaupapa Māori meets retrospective cohort. *He Pukenga Kōrero*, 5(1), 12–17.
- Kirkness, V. J., & Barnhardt, R. (1991). First nations and higher education: The four R's—respect, relevance, reciprocity, responsibility. *Journal of American Indian Education*, 30(3), 1–15.
- Kovach, M. (2009). *Indigenous methodologies; characteristics, conversations, and contexts*. University of Toronto Press.
- Kukutai, T., & Taylor, J. (Eds.). (2016). *Data sovereignty for indigenous peoples: Current practice and future needs*. ANU Press.
- Lane, R. (2020). *The impact of COVID-19 on indigenous peoples*. United Nations Department of Economic and Social Affairs. Retrieved from https://www.un.org/development/desa/dpad/wp-content/uploads/sites/45/publication/PB_70.pdf. (Accessed 22 March 2021).
- Lavallée, L. F. (2009). Practical application of an indigenous research framework and two qualitative indigenous research methods: Sharing circles and anishinaabe symbol-based reflection. *International Journal of Qualitative Methods*, 8(1), 21–40. [10.1177/2160940690900800103](https://doi.org/10.1177/2160940690900800103).
- Lavoie, J. G. (2013). Policy silences: Why Canada needs a national first nations, Inuit and Métis health policy. *International Journal of Circumpolar Health*, 72(1), 22690. <https://doi.org/10.3402/ijch.v72i0.22690>
- Lavoie, J., & Forget, E. L. (2011). Legislating identity: The legacy of the Indian Act in eroding access to care. *Canadian Journal of Native Studies*, 31(1), 125–138.
- Lee, N. (2020). Addressing the knowledge gap of indigenous public health: Reflections from an indigenous public health graduate. *The Australian Journal of Indigenous Education*, 49, 110–118.
- Leung, M. W., Yen, I. H., & Minkler, M. (2004). Community-based participatory research: A promising approach for increasing epidemiology's relevance in the 21st century. *International Journal of Epidemiology*, 33, 499–506.
- Maar, M. A., Lightfoot, N. E., Sutherland, M. E., Strasser, R. P., Wilson, K. J., Lidstone-Jones, C. M., et al. (2011). Thinking outside the box: Aboriginal people's suggestions for conducting health studies with Aboriginal communities. *Public Health*, 125(11), 747–753.
- Maher, B. L. (2018). *Decolonising public health: Applying epidemiology and Indigenous worldview to how health and well-being is considered by Aboriginal and Torres Strait Islander people*. Master's thesis, Australian National University. Australian National University Open Research Library.
- Mashford-Pringle, A., Ring, I., Al-Yaman, F., Waldeon, J., & Chino, M. (2019). Rethinking health services measurement for indigenous populations. *Statistical Journal of the IAOS*, 35(1), 139–146. <https://doi.org/10.3233/SJ-180465>
- McCallum, L., & Perry, A. (2018). *Structures of Indifference: An Indigenous Life and Death in a Canadian City*. University of Manitoba Press.
- Minkler, M., & Wallerstein, N. (Eds.). (2003). *Community-based participatory research in health*. Jossey-Bass.
- Morgan, A., & Ziglio, E. (2007). Revitalising the evidence base for public health: An assets model. *Promotion and Education*, 14(2_suppl), 17–22. [10.1177/2F10253823070140020701x](https://doi.org/10.1177/2F10253823070140020701x).
- Moser, M., Ramiah, K., & Ibrahim, M. (2008). Epidemiology core competencies for master of public health students. *Public Health Reports*, 123(Suppl. 1), 59–66.
- Ngā Pae O Te Māramatanga. (2020). *Kaupapa Māori epidemiology in health research; finding our own standards*. Ngā Pae O Te Māramatanga. Retrieved from <http://www.maramatanga.co.nz/project/kaupapa-m-ori-epidemiology-health-research-finding-our-own-standards>. (Accessed 22 March 2021).
- Olsen, A., & Banwell, C. (2013). Context and environment: The value of considering lay epidemiology. In C. Banwell, et al. (Eds.), *When culture impacts health: Global lessons for effective health research* (pp. 85–93). Elsevier Science & Technology.
- O'Neil, J., Reading, J. R., & Leader, A. (1998). Changing the relations of surveillance: The development of a discourse of resistance in aboriginal epidemiology. *Human Organization*, 57(2), 230–237.
- National Inquiry into Missing and Murdered Indigenous Women and Girls. (2019). *Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls*. Retrieved from <https://www.mmiwg-ffada.ca/final-report/> (Accessed July 19, 2021).
- Open North, & British Columbia First Nations Data Governance Initiative. (2017). *Decolonizing data: First nations data sovereignty paper*. British Columbia First Nations'

- Data Governance Initiative. Retrieved from https://www.bcfndgi.com/s/Decolonizing-Data-FN_DATA_SOVEREIGNTY_PAPER.docx. (Accessed 23 March 2021).
- Our Health Counts. (2012). *Research project objectives. Our health Counts*. Retrieved from <http://ourhealthcounts.ca/index.php/about-ohc/research-objectives/our-health-counts-research-objectives>. (Accessed 22 March 2021).
- Paradies, Y. (2016). Colonisation, racism and indigenous health. *Journal of Population Research*, 33, 83–96. <https://doi.org/10.1007/s12546-016-9159-y>
- Patel, M. S., & Phillips, C. B. (2009). Strengthening field-based training in low and middle-income countries to build public health capacity: Lessons from Australia's Master of Applied Epidemiology program. *Australia & New Zealand Health Policy*, 6 (5).
- Power, T., Wilson, D., Best, O., Brockie, T., Bourque Bearskin, L., Millender, E., et al. (2020). COVID-19 and Indigenous Peoples: An imperative for action. *Journal of Clinical Nursing*, 29(15–16), 2737–2741. [10.1111%2Fjocn.15320](https://doi.org/10.1111%2Fjocn.15320).
- Prussing, E. (2018). Critical epidemiology in action: Research for and by indigenous peoples. *SSM Population Health*, 6, 98–106. [10.1016%2Fj.ssmph.2018.09.003](https://doi.org/10.1016%2Fj.ssmph.2018.09.003).
- Prussing, E. (2019). Through a critical lens: Expertise in epidemiology for and by indigenous peoples. *Science, Technology & Human Values*, 45(6), 1142–1167. [10.1177%2F0162243919887448](https://doi.org/10.1177%2F0162243919887448).
- Public Health Agency of Canada. (2008). *Core competencies for public health in Canada: Release 1.0*. Retrieved from: <https://www.canada.ca/content/dam/phac-aspc/documents/services/public-health-practice/skills-online/core-competencies-public-health-canada/cc-manual-eng090407.pdf>. (Accessed 20 July 2021).
- Pyper, E., Henry, D., Yates, E. A., Mecredy, G., Ratnasingham, S., Slegers, B., et al. (2018). Walking the path together: Indigenous health data at ICES. *Healthcare Quarterly*, 20(4), 6–9.
- Ravitch, S. M., & Mittenfelner Carl, N. (2020). *Qualitative research: Bridging the conceptual, theoretical, and methodological* (2nd ed.). Sage.
- Restoule, J. P. (2008). The values carry on: Aboriginal identity formation of the urban-raised generation. *Canadian Journal of Native Education*, 31(2), 15–33.
- Rotondi, M. A., O'Campo, P., O'Brien, K., Firestone, M., Wolfe, S. H., Bourgeois, C., et al. (2017). Our health counts Toronto: Using respondent-driven sampling to unmask census undercounts of an urban indigenous population in Toronto, Canada. *BMJ Open*, 7, Article e018936. <https://doi.org/10.1136/bmjopen-2017-018936>
- Roy, A. (2014). Aboriginal worldviews and epidemiological survey methodology: Overcoming incongruence. *International Journal of Multiple Research Approaches*, 8 (1), 117–128. <https://doi.org/10.5172/mra.2014.8.1.117>
- San Sebastián, M., & Hurtig, A. K. (2004). Oil development and health in the amazon basin of Ecuador: The popular epidemiology process. *Social Science & Medicine*, 60 (4), 799–807.
- Sapienza, J. N., Corbie-Smith, G., Keim, S., & Fleischman, A. R. (2007). Community engagement in epidemiological research. *Ambulatory Pediatrics*, 7(3), 247–252.
- Schnarch, B. (2004). Ownership, control, access, and possession (ocap) or self-determination applied to research: A critical analysis of contemporary first nations research and some options for first nations communities. *International Journal of Indigenous Health*, 1(1), 80–95. <https://doi.org/10.3138/ijih.v1i1.28934>
- Silliman, S. W. (2008). Collaborative indigenous archaeology: Trowling at the edges, eyeing the center. In S. W. Silliman (Ed.), *Collaborating at the trowel's edge, teaching and learning in indigenous archaeology*. University of Arizona Press.
- Simmonds, S., Robson, B., Cram, F., & Purdie, G. (2008). Kaupapa maori epidemiology. *Australasian Epidemiologist*, 15(1), 3–6. <https://search.informit.org/doi/10.3316/informit.239017476323220>.
- Simmonds, S. M., Robson, B., & Purdie, G. (2006). Implications of an indigenous standard population for Pacific health data in New Zealand. *Australasian Epidemiologist*, 13(3), 68. <https://search.informit.org/doi/10.3316/informit.866153075684931>.
- Simonds, V. W., & Christopher, S. (2013). Adapting western research methods to indigenous ways of knowing. *American Journal of Public Health*, 103(12), 2185–2192. [10.2105%2FAJPH.2012.301157](https://doi.org/10.2105%2FAJPH.2012.301157).
- Smith, M. H. (1998). Community-based epidemiology: Community involvement in defining social risk. *Journal of Health & Social Policy*, 9(4), 51–65. https://doi.org/10.1300/J045v09n04_05
- Smylie, J. (2009). *Achieving strength through numbers: First nations, Inuit, and Métis health information*. National Collaborating Centre for Aboriginal Health. Retrieved from <https://www.nccih.ca/docs/context/FS-AchievingStrengthNumbers-Smylie-EN.pdf>. (Accessed 19 May 2021).
- Smylie, J., & Anderson, M. (2006). Understanding the health of Indigenous peoples in Canada: Key methodological and conceptual challenges. *Canadian Medical Association Journal*, 175(6), 602. <https://doi.org/10.1503/cmaj.060940>
- Smylie, J., Crengle, S., Freemantle, J., & Taulii, M. (2010). Indigenous birth outcomes in Australia, Canada, New Zealand and the United States – an overview. *The Open Women's Health Journal*, 4, 7–17. [10.2174%2F1874291201004010007](https://doi.org/10.2174%2F1874291201004010007).
- Smylie, J., & Firestone, M. (2015). Back to the basics: Identifying and addressing underlying challenges in achieving high quality and relevant health statistics for indigenous populations in Canada. *Statistical Journal of the IAOS*, 31(1), 67–87. <https://doi.org/10.3233/sji-150864>
- Smylie, J., Firestone, M., Spiller, M. W., & Tungasuvvingat, I. (2018). Our health counts: Population-based measures of urban Inuit health determinants, health status, and health care access. *Canadian Journal of Public Health*, 109, 662–670. <https://doi.org/10.17269/s41997-018-0111-0>
- Smylie, J., Lofters, A., Firestone, M., & O'Campo, P. (2012). Population-based data and community empowerment. In P. O'Campo, & J. R. Dunn (Eds.), *Rethinking social epidemiology: Towards a science of change*. Springer.
- Solomon, T. G. A., & Randall, L. L. (2014). Overview of epidemiology and public health data in native American populations. In T. G. A. Solomon, & L. L. Randall (Eds.), *Conducting health research with native American communities*. APHA Press. <https://ajph.aphapublications.org/doi/abs/10.2105/9780875532028ch02>.
- Spence, N., & White, J. P. (2010). Scientific certainty in a time of uncertainty: Predicting vulnerability of Canada's first nations to the H1N1/09 pandemic. *International Indigenous Policy Journal*, 1(1). <https://doi.org/10.18584/iipj.2010.1.1.1>
- Swadener, B. B., & Mutua, K. (2008). Decolonizing performances: Deconstructing the global postcolonial. In N. K. Denzin, Y. S. Lincoln, & L. Tuhiwai Smith (Eds.), *Handbook of critical and indigenous methodologies*. Sage.
- Thompson, S. J. (1999). Participatory epidemiology: Methods of the living with diabetes project. *The International Quarterly of Community Health Education*, 19(1), 3–18.
- Thompson, S., & Thorpe, L. (1998). The living with diabetes project: A community based approach to questionnaire development. *Aboriginal and Islander Health Worker Journal*, 22(1), 15–20.
- Thurber, K. A., Thandrayen, J., Banks, E., Doery, K., Sedgwick, M., & Lovett, R. (2020). Strengths-based approaches for quantitative data analysis: A case study using the Australian longitudinal study of indigenous children. *SSM Population Health*, 12, Article 100637. <https://doi.org/10.1016/j.ssmph.2020.100637>
- Tribal Epidemiology Centers. (2013). *Best practices in American Indian & Alaska native public health: A report from the tribal epidemiology Centers*. Tribal Epidemiology Centers. Retrieved from <https://tribalepidcenters.org/wp-content/uploads/2016/03/TEC-Best-Practices-Book-2013.pdf>. (Accessed 22 March 2021).
- Trostle, J. (2005). *Epidemiology and culture*. Cambridge: University Press.
- Tuhiwai Smith, L. (2012). *Decolonizing methodologies: Research and indigenous peoples* (2nd ed.). Zed Books.
- United Nations General Assembly. (2007). *United nations Declaration on the Rights of indigenous peoples*. United Nations. Retrieved from https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf. (Accessed 22 March 2021) Accessed.
- Urdan, T. C. (2005). *Statistics in plain English*. Lawrence Erlbaum Associates.
- Walker, J., Lovett, R., Kukutai, T., Jones, C., & Henry, D. (2017). Indigenous health data and the path to healing. *Lancet*, 390(10107), 2022–2023.
- Walter, M. (2005). Using the 'power of the data' within Indigenous research practice. *Australian Aboriginal Studies*, 2, 27–34.
- Walter, M. (2016). Data politics and indigenous representation in Australia statistics. In T. Kukutai, & J. Taylor (Eds.), *Indigenous data sovereignty: Towards an agenda* (pp. 79–97). ANU Press.
- Walter, M., & Andersen, C. (2013). *Indigenous statistics: A quantitative research methodology*. Routledge.
- Walter, M., & Suina, M. (2019). Indigenous data, indigenous methodologies and indigenous data sovereignty. *International Journal of Social Research Methodology*, 22 (3), 233–243. <https://doi.org/10.1080/13645579.2018.1531228>
- Weber-Pillwax, C. (2004). Indigenous researchers and indigenous research methods: Cultural influences or cultural determinants of research methods. *Pimatisiwin*, 2, 78–90.
- Wilson, S. (2001). What is an indigenous research methodology? *Journal of Native Education*, 25, 175–179.
- Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Fernwood Publishing.
- Wong, N. (2020). *First Nations-specific data being collected after agreement struck*. Winnipeg Sun. Retrieved from <https://winnipegnews.com/news/news-news/first-nations-specific-data-now-being-collecting-after-agreement-struck>. (Accessed 22 March 2021).
- Woodbury, R. B., Beans, J. A., Hiratsuka, V. Y., & Burke, W. (2019). Data management in health-related research involving indigenous communities in the United States and Canada: A scoping review. *Frontiers in Genetics*, 10(942). <https://doi.org/10.3389/fgene.2019.00942>
- Wyton, M. (2020). Race matters in a pandemic, but we're not gathering basic data. *The tyee*. Retrieved from <https://thetyee.ca/News/2020/04/30/Race-Matters-Pandemic-Data/>. (Accessed 22 March 2021).
- Yunong, H., & Xiong, Z. (2008). A reflection on the indigenization discourse in social work. *International Social Work*, 51(5), 611–622.